

Cost borne by families of children hospitalised in a paediatric intensive care unit: a pilot study

Jean-Blaise Wasserfallen^a, Christine Bossuat^b, Eliane Perrin^c, Jacques Cotting^b

^a Health Technology Assessment Unit, University Hospital (CHUV), Lausanne, Switzerland

^b Paediatric Intensive Care Unit, University Hospital (CHUV), Lausanne, Switzerland

^c Health Economics and Management Institute, University Hospital (CHUV), Lausanne, Switzerland

Summary

Question under study: Hospitalisation of a child in a paediatric intensive care unit (PICU) involves major stress for parents. They wish to stay at their child's bedside while at the same time giving the usual attention to their other children. The resultant out-of-pocket expenses have rarely been studied.

Methods: Over a 6-month period all the families of children hospitalised in our PICU for more than 4 days, speaking French and insured by our social security system, were eligible for inclusion. Participation was proposed only after diagnosis, treatment and prognosis had been determined. Costs were retrieved from a diary list of customised items and computed as the amount in excess of usual expenses until the end of the hospital stay.

Results: 117 children were hospitalised in our

PICU for a total of 131 stays. The families of 16 fulfilled the inclusion criteria. One dropped out after a week at the parents' request. The children's age was 2.9 ± 3.8 years and 67% were male. The majority had malformations (53%) or infections (33%). The total length of stay was 49 ± 51 days, of which 24 ± 41 were spent in the PICU. On average, parents spent CHF 86 ± 31 every day, mainly on travel and meals. Over the entire hospital stay their expenses amounted to CHF $4,078 \pm 4,552$.

Conclusions: Direct out-of-pocket expenses for parents of children hospitalised in the PICU are considerable. Improvement in the social security system may be necessary to address this issue.

Key words: cost; parents; intensive care; paediatrics

Introduction

Hospitalisation of a child in a paediatric intensive care unit (PICU) involves major stress for the parents. Most publications in the literature [1 for a review] focus on the adjustment phase, and in particular on stressors, family resources, perception of stressors, and outcomes. A few studies address the way families cope with this kind of situation [2], while others study the influence of illness severity and family resources on maternal uncertainty in this type of setting [3].

It is also well known that the parents' presence at the child's bedside is highly important in speeding recovery and facilitating medical and nursing care, although it is often difficult to deal with parents' fears and expectations. On the one hand, the needs of critical care patients' relatives have been shown to be well perceived by physicians and nurses [4]. On the other hand, major differences in preferences for health states have been shown between health care professionals, parents and adolescents, at least as far as neonatal outcomes are concerned [5].

To be able to spend time with their child in the PICU parents need to modify their lifestyle, while at the same time attending to their other children as usual. This dilemma can generate additional out-of-pocket costs for the parents which are often overlooked by other professional categories involved in the health care system, such as the payers, the politicians or even the health care professionals.

In Switzerland, health insurance is mandatory but based on a system of private insurance companies which collect health care premiums directly from the insured. For children this means that premiums are paid by their parents. There is no co-payment or deduction for child care, but on the other hand the law grants parents of sick children only 5 days off work, and no other social support exists for them.

We wished to prospectively study the type and amount of costs faced by parents of children hospitalised in our PICU over a 6-month period.

Abbreviations

CHF = Swiss francs
PICU = Paediatric
intensive care
unit

Financial support:
none.

Patients and methods

Over a 6-month period, all families of children hospitalised in our PICU on an emergency or elective basis for surgical or medical treatment and insured by our social security system were eligible for inclusion. As we wished to obtain complete and valid data reflecting the impact of a PICU stay on the native population, and for conditions other than the usual care and monitoring after routine surgery, exclusion criteria were children hospitalised for humanitarian reasons, families of children requesting asylum or not understanding and/or speaking French, atypical families (child raised by persons other than the father or mother), families of children hospitalised for less than 4 days, unavailability of the research team, children transferred from other hospital units, uncertain clinical prognosis, and parental refusal.

Parents were requested to participate only after being provided with medical information on their child's disease, possible treatment and prognosis, to avoid increasing their anxiety because of the study. Informed consent was requested and costs were retrieved from a diary list of customised items including meals, travel costs, communication costs, gifts to the child and/or the family, loss of income, and other expenses directly linked to the hospitalisation, such as domestic help for cleaning or housing pets. Meals and travel costs were computed on the basis of incurred costs and price lists available from the French-speaking consumer association respectively [6]. Both were

computed as the amount of parental out-of-pocket costs in excess of usual expenses. Information provided by the families was discussed with the investigator and clarified if need be.

Families were classified by type of admission (emergency versus elective hospitalisation), and by type of decision concerning attendance on their hospitalised child (families electing to travel versus families choosing to stay at the hospital). Families were further characterised by the existence and number of other children and by the father's type of work (with major, intermediate, or no responsibilities), while the distance between home and hospital was recorded for each family.

Costs were collected until the end of the hospital stay. When the child was transferred to another hospital, the costs connected with this second stay were imputed on the basis of the average cost of the last week before transfer. For international comparisons, CHF 1 = € 0.67. The study was approved by the local ethics committee of our institution.

Analysis was carried out with chi square tests, Fisher's exact test for categorical variables and Mann-Whitney U-tests for continuous variables, as the distribution was not normal. The impact of family characteristics on travel decisions was explored by logistic regression. Statistical significance was assumed for p value <0.05 .

Results

Over the 6-month period 117 children were hospitalised in our PICU for a total of 131 stays. The families of 16 fulfilled the inclusion criteria, while one dropped out after a week at the parents' request as their child was suffering from a brain tumour with an unfavourable prognosis. The distribution of the exclusion criteria is shown in table 1.

The children's and families' characteristics are shown in table 2. The only difference between emergency and elective admission groups was the distance from home, which is not relevant to our study. There was no difference between travelling and non-travelling families as far as these characteristics are concerned.

The distribution of the different types of expense is shown in table 3. Altogether these families spent an average of CHF 86 (€ 57) per day, the two major centres of cost being travel and meals. No family characteristics such as availability of a car, distance from home, presence of other children, responsibility level of father's employment or type of disorder or admission played a significant role in the travelling decision. Non-travellers spent more on meals and communications on a daily basis than travellers. There was a very wide variation in the amount of incurred costs between the individual families and between the different cost categories, but no statistically significant difference was recorded. Over the whole hospital stay,

Table 1
Distribution of
exclusion criteria.

Exclusion criterion	Patient number	Number of stays
Chronic patient	17	23
Humanitarian patient	17	20
Patient living abroad	10	13
Patient admitted to neonatal intensive care unit and secondarily transferred	10	10
Patient requesting asylum	9	11
Unavailability of the research team	11	11
Patients transferred from other wards	6	6
Length of stay <4 days	31	31
Uncertain clinical prognosis	6	6
Parents' refusal	0	0
Total	117	131

these families spent an average of CHF 4,078 (€ 2,720) as direct out-of-pocket expenses for visiting/staying with their hospitalised child.

In addition, 8 families (53%) experienced various levels of earnings loss directly related to the hospitalisation of their child. The families most severely affected were those with other children (67%), with jobs allowing less flexibility in the

working schedule (60% of families with low level and 67% of families with intermediate level of responsibility were affected), whereas the travel distance did not play an important role. The amount of the earning loss was variable, ranging from CHF 1,175 (€ 783) to CHF 3,346 (€ 2,231), during the hospital stay.

Table 2
Patient and family characteristics, for the whole group and by type of admission.

Patient and family characteristics	All (n = 15)		Emergency admission (n = 12)		Elective admission (n = 3)	
	N	(SD or %)	N	(SD or %)	N	(SD or %)
Mean age (SD)	2.9	(3.8)	2.6	(3.9)	3.9	(3.6)
Male gender (%)	10	(67)	8	(67)	2	(67)
Type of disease (%)						
malformation	8	(53)	5	(42)	3	(100)
infection	5	(33)	5	(42)		
tumour	1	(6)	1	(8)		
accident	1	(6)	1	(8)		
Total LOS (SD)	49	(51)	54	(56)	28	(10)
PICU LOS (SD)	24	(41)	26	(45)	14	(10)
SSMI cat 1 (SD)	6.5	(8.5)	7.3	(9.4)	3.3	(2.3)
Max PRISM score (SD)	12.9	(6.5)	13.5	(7.1)	10.7	(3.2)
Family characteristics						
Father's professional responsibilities (%)						
major	4	(27)	3	(25)	1	(33)
intermediate	6	(40)	5	(42)	1	(33)
none	5	(33)	4	(33)	1	(33)
Other children (%)	6	(40)	4	(33)	2	(67)
Travellers (%)	8	(53)	4	(33)	1	(33)
Mean km distance from home (SD)	55.4	(23)	49.6	(22)	78.7	(9)*
km travelled (SD)	3157	(3661)	3348	(3913)	2393	(2921)
km per day (SD)	71	(46)	72	(44)	69	(68)

Abbreviations: LOS = Length of stay; SSMI = Swiss Society of Intensive Medicine categories; * = p <0.05

Table 3

Out-of-pocket expenses for family (CHF), by type of costs, for the whole group, by type of admission and by type of decision about travelling.

	All (n = 15)		Emergency admission (n = 12)		Elective admission (n = 3)		Difference by admission type P value	Travellers (n = 7)		Non-travellers (n = 8)		Difference by type of travelling P value
	N	(SD)	N	(SD)	N	(SD)		N	(SD)	N	(SD)	
Daily average												
Meals	16	(15)	18	(16)	11	(15)	0.536	7	(10)	24	(16)	0.021
Travel	50	(28)	50	(28)	50	(33)	0.945	58	(28)	43	(27)	0.336
Communication	7	(5)	7	(5)	7	(3)	0.633	4	(2)	9	(5)	0.054
Gifts	7	(8)	6	(8)	12	(6)	0.136	4	(4)	10	(10)	0.536
Others	6	(10)	7	(11)	2	(3)	0.536	6	(11)	5	(10)	0.336
Total	86	(31)	87	(34)	82	(18)	1.000	80	(31)	92	(32)	0.397
Whole hospital stay												
Meals	677	(812)	786	(870)	243	(311)	0.233	563	(690)	777	(941)	0.694
Travel	2232	(2319)	2394	(2511)	1585	(1474)	0.840	3112	(2690)	1462	(1760)	0.121
Communication	293	(454)	315	(508)	203	(106)	0.840	180	(106)	392	(616)	0.955
Gifts	482	(1208)	529	(1357)	293	(90)	0.365	129	(81)	791	(1636)	0.463
Others	394	(735)	477	(805)	63	(109)	0.448	492	(748)	308	(764)	0.336
Total	4078	(4552)	4501	(5007)	2387	(1347)	0.945	4476	(3347)	3730	(5617)	0.336

Discussion

This preliminary study on 15 families whose children totalled 695 hospital days in the PICU showed that these families spent an average out-of-pocket amount of CHF 86 (€ 57) per day or CHF 2,616 (€ 1,710) per month for travel and/or meals and communication costs. This is a very heavy burden for them which may be worsened by additional significant loss of earnings. The consequences are markedly different if the hospitalisation occurs as an emergency or is elective. In the former case, parents' possibilities of arranging leave from work are very limited, as our legal system offers no protection in this domain. In the latter case, professional leave can be arranged in advance.

Several studies have been devoted to the stress these families face when their child is hospitalised in a PICU, and the importance of coping mechanisms for families' survival [1]. Very few studies have addressed the economic impact of illness on these families. In addition, they often examine both medical costs (such as co-payments for drugs), and non-medical costs (such as travel costs). In paediatrics, only one study has assessed the global out-of-pocket financial burden of health care expenditures for families with children in the United States. Using the Household Component of the Medical Expenditure Panel Survey, it showed that this burden was highest in low income families, and was lowered more markedly by full-year public than private insurance coverage [7]. Two disease-specific studies were published. The first addressed the psychosocial and economic problems of parents of children suffering from epilepsy in India. A structured questionnaire administered to parents of 50 children aged 5 to 10 years and suffering from epilepsy of more than one year's duration showed a decline in social activities in 80% of the parents, a significant impact on daily routines in over 75%, and financial difficulties in 60%. The most important cost categories were drugs acquisition and travel (54% and 36% respectively) [8].

Using the same type of questionnaire as ours [9], another study quantified time and out-of-pocket expenses associated with respiratory syncytial virus hospitalisations in the specific context of the US health care system. It showed that the average total economic burden per admission amounted to \$ 4,517 for premature and \$ 2,135 for full-term children, and that losses continued following discharge [10].

In our study, carried out in a very different system and setting, the two most important cost categories were meals and travel. Our hospital offers some support in alleviating the burden faced by these families by providing a room for one of the

parents free of charge. This means that the cost figures we computed are low estimates as compared with other institutions which would not provide this kind of economic support. In addition, earnings loss directly occasioned by the hospitalisation was unevenly distributed between the different families, but affected 53% of them and could be substantial for some, even extending beyond the hospital stay.

Communication between patient and physician on out-of-pocket costs is an important topic, but not well studied. A survey in 484 adult patients treated by 133 physicians showed that 63% of the patients wanted to talk about this issue with their physician, whereas while 79% of the physicians believed that the patients wanted to discuss the issue only 35% of physicians and 15% of patients reported having discussed it. This discussion was much more likely to occur when the burden was high (prevalence ratio PR 2.55, 95% CI 1.62–3.76), and with patients seen in a community practice (PR 5.19, 95% CI 1.86–8.93) [11].

Our study also has limitations: it was carried out in a given health care system, in a single centre, in relatively few families excluding all non-native families and hospital stays related to routine surgical procedures. It focused on non-medical costs and did not include earnings forgone because of the hospitalisation. In addition, it did not study the reasons behind families' spending decisions or whether these costs could have been reduced in one way or another. Our results should thus be considered preliminary and verified on a larger sample of families. The health care systems of different countries also have different insurance systems and provide varying protection for families of children requiring hospitalisation in a PICU. Our results must therefore be translated to other settings and their specificities before they can be generalised. However, even if underestimated these figures are troubling and should alert policy makers to the need to provide help for such families.

As virtually no data are available on this issue, this type of inquiry should be repeated on larger family samples and different types of hospitalisation before appropriate policies are designed and implemented to address it. It is an issue of importance, since social stress such as financial burdens may adversely affect patients' overall outcome.

Correspondence:

J.-B. Wasserfallen, MD MPP

Medical Direction

University Hospital (CHUV)

CH-1011 Lausanne

E-Mail: jwasserf@chuv.hospvd.ch

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