

# Impact on parents during hospitalisation for acute diarrhoea in young children

Way-Seah Lee<sup>1</sup>, FRCPCH, MD, Pei-Fan Chai<sup>1</sup>, MBBS, MRCPCH, Zulkifli Ismail<sup>2</sup>, MBBS, MMed

**INTRODUCTION** This study aimed to determine the emotional impact on parents of young children who require hospitalisation for acute diarrhoea (AD), and the disruption of daily activities experienced and costs incurred by them.

**METHODS** A prospective study was conducted on children below two years of age with AD admitted to two urban hospitals in Malaysia. Parents were interviewed on the emotional impact and disruption of daily activities experienced by them, as well as the extra costs incurred as a result of the hospitalisation of their child.

**RESULTS** The parents of 85 children (median age 13 months; boys n = 58, 68%; girls n = 27, 32%) were recruited for the study. The proportions of parents who reported that they were very worried about the symptoms of diarrhoea, vomiting and fever in their child were 82%, 83% and 78%, respectively. Parents also reported being upset, helpless, mentally and physically exhausted, and having experienced loss of sleep and disruption of daily routine during the hospitalisation of their child (median four days). The median extra cost (including out-of-pocket cost and loss of income) incurred by parents as a result of the hospitalisation was USD 252.86, which constituted 16% of the combined monthly family income.

**CONCLUSION** Although short, AD-related hospitalisation in young children has considerable emotional impact and creates significant distress, in addition to causing significant financial burden for parents.

*Keywords: acute diarrhoea, hospitalisation, parental distress*  
*Singapore Med J 2012; 53(11): 755–759*

## INTRODUCTION

Hospital-based surveillance studies in Asia, Africa and Latin America show that 25%–55% of hospitalisations for diarrhoea among children younger than five years of age are associated with rotavirus (RV) infection.<sup>(1)</sup> RV disease causes significant health and economic burden worldwide.<sup>(2)</sup> In Malaysia, Lee et al estimated that in 2002, the cost of providing inpatient care for each episode of hospital admission for RV gastroenteritis was USD 2,112, while according to Chai and Lee, the estimated out-of-pocket cost incurred by caregivers associated with hospitalisation for RV diarrhoea was USD 194 in 2009.<sup>(2,3)</sup> In Vietnam, Fischer et al found that non-medical direct and indirect costs of diarrhoeal disease constituted a considerable fraction of the overall costs associated with the disease in both urban (25%) and rural (43%) settings.<sup>(4)</sup> These findings provided justification for the inclusion of non-medical direct and indirect costs as well as hospital costs in cost-effectiveness analyses of vaccines preventing diarrhoea.

In addition to extra costs, there is also evidence suggesting that parents of hospitalised infants and children experience considerable emotional distress.<sup>(5,6)</sup> Parental anxiety may even lead to family instability and a deterioration in family functioning during a child's hospitalisation.<sup>(5)</sup> Hospitalisation of a child is a stressful event for caregivers, and more so if such a hospital admission is for a life-threatening or chronic illness. However, little is known whether parents or caregivers also experience similar emotional distress when their children are admitted for acute transient illnesses. The objective of the present study was to assess the emotional impact on parents of young children who

require hospitalisation for acute diarrhoea (AD) in Malaysia, and determine the disruption of daily activities experienced, as well as the costs incurred by these parents.

## METHODS

This prospective two-centre study was conducted between July 2007 and January 2009 (duration 19 months) at the children's wards of two urban hospitals in Kuala Lumpur, Malaysia, namely University Malaya Medical Centre (UMMC) and Selangor Medical Centre (SMC). UMMC is an urban government hospital in Kuala Lumpur, mainly serving the urban low-to-middle socioeconomic classes, while SMC is a private hospital in the state of Selangor that caters primarily to the upper-to-middle socioeconomic classes of Malaysians. This study was approved by the institutional ethics review committees of the participating centres.

All children aged less than 24 months who were hospitalised for AD – defined as the presence of three or more loose stools in a 24-hour period and lasting less than ten days in duration – were included in the study. Children admitted for other medical reasons but who subsequently developed symptoms of AD were considered to have nosocomial diarrhoea and were thus excluded. After obtaining verbal consent, the parents or caregivers of all patients were interviewed on admission by the study personnel using a standard questionnaire. Data collected included information on basic demography, the socioeconomic aspects of the family, physical symptoms and behaviour of the child during the AD episode, the out-of-pocket costs incurred by parents and the emotional impact of hospitalisation on parents.

<sup>1</sup>Department of Paediatrics, University of Malaya Medical Centre, Kuala Lumpur, <sup>2</sup>Selangor Medical Centre, Shah Alam, Malaysia

**Correspondence:** Dr Lee Way-Seah, Professor, Department of Paediatrics, University of Malaya Medical Centre, 59100 Kuala Lumpur, Malaysia. leews@um.edu.my

**Table I. Severity of symptoms in children aged less than two years (n = 85) who were hospitalised for acute diarrhoea.**

| Symptom                  | No. of respondents | Median | Mean ± SD  | 95% CI  |
|--------------------------|--------------------|--------|------------|---------|
| <b>Diarrhoea</b>         |                    |        |            |         |
| Frequency (episodes/day) | 85                 | 4.0    | 3.2 ± 3.00 | 2.9–3.6 |
| Duration (days)          | 85                 | 4.0    | 4.0 ± 2.10 | 3.5–4.3 |
| <b>Vomiting</b>          |                    |        |            |         |
| Frequency (episodes/day) | 81                 | 4.0    | 2.7 ± 2.53 | 2.5–3.1 |
| Duration (days)          | 81                 | 2.0    | 2.6 ± 2.08 | 2.2–3.1 |
| <b>Fever</b>             |                    |        |            |         |
| Duration (days)          | 84                 | 2.0    | 2.3 ± 1.84 | 1.9–2.7 |
| <b>Loss of appetite</b>  |                    |        |            |         |
| Duration (days)          | 81                 | 3.0    | 3.4 ± 1.76 | 3.0–3.8 |

CI: confidence interval; SD: standard deviation

The components of out-of-pocket cost were similar to those described in previous studies,<sup>(3)</sup> namely (a) medical costs, which included hospital bills and expenses on medical consultation and medication prior to hospitalisation; (b) other extra expenses incurred such as those for special food or diet, transport, extra diapers, etc; and (c) workday-related loss for parents during the entire period of the diarrhoeal disease (such as during pre-admission, admission and post-discharge) and other costs incurred by family members. Workday loss was estimated directly from the number of workdays missed prior to, during and after hospitalisation, when information on the daily wages of these parents was available.

The emotional impact on the parents of children with symptoms of AD was assessed by means of anxiety-related questions and questions that addressed the impact of AD on parents' daily activities. In addition, parents were requested to rate their perception of the severity of six physical symptoms experienced by their child during the AD episode. The questionnaire was modelled after studies that had focused on parental stress during the hospitalisation of a child,<sup>(5,6)</sup> suitably modified for the local population based on its educational status. A Malay language version of the questionnaire, which was validated for the purpose of the present study, was available upon request by the interviewee.

Data collected were analysed using the Statistical Package for the Social Sciences for Windows version 11.0 (SPSS Inc, Chicago, IL, USA). All costs were converted into United States dollars (USD; on average, USD 1 = Ringgit Malaysia 3.60 during the entire study period), and expressed as median and 95% confidence interval (CI) or mean ± standard deviation (SD). The *t*-test was used to compare the means and the Wilcoxon rank sum test was used to compare medians.

## RESULTS

The parents or caregivers of 85 children aged less than 24 months who were admitted for severe AD to the two participating centres and who consented to take part in the study were enrolled. All respondents to the questionnaire were parents of the hospitalised children (mothers n = 72, 85%; fathers n = 13, 15%). The mean age of the respondents was 30 ± 5.2 years. Two-thirds

(n = 58, 68%) of the children admitted were boys (male-to-female ratio 2.15:1.00). The median age of the children was 12 (mean age 13 ± 5; range 1–23) months. In a majority of the cases, the patient was the only child in the family (n = 50, 59%). 19 (22%) patients had one sibling, while the remaining 16 (19%) had two or more siblings.

The severity of symptoms reported in the children during the AD episode is presented in Table I. All 85 (100%) patients had diarrhoea (median duration 4 days; range 1–7 days), with a median frequency of four episodes/day (range 3 to > 10 episodes/day). 90% of the patients (72/81) had vomiting (median duration 4 days; range 1–7 days; frequency 1 to > 10 times per day). The median duration of fever was two days, while that of loss of appetite was three days. The median duration of hospitalisation was four days (mean 4.2 ± 2.5 days). No persistent diarrhoea or death was observed among the patients studied.

In the study cohort, a majority of the fathers had university degrees (n = 46, 54%) while the remaining had secondary education (n = 37, 46%). 47% of the mothers (n = 40) had university degrees and 52% (n = 44) had secondary education. Most of the fathers (n = 77, 91%) and nearly two-thirds of the mothers (n = 62, 73%) were employed full time. The mean combined monthly income of the parents was USD 1,575. Half of the parents surveyed had a combined monthly income < USD 1,100 (n = 43, 51%), while another 41% of families (n = 35) had a combined monthly income of between USD 1,100 and USD 2,777.

An analysis of the impact of diarrhoeal illness on the child's behaviour, as reported by the parents, showed that 60% of parents reported that their children were either often or always sleepy, and 70% reported their children as either often crying or always crying more than usual (Table II). In addition, 62% were reported to be either often or always irritable, and 77% were either often or always physically less active than usual. Overall, most of the parents were very worried about their child's symptoms during the diarrhoeal episodes (Table III). Vomiting and diarrhoea were the two symptoms that caused the most anxiety among the parents. 83% of parents described themselves as very worried about vomiting in their child, while 82% were very worried about diarrhoea. In contrast, only slightly over half of the parents (55%) reported being very worried about weight loss in their child.

**Table II. Impact of illness on child's behaviour during an acute diarrhoeal episode, as reported by parents.**

| Child's behaviour              | No. of respondents (%) |           |         |         |                       | Total |
|--------------------------------|------------------------|-----------|---------|---------|-----------------------|-------|
|                                | Never                  | Sometimes | Often   | Always  | Often/always combined |       |
| Sleeping more than usual       | 14 (17)                | 18 (22)   | 33 (41) | 16 (20) | 49 (60)               | 81    |
| Crying more than usual         | 3 (4)                  | 21 (26)   | 40 (49) | 17 (20) | 57 (70)               | 81    |
| More irritable than usual      | 8 (10)                 | 23 (28)   | 34 (42) | 16 (20) | 50 (62)               | 81    |
| Less active/playful than usual | 4 (5)                  | 15 (18)   | 39 (48) | 24 (29) | 63 (77)               | 82    |
| Physically exhausted           | 6 (7)                  | 8 (10)    | 41 (51) | 26 (32) | 67 (83)               | 81    |
| Less alert                     | 20 (25)                | 22 (28)   | 24 (30) | 13 (16) | 37 (47)               | 79    |

**Table III. Parental anxiety regarding their child's symptoms during an acute diarrhoeal episode.**

| Symptom          | No. of respondents (%) |                  |               |              |                             | Total |
|------------------|------------------------|------------------|---------------|--------------|-----------------------------|-------|
|                  | No worry at all        | Slightly worried | Quite worried | Very worried | Quite/very worried combined |       |
| Vomiting         | 0 (0)                  | 0 (0)            | 13 (17)       | 60 (83)      | 73 (96)                     | 76    |
| Diarrhoea        | 0 (0)                  | 2 (2)            | 13 (16)       | 67 (82)      | 80 (98)                     | 82    |
| Fever            | 0 (0)                  | 2 (3)            | 14 (19)       | 56 (78)      | 70 (97)                     | 72    |
| Pain             | 0 (0)                  | 3 (4)            | 13 (19)       | 52 (77)      | 65 (96)                     | 68    |
| Dehydration      | 0 (0)                  | 1 (1)            | 17 (24)       | 54 (75)      | 71 (99)                     | 72    |
| Loss of appetite | 2 (3)                  | 5 (6)            | 14 (17)       | 60 (74)      | 74 (91)                     | 81    |
| Loss of weight   | 2 (3)                  | 8 (12)           | 21 (30)       | 39 (55)      | 60 (86)                     | 70    |

**Table IV. Reactions of parents and impact of hospitalisation of the child for acute diarrhoea.**

| Parental reaction/impact    | No. of respondents (%) |          |         |                           |                          | Total |
|-----------------------------|------------------------|----------|---------|---------------------------|--------------------------|-------|
|                             | Not at all             | A little | A lot   | Extremely/a great deal of | A lot/extremely combined |       |
| Upset                       | 3 (4)                  | 5 (6)    | 37 (45) | 38 (46)                   | 75 (90)                  | 83    |
| Helpless                    | 23 (28)                | 30 (37)  | 17 (21) | 12 (15)                   | 29 (35)                  | 82    |
| Mentally exhausted          | 15 (18)                | 25 (30)  | 26 (31) | 17 (21)                   | 43 (52)                  | 83    |
| Physically exhausted        | 13 (16)                | 21 (25)  | 30 (36) | 19 (23)                   | 49 (59)                  | 83    |
| Fed up                      | 61 (73)                | 18 (22)  | 2 (2)   | 2 (2)                     | 4 (5)                    | 83    |
| Loss of sleep               | 1 (1.2)                | 19 (24)  | 36 (44) | 25 (31)                   | 61 (75)                  | 81    |
| Disruption of daily routine | 26 (32)                | 19 (24)  | 8 (10)  | 28 (35)                   | 36 (44)                  | 81    |

**Table V. Financial impact and out-of-pocket cost incurred by parents during hospitalisation of the child for acute diarrhoea.**

| Financial impact             | No. of respondents | Median <sup>†</sup> | Mean $\pm$ SD       | 95% CI        |
|------------------------------|--------------------|---------------------|---------------------|---------------|
| Missed paid work days (days) | 17                 | 3.00                | 3.3 $\pm$ 2.0       | 2.8–3.8       |
| Income loss/day (USD)        | 27*                | 20.83               | 22.94 $\pm$ 14.73   | 18.53–27.34   |
| Travelling cost (USD)        | 79                 | 6.94                | 7.78 $\pm$ 4.10     | 6.87–8.67     |
| Medical cost (USD)           | 71                 | 225.09              | 240.28 $\pm$ 209.04 | 200.01–297.25 |

\*Only 27 parents reported loss of income as a result of the child's hospitalisation.

<sup>†</sup> Total median out-of-pocket cost incurred by parents is USD 252.86.

CI: confidence interval; SD: standard deviation

Parents also reported experiencing significant emotional distress during the hospitalisation of their child (Table IV). Close to half of the parents (46%) reported being extremely upset about their child's physical illness, while another 15% reported feeling extremely helpless. Nearly a quarter of the parents reported being extremely physically (23%) or mentally (21%) exhausted. In addition, the activities and daily living of parents were also affected by the hospitalisation of their child due to AD. 75% of parents reported that they had either 'a lot' or 'a great deal' of loss of sleep during the diarrhoeal episode (Table IV). Another 44%

reported that their daily routines were either 'a lot' or 'extremely' disrupted as a result of the child's hospital admission. Only 57% of patients (n = 49) were making use of day-care facilities. The median duration for which these patients were kept away from day-care facilities was four (mean 3.5  $\pm$  2.5) days.

Out of the 85 parents, 81 responded to questions on workdays missed due to the hospitalisation of their child for AD (Table V). 14 parents (all mothers) were not in any form of full-time employment, while another six parents reported no loss of paid work. Among the remaining 61 respondents, the median number

of workdays missed was three (range 0.5–8.0) days. A total of 79 parents responded to questions on the financial implications of their child's hospitalisation for AD. A majority of parents ( $n = 52$ , 66%) indicated no loss of income. Of the remaining 27 parents, 12 (15%) reported a little loss of income, ten (13%) had some loss of income and five (6%) had substantial loss of income. The greatest costs incurred by parents out of their own pockets were related to medical expenses (median USD 225.09), followed by a loss of income as a result of being unable to go to work (median USD 20.83) and the travelling cost (median USD 6.94). The median total cost incurred by parents (out-of-pocket costs and loss of income) was USD 252.86, which constituted approximately 16% of the combined monthly family income.

## DISCUSSION

Recent research evidences an interest in ascertaining the financial burden of a disease in addition to determining mortality and morbidity related to illnesses. However, few studies have researched the emotional impact of the physical illness of a child with AD and the subsequent hospitalisation on parents. The hospitalisation of a child is a stressful time for caregivers, and more so if the hospitalisation is for life-threatening or chronic illnesses. We found that most of the studies on the subject of the emotional impact of a child's physical illness on parents either concentrated on severe life-threatening illnesses such as leukaemia<sup>(7)</sup> or chronic debilitating illness such as traumatic brain injury.<sup>(8)</sup> For instance, Mostert et al reported the profound impact of the treatment of childhood leukaemia on families from Indonesia.<sup>(7)</sup> In this study from a low-income country, the authors reported significant loss of income, financial difficulties as well as debt often resulting in postponement or withdrawal from part of the treatment.<sup>(7)</sup> Aitken et al, in their study, noted that poor functioning of the child after traumatic brain injury often led to prolonged family burden.<sup>(8)</sup> It is less known whether hospital admission for acute transient illnesses such as AD causes emotional distress among parents and caregivers. Recently, Commodari reported that parental perceptions of stress were determined by the duration of hospitalisation of their child and that hospitalisation for acute transient illnesses may also be a cause for emotional distress among parents.<sup>(6)</sup> The results of the present study confirm that parents may experience considerable emotional distress even when their child is hospitalised for acute transient illness such as AD. The 85 children enrolled in the present study had typical symptoms of AD with fever, vomiting and diarrhoea.<sup>(9,10)</sup> The median duration of hospital admission in a previous study was four days,<sup>(2)</sup> which was also similar to our findings. Our results show that during the hospitalisation of a child for AD, a great majority of parents reported being either 'quite' or 'very' worried about the symptoms of AD such as diarrhoea, vomiting and fever. Generally, parents were more worried about visible symptoms, such as vomiting, diarrhoea and fever, and comparatively less worried about symptoms that are less visible, such as the loss of weight. In addition, parents also reported the impact of AD on the general wellbeing of their child,

such as the child being sleepier, more irritable and crying more frequently during an AD episode.

In this study, considerable emotional distress was apparent among parents whose children were hospitalised for AD. More than 90% of parents reported being upset during the duration of AD in their child. More than half of respondents also reported feeling either 'a lot' of mental and physical exhaustion, or they were 'extremely' mentally and physically exhausted during the episodes. However, they were less likely to feel helpless in such situations, as admission to a hospital presumably offered parents reassurance that their child would receive appropriate medical care. Hospitalisation caused some disruption to the daily routine of parents, with three-quarters of them reporting a significant loss of sleep and slightly less than half reporting disruptions to their routines during hospitalisation.

In 2006, the population of Malaysia was 26 million.<sup>(11)</sup> The gross national income (GNI) per capita was USD 12,160 in 2006 and the GNI per capita per month was USD 1,108.<sup>(12)</sup> In 2007, the average monthly household income per person was estimated to be USD 1,023 (USD 1,210 in the urban areas and USD 634 in rural areas). In light of the above figures, our results indicate that parents of children hospitalised for AD experienced considerable financial burden, as the median extra cost (including out-of-pocket cost and loss of income) incurred by parents in our study as a result of such hospitalisation was USD 252.86, which constituted nearly 16% of the combined monthly family incomes.

In a previous study in 2009, we reported an out-of-pocket cost of USD 194 incurred by parents during their child's hospitalisation due to RV gastroenteritis in Malaysia.<sup>(3)</sup> In the present study, we found the estimated total out-of-pocket cost incurred by parents (USD 252.86) to be significantly higher than our previous estimate. A probable reason for this disparity may be the inclusion of patients hospitalised in a private hospital (in addition to a public hospital) in this study, which would likely incur higher medical costs than a public hospital, whereas the previous study only estimated the costs of patients admitted to a public hospital.

There are some potential limitations in the present study. Firstly, there was no concomitant study performed on the aetiology of AD seen in the patients hospitalised in our study. However, many studies from Malaysia have shown that RV is the most important cause of childhood diarrhoea requiring hospital care.<sup>(2,3,9,13)</sup> Secondly, as the severity of illness was not quantified for our patients, the authors were unable to ascertain whether a higher degree of dehydration would have caused greater emotional distress among parents. Thirdly, no follow-up interviews were performed for parents in the present study, thus we were unable to deduce the duration of emotional distress experienced by the parents following their child's discharge from the hospital. Finally, we could not determine whether the presence of such extended emotional distress in parents would eventually lead to compromised family health and functioning.<sup>(5)</sup>

To summarise, the results of this study indicate that the hospitalisation of children for AD causes considerable emotional

distress and financial burden to the parents, in addition disruptions to their daily routines and missed workdays. The parents were significantly worried about the physical symptoms of AD as well as the impact of AD on the general wellbeing of their child.

### ACKNOWLEDGEMENTS

The present study was funded by an unrestricted research grant from GlaxoSmithKline (GSK) Malaysia. GSK Malaysia played no role in the design, data collection or writing of the present study.

### REFERENCES

1. Glass RI, Bresee JS, Turcios R, et al. Rotavirus vaccines: targeting the developing world. *J Infect Dis* 2005; 192(Suppl 1):S160-6.
2. Lee WS, Poo MI, Nagaraj S. Estimates of economic burden of providing inpatient care in childhood rotavirus gastroenteritis from Malaysia. *J Paediatr Child Health* 2007; 43:818-25.
3. Chai PF, Lee WS. Out-of-pocket expenditure associated with rotavirus gastroenteritis requiring hospitalization in Malaysia. *Vaccine* 2009; 27 (Suppl 5):F112-5.
4. Fischer TK, Anh DD, Antil L, et al. Health care costs of diarrheal disease and estimates of the cost effectiveness of rotavirus vaccination in Vietnam. *J Infect Dis* 2005; 192:1720-6.
5. Leidy NK, Margolis MK, Marcin JP, et al. The impact of severe respiratory syncytial virus on the child, caregiver, and family during hospitalization and recovery. *Pediatrics* 2005; 115:1536-46.
6. Commodari E. Children staying in hospital: a research on psychological stress of caregivers. *Ital J Pediatr* 2010; 36:40.
7. Mostert S, Sitaresmi MN, Gundy CM, Sutaryo, Veerman AJ. Parental experiences of childhood leukemia treatment in Indonesia. *J Pediatr Hematol Oncol* 2008; 30:738-43.
8. Aitken ME, McCarthy ML, Slomine BS, et al. Family burden after traumatic brain injury in children. *Pediatrics* 2009; 123:199-206.
9. Lee WS, Veerasingam PD, Goh AY, Chua KB. Hospitalization of childhood rotavirus infection from Kuala Lumpur, Malaysia. *J Paediatr Child Health* 2003; 39:518-22.
10. Ng YJ, Lo YL, Lee WS. Pre-admission therapy for childhood acute diarrhoea --a hospital-based study. *J Clin Pharm Ther* 2009; 34:55-60.
11. World Health Organization. Country Report – Malaysia (online). Available at: [www.who.int/countries/mys/en](http://www.who.int/countries/mys/en). Accessed October 12, 2010.
12. Malaysia National News Agency. Available at: [www.bernama.com/bernama/v3/news.php?id=318742](http://www.bernama.com/bernama/v3/news.php?id=318742). Accessed October 12, 2010.
13. Goh CT, Cheah PK, Soo TL, Lee WS. The epidemiology and burden of childhood rotavirus infection in Sabah, Malaysia. *Med J Malaysia* 2009; 64:146-9.

## *Singapore Medical Journal Honour Roll of Editors*

### **Honorary Editor**

Dr Gwee Ah Leng

Dr Tan Kheng Khoo

Prof Lim Pin

Prof Feng Pao Hsii

Prof Chee Yam Cheng

Prof Tan Choon Kim

Prof Kua Ee Heok

Prof C Rajasoorya

Prof Wilfred CG Peh

Prof Teo Eng Kiong

### **Term of Service**

1960 – 1971

1971 – 1975

1975 – 1978

1978 – 1987

1988 – 1995

1995 – 1996

1996 – 1999

2000 – 2003

2004 – 2009

From 2010