

## The Hidden Impact of Childhood Cancer on the Family: A Multi-Institutional Study from Singapore

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### Abstract

**Introduction:** The care of children with cancer creates emotional and financial hardships for their families. There is a lack of information on the impact of childhood cancer on the family as a whole in Singapore. Thus, we set out to assess the financial impact as well as its psychosocial impact in our local context. **Materials and Methods:** All patients diagnosed and treated for cancer at the Departments of Paediatrics, KK Women's and Children's Hospital and National University Hospital, Singapore were eligible for this study. Families of these patients completed 2 self-administered questionnaires: (i) About-you and your-family and (ii) the Impact-On-Family scale. For the latter, the total score was obtained by the summation of all scores, where high scores correlated to high impact. **Results:** Seventy-nine parents were enrolled during the study period from October 2008 to February 2009. Being of Malay/Indian origin was associated with a high overall family burden. On the other hand, being of Malay/Indian origin was also associated with most successful at mastery when a child was diagnosed with cancer ( $P = 0.001$ ). In addition, when compared to caregivers who remained employed, those who were asked to quit their job, experienced a higher Financial Burden ( $P = 0.03$ ), a high Familial/Social Burden ( $P = 0.05$ ) and a high Personal Strain ( $P = 0.03$ ). **Conclusion:** Childhood cancer impacted family life in Singapore at many levels. In particular, the factors involved are various cultural discourses; employment status of caregivers; and those whose leave/pay are affected.

Ann Acad Med Singapore 2012;41:170-5

**Key words:** Burden, Cancer, Psychosocial

### Introduction

Chronic childhood illnesses have varying degrees of impact on the children and their families. Some chronic conditions that have little or no impact on the children and their families whereas those at the other end of the spectrum that has a high impact, for example, the diagnosis of cancer.<sup>1</sup> Childhood cancer diagnosis has considerable consequences for the family. It is an extremely distressing experience for everyone involved and requires a significant degree of support, coping, and adaptation.<sup>2,3</sup> The impact on the family can be in the form of increased burden and responsibility of caring for the sick child or adolescent at home for which families have varying physical and emotional capabilities. Furthermore, as most of medical treatments are delivered

during the working hours, there is a potential for increased loss of income for the caregivers in the family leading to financial strain.

Several studies have found that having a child in the family with a chronic illness can induce feelings of stress, imposes major psychological and social adjustments, increases the burden of care and places the entire family at risk.<sup>4-7</sup> In a study by Sloper et al<sup>8</sup> who assessed the needs and responses of parents following the diagnosis of childhood cancer, 55% of mothers and 41% of fathers indicated high levels of emotional distress. The authors found that the parental concerns included a possible delay in diagnosis and dissatisfaction in the lack of

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communication by the healthcare team post-diagnosis. In another 2-year prospective study by Sawyer et al<sup>9</sup> in children with cancer and their parents at diagnosis, at 1-year and 2-year post-diagnosis, the authors found that they experienced significantly more emotional distress during the period immediately after diagnosis than compared to those children and parents from the community, the control group. However, the number of problems experienced by the children with cancer and their parents declined during the first year after the children's diagnosis and stabilised at a level comparable with that found among children and parents in the general community.

The increasing costs involved in the care for children with cancer comprised 3 major categories: direct, indirect, and intangible costs. Direct costs include direct medical costs such as costs of medical services obtained and non-medical costs such as costs incurred in receiving medical care, for example transportation fees. Indirect costs include loss of productivity related to the illness when a parent has to take leave. Whilst intangible costs are, for example, costs of pain and suffering related to the diagnosis of cancer and its treatment. In a landmark study conducted in 1979 by Lansky and co-workers,<sup>10</sup> the authors collected financial cost information from 70 families of children with cancer. They found that more than half of the families were paying more than 25% of their weekly income for non-medical expenses which were inclusive of loss in pay associated with the child's illness. The factors influencing the extent of cost in this study were a higher level of care received, a poorer patient performance status, a longer distance required to travel from the treatment centre to home, and a larger family size. In their follow-up study in 1983, these authors demonstrated that the costs varied by the treatment phase, with the early diagnostic and the terminal phases of the illness being the most expensive.<sup>11</sup> In another study, Barr et al<sup>12</sup> demonstrated that the family-borne costs represented at least one third of the average family's after-tax income during the treatment of 3 paediatric malignancies namely acute lymphoblastic leukaemia, Wilms' tumour and neuroblastoma. In a retrospective, cross-sectional study by Heath et al<sup>13</sup> using the IOF scale in 56 families of children with cancer, the authors revealed that the perceived financial burden had the highest impact on the families with cancer. The factors which were found to contribute to this higher impact were single parenthood, lower income, and greater distance needed to travel to the hospital.

In Singapore, approximately 120 children are diagnosed with cancer each year. Medical costs for the treatment can vary from S\$20,000 to S\$250,000. Furthermore, the care for these children creates emotional, psychological and social adjustments and places the family unit at risk. To date, there is limited information regarding the financial,

social, and emotional burden on families of children diagnosed with cancer in Singapore. Hence, we set out to evaluate the financial, psychological, social, emotional and the coping strategies associated with childhood cancer and the impact of the diagnosis on the children and their families in Singapore.

## Materials and Methods

All paediatric patients diagnosed and treated for childhood cancer under the age of 21 years at Department of Paediatrics, KK Women's and Children's Hospital (KKH) and National University Hospital (NUH), Singapore were eligible to participate in the study. Their cancer diagnosis had to have been made at least 6 months prior to enrolment into the study. As the country strives towards being a medical hub for the rest of the Southeast Asia region, foreign patients receiving treatment for childhood cancer from countries such as Malaysia, Indonesia, Vietnam, and Sri Lanka, who sought care in Singapore, were also included in the study. Exclusion criteria were those whose cancer diagnosis was made less than 6 months prior to enrolment and those who did not consent to participate in the study. Also excluded were those undergoing bone marrow transplant (BMT) at the request of the primary medical provider either due to illness severity or extreme parental emotional distress due to BMT. Ethical approval by the institutional review boards of both KKH and NUH were obtained prior to the enrolment onto the study. Eligible participants were approached at their regularly scheduled outpatient follow-up. Upon agreeing to participate and after informed consent was obtained, they were given 2 self-administered questionnaires for completion: (i) About-you and your-family and (ii) Impact-On-Family Scale (IOF).<sup>14,15</sup>

The About-you and your-family questionnaire contained information, such as the child's cancer, demographic characteristics of the family, employment status of the caregiver, and financial information of the family. This questionnaire was formulated with the aim of obtaining basic characteristics of the study population. The second questionnaire used in our study, the original Impact-on-Family Scale is a 24-item questionnaire measuring 4 dimensions of impact. Financial Burden refers to the economic consequences for the family. Familial/Social impact concerns the level of disruption of social interaction for the family. Personal Strain assesses the psychological burden experienced by the primary caretaker for the child with cancer. Mastery refers to the coping strategies employed by the family.<sup>14,15</sup> Cronbach alpha reliabilities for the 4 dimensions of the IOF scale are 0.72, 0.86, 0.81, 0.60, respectively and 0.88 for the total score.<sup>15</sup> Since its original publication in 1980 by Stein & Reissman, the Impact-on-Family Scale has been used in a vast number of

studies in various cultures concerning a range of chronic childhood illnesses. When validity was tested, the IOF scale proved to discriminate between chronic illness e.g. cancer and non-neoplastic illnesses and acute illnesses e.g. gastro-intestinal, respiratory, or skin disorders. In addition, it has been found that the more severe and/or debilitating the illness, the greater is the impact on the family.<sup>16-20</sup> The original 24-item IOF has since been expanded into a 33-item self-administered questionnaire to further include 6 items relating to financial impact and sibling impact.<sup>21</sup> In our study, we used the shorter original version, the 24-item IOF scale as the majority of the children did not have siblings and the aim of our study was to focus more on the impact the child's cancer diagnosis has on the family as a whole.

A total score for the IOF Scale was obtained by the summation of all 24 scores as a general measure of impact, where a higher score indicates a greater impact. Individuals with the highest 30% impact scores were defined as the 'high impact group'. A weighted score, the total score for each domain divided by the number of items in each domain, was also obtained for each item. Univariate logistic regression analysis was performed to find out which factors were significantly associated with a high impact for the overall score and for each domain separately. Internal validity of the questionnaire was tested by Cronbach's alpha. All analyses were performed using Statistical Package for Social Science 17.0 Window version (SPSS v17.0).<sup>22</sup>

## Results

From October 2007 to October 2009, a total of 376 patients seen and treated at KKH and NUH. Among them, 205 patients were excluded due to the following reasons: ineligible criteria as outlined by the eligibility checklist (n = 156); lack of follow-up information (n = 29); and lost to follow-up (n = 20). Of the remaining 171 patients, 96 patients who presented to either KKH or NUH for their scheduled follow-up during the study period were approached for participation in the study. Twelve caregivers who refused to participate cited various reasons citing time constraint or inconvenience while another 5 with incomplete questionnaire responses were excluded. Our final analysis was based on 79 valid responders who represented 82% respondent rate for the study.

The study cohort comprised 48 males (61%) and 31 females (39%). Forty (51%) children were diagnosed before 5 years of age, 20 (25%) between 5 and 10 years of age and 19 (24%) after 10 years of age. Majority of the respondents were parent of Chinese origin (54%) followed by foreign patients at 33%. Lastly, respondents of Malay and Indian origin made up the remainder of 13%. The most prevalent diagnoses were haematologic malignancies such

as acute leukaemia or lymphoma (56%) followed by solid tumours (38%). Five patients (6%) were diagnosed with a tumour not otherwise specified (NOS). The majority of the children, (n = 45) were still undergoing treatment at the time of enrolment into the study. In terms of family characteristics, 57 (72%) of the respondents were mothers. The highest level of education achieved for the parent or caregiver was primary/secondary school in 32 (40%), undergraduate in 31 (39%), and postgraduate/professional in 16 (20%). Twenty-four (30%) participants reported their monthly household income as ≤S\$2000, while 24% had an income of ≥S\$5001. Financial assistance was being offered

Table 1. Patient and Family Characteristics

Patient Characteristic	n = 79 (%)
<b>Age (years)</b>	
< 5	40 (51%)
5 – 10	20 (25%)
> 10	19 (24%)
<b>Gender</b>	
Male	48 (61%)
Female	31 (39%)
<b>Race</b>	
Chinese	43 (54%)
Malay / Indian	10 (13%)
Foreign	26 (33%)
<b>Diagnosis</b>	
Haematologic Malignancy	44 (56%)
Solid Tumor	30 (38%)
Not Otherwise Specified	5 (6%)
<b>Phase of Treatment</b>	
Completed	12 (15%)
Ongoing	45 (57%)
Not Specified	22 (28%)
<b>Relationship to Child</b>	
Mother	57 (72%)
Father	19 (23%)
Guardian / Other	4 (5%)
<b>Marital Status</b>	
Married	75 (95%)
Not married/ Divorced/ Separated	4 (5%)
<b>Number of People in Family</b>	
2 – 3	10 (13%)
4 – 6	60 (76%)
≥ 7	9 (11%)
<b>Level of Education</b>	
Primary/Secondary school	32 (40%)
Undergraduate	31 (39%)
Postgraduate/Professional	16 (20%)

Table 1. (con't) Patient and Family Characteristics

Patient Characteristic	n = 79 (%)
<b>Employment Status at Present</b>	
Working	39 (49%)
Not working	21 (27%)
Home-maker / NA	19 (24%)
<b>Household Income / Month (SG\$)</b>	
≤ 2000	24 (30%)
2001 – 5000	29 (37%)
≥ 5001	19 (24%)
Not Answered	7 (9%)
<b>Financial Assistance</b>	
Yes	48 (61%)
No / Not answered	31 (39%)

Table 2. Reliability Analysis Cronbach's Alpha Impact on Family in Singaporean, Italian, and United States Chronically Ill Children<sup>15,23</sup>

	Singaporean (n = 79)	Italian (n = 387)	US (n = 100)
Financial Burden	0.69	0.70	0.72
Familial/ Social impact	0.88	0.81	0.86
Personal strain	0.79	0.65	0.81
Mastery	0.61	0.32	0.60
Total Score	0.64	-	0.88

to 48 (61%) of patients (Table 1).

The internal consistency of the Impact-on-Family questionnaire for our study was acceptable as shown by an overall Cronbach's alpha of 0.64. Cronbach's alpha for the Mastery subscale was the lowest at 0.61 whilst Cronbach's alpha was 0.88 for the Financial/Social Burden subscale (Table 2). Of the 4 domains, the highest weighted score (3.80), hence the highest impact was in the perceived Familial/Social Burden, followed by Financial Burden (3.41) and Personal Strain (2.89). The Mastery scale or the coping of the family with the child's illness posed a lower burden (1.45). The total score for all 4 domains of impact was 65.2, range, 28 to 82 shown in Table 3.

Current 'leave status' of the caregiver, i.e. voluntary leave, affected pay or being asked to quit the job, was significantly associated with higher financial burden and high social impact ( $P = 0.03$  and  $P = 0.05$  respectively). Furthermore, no Malay/Indian parents reported a high Familial/Social impact, compared with 30% of Chinese parents and 42% of foreign parents ( $P = 0.05$ ). Unlike the other domains, a higher score in the perceived Mastery domain actually means that the families reported a high level

Table 3. Summary of Impact Scores in Singaporean Children

Dimension	No. of Items	Mean	Weighted		Min	Max
			SD	Mean		
Financial Burden	4	13.6	2.41	3.41	7	16
Familial/ Social Impact	9	26.9	6.33	3.80	9	36
Personal Strain	6	17.3	3.99	2.89	6	24
Mastery	5	7.25	2.04	1.45	5	15
Total Score	24	65.2	11.2	10.74	28	82

No.: number; SD: standard deviation; Min: minimum; Max: maximum

Table 4. Associations Between Patient Characteristic and Impact Score by Domain

Domain / Impact	P value
<b>Domain I — Financial Burden</b>	
Leave Status	0.03
<b>Domain II — Familial / Social</b>	
Race	0.05
Leave Status	0.05
<b>Domain III — Personal Strain</b>	
Race	0.03
Leave Status	0.05
<b>Domain IV — Mastery</b>	
Race	0.00
Religion	0.00

of successfully coping when the child was diagnosed with a cancer. We found that the greatest proportion of the Malay/ Indian parents reported the highest in the Mastery subscale, i.e. they were the group who had the best success in their coping skills ( $P = 0.001$ ). Our foreign patients' families were the next group who reported as having the second higher ability in coping when the child was diagnosed with a cancer. In the subgroup of religions, Buddhists reported the perceived highest impact score in Mastery, i.e. they appear to be the most successful group in coping with the diagnosis in Table 4 ( $P = 0.001$ ).

### Discussion

A diagnosis of childhood cancer impacted the family life at many levels. We found that the factors which may adversely influence the context in which the families care for these children include: being of Chinese race when compared to Malay or Indian race; the caregiver being unemployed; and the caregiver whose leave status or pay are negatively affected. Being of Malay/Indian race however, correlated positively with a lower Familial/Social and Personal Strain domains. The overall internal validity with a Cronbach's alpha of 0.64 was acceptable in our study population.

However, our findings suggest that the use of IOF scale needs further research and validation specifically in our local families whilst taking into account the cultural variations and the multilingual nature of Singapore.

When comparing the mean impact scores of Singaporean families to Italian and American children, the Singaporean caregivers scored similarly in all 4 domains when compared to their Caucasian counterparts. Only in the Familial/Social domain, the Singaporeans scored relatively high, i.e. the mean impact score of 26.9 compared to 13.69 in the Italians and 22.09 in the Americans.<sup>23</sup> Perhaps, these findings are due to the cultural differences which exist between the 3 ethnically diverse groups. There exists an assumption in Asian culture that people often place a higher value on the opinions of other family members and neighbours, which may contribute towards a perceived higher Familial and Social burden. Additionally, Chinese cultural beliefs such as considering the child's illness as 'fate' also may influence the parents' responses socially. However, further studies in obtaining relevant data in various cultural differences and perceptions are needed.

We also found that recipients of financial aid experienced lower Financial Burden impact. Those who took leave or had their pay reduced contributed to the largest proportion of respondents with the highest financial impact score. However, factors such as marital status, education level of the caregiver, the income level, or the distance and time needed to travel to the doctor did not have significant impact on the Financial Burden. Similarly, in an Indonesian study, the parents reported a high prevalence of financial difficulties (78%) and lost jobs (29%) leading to postponing or withdrawal of treatments in 18% of the cases.<sup>24</sup> In contrast, an Australian study in 56 children with cancer showed that determinants of a high financial burden included single parenthood, lower income, and greater distance needed to travel to the hospital.<sup>13</sup> The possible explanations why our study did not find any significant associations between the financial burden and race, religion, or marital status of the caregivers include a small sample size, the fact that a majority of the care givers are 'married', hence providing a continued income and spousal support, and the differences in culture. Additionally, a larger proportion of the financially needy local population are given the necessary financial aid. Furthermore, Singapore is a geographically small country of 252 square miles, hence the distance needed to travel to seek medical care is rather short to make a significant burden.

In domain II, we found that none of the Malay or Indian caregivers reported a high disruption in Familial/Social burden, whilst a large proportion of Chinese reported a high score. Additionally, those who took leave or had their pay reduced also reported the highest impact on Familial/Social burden ( $P = 0.05$ ). In a study conducted in United Kingdom

on 20 parents of children with cancer, the caregivers of children with cancer reported new responsibilities and role expectations, and they felt that the 'proximity', i.e. being able to provide 'comfort', or 'keep-watch' to the sick child was of importance. This in turn compromised their ability to function in other roles, i.e. the role as parent of other children who are healthy.<sup>25</sup>

When evaluated for Personal Strain, we found that the mothers (75%) reported a higher personal strain when compared to the fathers, although this was not statistically significant. Of note, the mothers made up a higher proportion of all respondents (71%) in our study. In terms of the 'present employment status', the proportion who reported as 'working' had the highest impact in Personal Strain (56%;  $P = 0.09$ ). In the 'leave status', the proportion of those who took leave or had their pay reduced had the highest psychological burden (64%;  $P = 0.05$ ). Similarly, in an American study, although both parents reported normative levels of psychological distress, the fathers were reported to undergo more psychological stress and depression ( $P =$  not significant).<sup>26</sup>

Surprisingly, in our study the ethnic Chinese (64%) had the most difficulties in mastering when their child was diagnosed with a cancer. In contrast, a higher proportion of Malay/Indian parents followed by foreign caregivers of varying ethnicity reported having the least difficulties in Mastery ( $P = 0.001$ ). It is unclear whether this difference is a true difference rather than a cultural variation or due to the small sample size. It is of interest to note that a local study done by Ow et al<sup>27</sup> in 2003 also revealed that the subjective burden was higher in the Singaporean parents of all races during the initial phase of treatment and after discharge from a diagnosis of childhood cancer.<sup>27</sup>

We acknowledge that there are limitations of our study: this is a small sample size, hospital-based study. Moreover, the IOF questionnaire has not been validated or translated for our local context. The cross-sectional nature of the study further limits our findings and the benefits of longitudinal research needs to be taken into account especially when one is studying the impact and coping mechanisms in these families. However, the strengths of our study are that it is a multi-centre study encompassing the majority (>90%) of childhood cancer cases in Singapore and this study is the first of its kind in a multi-ethnic Asian setting.

## Conclusion

Overall, the burden of childhood cancer in Singapore is comparable to other countries. However, we see a higher impact in Financial Burden and Social/Familial domains. The factors associated with high impact in our study cohort are: being of Malay or Indian origin; loss of employment

status; and being asked to leave or quit the job. Locally, there has been little research efforts to understand the psychosocial consequences of the arduous cancer treatment to the child or the impact it has on the child's family. Based on our initial findings, we aim to strive further to identify the gaps in the provision of a holistic medical and psychosocial care, prevent or ameliorate of the impact of childhood cancer, and strengthen the coping capacity for children and their families once a child is diagnosed with cancer. Once we can identify these gaps and the lack in the support systems, we can then inform the healthcare policy makers and providers in better structuring the available supportive mechanisms for these children and their families. We believe that this will, in turn, help improve the delivery of better healthcare services for childhood cancer patients in Singapore and the surrounding region.

#### Acknowledgements

*Supported by Singapore Cancer Society.*

#### REFERENCES

1. Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity and impact. *Am J Public Health* 1992;82:364-71.
2. Kazak AE. The social context of coping with childhood chronic illness: Family systems and social support. In: La Greca AM, Siegel LJ, Wallander JL, Walker CE, editors. *Stress and Coping in Child Health*: New York: Guilford Press, 1992.
3. Kazak AE, Segal-Andrews AM, Johnson K. Paediatric psychology, research and practice: A family/systems approach. In: Roberts MC, editors. *Handbook of Paediatric Psychology*: New York: Guilford Press, 1995.
4. Hoddap RM, Dykens EM, Masino LL. Families of children with Prader-Willi syndrome – stress-support and relations to child characteristics. *J Autism Dev Disord* 1997;27:11-24.
5. Martin C, Nisa M. Meeting the needs of children and families in chronic illness and disease: a greater role for the G.P.? *Aust Fam Physician* 1996;25:1273-81.
6. Woods NF, Haberman MR, Packard NJ. Demands of illness and individual, dyadic, and family adaptation in chronic illness. *West J Nurs Res* 1993;15:10-25.
7. Jackson AC, Stewart H, Maree O'Toole M, Tokatljan N, Kate Enderby K, Miller J, et al. Pediatric brain tumor patients: their parents' perceptions of the hospital experience. *J Pediatr Oncol Nurs* 2007;24:95-105.
8. Sloper P. Needs and responses of parents following the diagnosis of childhood cancer. *Child Care Health Dev* 1996;22:187-202.
9. Sawyer M, Antoniou G, Toogood I, Rice M. Childhood cancer: a two-year prospective study of the psychological adjustment of children and parents. *J Am Acad of Child Adolesc Psychiatry* 1997;36:1736-43.
10. Lansky SB, Cairns NU, Clark GM, Lowman J, Miller L, Trueworthy R. Childhood cancer: nonmedical costs of the illness. *Cancer* 1979;43:403-8.
11. Lansky SB, Black JL, Cairns NU. Childhood cancer: medical costs. *Cancer* 1983;52:762-6.
12. Barr R, Furlong W, Henwood J, Feeny D, Wegener J, Walker I, et al. Economic evaluation of allogeneic bone marrow transplantation: a rudimentary model to generate estimates for the timely formulation of clinical policy. *J Clin Oncol* 1996;14:1413-20.
13. Heath JA, Lintuuran RM, Rigguto G, Tikotlian N, McCarthy M. Childhood cancer: Its impact and financial costs for Australian families. *Pediatr Hematol Oncol* 2006;23:439-48.
14. Stein RK, Jessop D. Tables documenting the psychometric properties of a measure of the impact of chronic illness on the family. New York: Pact papers, Albert Einstein College of Medicine, 1985.
15. Stein RK, Riessman CK. The development of an Impact-on-Family Scale: Preliminary findings. *Medical Care* 1980;28:465-72.
16. Coster WJ, Haley S, Baryza MJ. Functional performance of young children after traumatic brain injury: A 6-month follow-up study. *Am J Occup Ther* 1994;48:211-8.
17. Cronin CM, Shapiro CR, Casiro OG, Cheang MS. The impact of very low-birth-weight infants on the family is long lasting. A matched control study. *Arch Pediatr Adolesc Med* 1995;149:151-8.
18. Gennaro S. Preterm low-birth weight infants: Health and family outcomes. *Family and Community Health* 1995;17:12-21.
19. Lesar S, Maldonado YA. The impact of children with HIV infection on the family system. *Families in Society. The Journal of Contemporary Human Service* 1997;78:272-9.
20. Zahr LK, Khoury M, Saoud NB. Chronic illness in Lebanese preschoolers: Impact of illness and child temperament on the family. *Am J Orthopsychiatry* 1994;64:396-403.
21. Stein RK, Jessop DJ. The Impact on Family Scale Revisited: Further Psychometric Data. *Journal of Developmental & Behavioral Pediatrics* 2003;24:9-16.
22. Statistical Package for Social Science 17.0 Window version.
23. Kolk AM, Schipper JL, Hanewald GJFP, Casari EF, Fantino AG. The impact-on-family scale: a test of invariance across culture. *J Paediatr Psychol* 2000;25:323-9.
24. Mostert S, Sitaresmi MN, Gundy CM, Sutaryo, Veerman AJ. Parental experiences of childhood leukaemia treatment in Indonesia. *J Pediatr Hematol Oncol* 2008;30:738-43.
25. Young B, Dixon-Woods M, Findlay M, Heney D. Parenting in a crisis: conceptualising mothers of children with cancer. *Soc Sci Med* 2002; 55:1835-47.
26. Bonner MJ, Hardy KK, Willard VW, Hutchinson KC. Brief report: psychosocial functioning of fathers as primary caregivers of pediatric oncology patients. *J Pediatr Psychol* 2007;32:851-6.
27. Ow R. Burden of care and childhood cancer: experiences of parents in an Asian context. *Health Soc Work* 2003;28:232-40.