

Childhood Leukaemia: Towards an Integrated Psychosocial Intervention Programme in Singapore

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Abstract

A hospital-based behavioural intervention programme was developed for families of children with newly diagnosed or relapsed Acute Lymphoblastic Leukaemia (ALL). The programme's aim was to enhance the families' ability to cope with the emotionally distressing aspects of the illness and the medical treatment. Eight children and 10 parents participated in the programme for 12 weeks. The children received individual therapeutic play sessions and computer-assisted distraction activities, while the parents participated in a structured support group. The subjects were evaluated before, immediately after, and 6 months post-intervention, using both self-administered questionnaires and clinical observation by the psychosocial intervention team and the hospital staff.

Findings indicated positive changes on the coping and the hopelessness measures, and an overall benefit for both parents and children. The hospital team reported better compliance and co-operation with treatment procedures by the children and their parents. The study concludes with an assessment of the benefits and feasibility of integrating a psychosocial programme into paediatric oncology services in Singapore.

Ann Acad Med Singapore 1998; 27:485-90

Key words: Cancer support groups, Coping, Paediatric psycho-oncology, Play therapy, Psychosocial intervention

Introduction

In the last two decades there has been a surge of interest concerning the psychosocial correlates of life-threatening illnesses. Research in this area has focused especially on cancer and the possible link between immunology and psychological factors. Recent studies in both Western^{1,2} and Asian countries^{3,4} have demonstrated significant relationships between selected psychosocial variables and adjustment to cancer. Some studies have strongly associated certain types of social support (e.g. group therapy⁵) with higher survival rates in patients with various cancers.

Although there is still an ongoing debate among researchers and clinicians regarding psychosocial versus biological predominance in survival among cancer patients,⁶ there seems to be a growing acceptance of the need to integrate emotional support and behavioural intervention in current practice settings.^{7,8}

With respect to childhood cancer, the chances of long-term survival and cure have vastly improved worldwide over the last 20 years.⁹ As a result, the focus of

attention has shifted from how to cope with death and dying to how to live with childhood cancer and its many repercussions for the young patient and his or her family. In paediatric oncology much attention has been paid to distress factors, such as anticipatory nausea and fear of invasive, painful procedures.¹⁰ Cognitive-behavioural interventions, and other forms of psycho-educational support have proven quite successful and have been implemented in the Memorial Sloan-Kettering Cancer Centre in New York,¹¹ and the Research Centre for Childhood Cancer in Bonn, Germany.¹²

In Singapore, approximately 40 new cases of childhood (<12 years) acute lymphoblastic leukaemia (ALL) are diagnosed annually.

Although these numbers appear small, they must be viewed in terms of the family impact, or the "ripple effect" they have, and within the long-term context of a chronic, life-threatening illness.

To date, there have been no psycho-oncological studies in Singapore, although the medical treatment and progress of leukaemic children have been docu-

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mented.^{13,14} In terms of formal social support programmes for this population, there are only limited psychosocial services available in Singapore's hospitals, and they tend to focus more on financial than on psycho-emotional aspects.

In view of the above, and working on the assumption that Singapore children with ALL and their families have similar needs to those observed elsewhere, the following intervention study was proposed and implemented.

Materials and Methods

The study had several objectives: the first two major aims were to provide a formal support service to the families and to gain a better understanding of their coping behaviour and psychosocial needs. The third was to find out how the family's coping behaviour could be enhanced through systematic intervention, and fourth was to assess how adequately equipped the health care services in Singapore currently are, to meet the multiple needs of these families.

The programme was set up in July 1994 in the paediatric department of the Singapore General Hospital (SGH). It was conducted for twelve consecutive weeks on the hospital's premises. The programme's behavioural intervention team included a medical social worker, a clinical psychologist and a play therapist trainee from the National University of Singapore (NUS). This team interacted closely with a paediatrician and several staff nurses from SGH throughout the duration of the programme.

The intervention for the children followed a cross-over design, where children received either of two modes of treatment conditions in reversed order:

1. Individual play sessions focusing on their illness, defined as problem-focused play (PFP).
2. Individual computer game sessions, defined as computer-assisted play (CAP).

Each session was planned to last for approximately one hour, depending on the child's age and clinical condition. While the PFP sessions utilised toys and games that related directly to the child's illness and hospital's experience, the CAP sessions were designed to provide maximum distraction from fear-evoking aspects of the illness, such as painful medical procedures and physical isolation. The toys utilised for these sessions were typically dolls representing the hospital staff and the patients, medical instrument kits and educational books on hospitalisation and body functions.

For the CAP sessions, age-appropriate software was utilised that was not related to illness.

In order to evaluate the effect of the two play conditions studied, appropriate research instruments were chosen according to the following criteria:

1. Their ability to measure aspects related to chronic childhood illness.
2. Their cultural compatibility: measurements that had been used and validated before for Asian populations, preferably in Singapore or at least in one other Asian country with a similar population make-up.

For the paediatric subjects, the Family Relations Test¹⁵ was selected because of its ability to assess the child's relationship and emotional attachment to significant others, such as family members and hospital staff. Also utilised were a specially designed Child's Coping Questionnaire and the Rutter Behaviour Checklist¹⁶ to detect any pre-existing emotional/behavioural problems.

The team also transcribed each individual session of play intervention, which was then carefully analysed for relevant content. For an example of an intervention session with a child, see excerpt in Figure 1.

The main method utilised for intervention with parents was the structured group session, which primarily employed a psycho-educational model. This model provides both informational and emotional support and promotes mutual sharing and bonding among group members.

The parents' group meetings were held once a week for a duration of two hours, in a room close to the children's ward. This enabled parents to be within reach should their child need them urgently, a fact which facilitated their participation in group meetings.

The sessions' content addressed the parents' need for general information on their child's illness and their

Excerpt of transcript of session no. 1 with YT, on 21 July 1994
 [Background information: The patient, a 5-year-old girl, had been diagnosed with acute lymphoblastic leukaemia about six weeks prior to this intervention. The following conversation took place while she was waiting for an injection.]

Play	Sometimes children in hospital have something that
Therapist (PT):	makes their worry better... talk about their worries...
YT:	Talk to their friends, watch TV like me, every time I watch TV I don't want to see anything else.
PT:	So watching TV helps. Does it make your worry go away?
YT:	Funny, then go away already, I see the cartoons, then go away. The last time, needle take out my hand, the needle red already, my skin so lock! [The needle couldn't penetrate.]
PT:	So was that funny or scary?
YT:	Scary, like a monster, the monster like ET. But when the real monster come, just kick monster away and monster scared already.
PT:	Wow! You are such a brave girl, I think kicking the monster is a real good idea!
YT:	I just make like dinosaurs, like that (demonstrates with a toy dinosaur).
PT:	You are really bigger than the monster, is that right?
YT:	The monster run away, run until my father's pocket.

Fig. 1. Transcript of problem-focused play session.

need to process the implications of this information. Much time was spent on discussing emotions and thoughts fairly typical in such situations, such as guilt and loss. Experience was shared on coping tactics and strategies that parents had found helpful. In addition, relaxation techniques were taught to help parents cope with the physical and emotional rigours of a prolonged hospital stay.

Originally, the intervention study intended to compare the effect of participation in a parental support group to controls, but this design was dropped on ethical grounds.

The criteria for selecting research instruments for adult subjects were the same as those used for the children.

The Beck Hopelessness Scale (BHS),¹⁷ consisting of 10 self-assessment questions and the Jalowiec Coping Scale (JCS),¹⁸ a 60-item Likert-type scale, were used to assess the major variables and were used pre- and post-intervention. In addition, a Subject Information Sheet (SIS) and a feedback questionnaire on the entire programme were obtained from the parents. In order to complement the parents' subjective assessment, all subjects were evaluated by the group facilitator on the basis of process recordings immediately following each group intervention session.

As coping with childhood leukaemia is a long-term process, the parents were contacted again, 6 months post-intervention, to repeat the BHS and JCS questionnaires.

Results

Of the 10 children referred to the programme, 5 were newly diagnosed and 5 had relapsed. Two children died during the period of study.

Of the remaining 8 children, 4 received a total of 20 sessions, half of them participated in problem-focused play and the other half in computer-assisted play. The other 4 children received 5 sessions of each play modality. Most of the sessions were conducted during the children's hospitalisation in the paediatric ward, and some were carried out during their outpatient visits.

The family relations test revealed that most children denied having negative emotions, while most positive emotions were assigned to family members, especially siblings. Only a few items were assigned to self and hospital staff. The Rutter behaviour checklist indicated that only one of the children had a possible conduct/emotional disorder. The children's coping questionnaire reflected that the problem-focused play was helpful to the entire group and the computer-assisted play helped all but 1 child.

In comparing the two modes of play intervention, it was found that while the computer-assisted play served the function of distracting the children from their medi-

cal conditions and unpleasant aspects of hospitalisation, the problem-focused play went beyond this objective, as it allowed for more meaningful communication and enabled the children to ventilate their emotions and anxiety.

Overall, the written and verbal feedback given by the children, their parents and the hospital staff indicated high level of satisfaction with the intervention programme for children. While the parents stated that it helped their child to deal with the emotional trauma of hospitalisation and invasive procedures, the hospital staff cited better cooperation with treatment procedures as a major contribution of the intervention.

Although a total of 17 parents participated in at least one group session throughout the entire intervention period, the average attendance for each session was 8 parents. Two couples dropped out following the death of their child. For most families, only 1 parent could attend the group meetings each time. Couples tended to rotate, so that eventually both parents had access to the support group.

Initially, the group intervention experienced some obstacles, such as language as the Group Facilitator spoke only English. Three couples had only very basic knowledge of English. As the sessions proceeded however, the group developed a strong desire to share and support each other emotionally and these barriers were overcome, with the help of parents who volunteered to serve as translators.

Overall, results for the parent support group were positive and encouraging. Most group participants had become more hopeful following the intervention and expressed a high level of satisfaction with the support group. Results from the BHS indicated that all parents had improved their scores on this scale and had moved up from being either severely or moderately hopeless at the beginning of the intervention to higher levels of hopefulness post-intervention.

Results from the JCS indicated that most parents experienced a positive change in their choice and effectiveness rating of coping strategies at the end of the intervention. Although researchers on coping and illness are still undecided on what exactly constitutes "good coping", they basically agree that it includes both a wide repertoire and more active types of coping strategies.^{19,20}

In our study sample, parents switched to using more active coping strategies more often following the intervention (e.g. confronting the problem or seeking emotional support). The results also reflected some interesting differences between the mothers' and the fathers' preferred coping styles. A summary of these findings is shown in Table I. At six months follow up however, it was found that most parents had reverted to the "origi-

TABLE I: GENDER DIFFERENCES IN PREFERRED USE OF COPING STRATEGIES

Jalowiec Coping Scale
Range of Scores: 0 (lowest) to 3 (highest)

Men (n = 4)

Rank	Pre-test use	Score	Post-test use	Score
1	Optimistic	2.30	Confrontative	3.00
2	Self-reliant	2.29	Optimistic	2.28
3	Supportive	2.10	Self-reliant	2.14

Women (n = 6)

Rank	Pre-test Use	Score	Post-test Use	Score
1	Supportive	1.93	Supportive	2.30
2	Optimistic	1.80	Confrontative	2.14
3	Confrontative	1.79	Optimistic	1.98

TABLE II: CHANGES IN PRE-TEST, POST-TEST I AND POST-TEST II ON JALOWIEC COPING SCALE

Jalowiec Coping Scale
Range of Scores: 0 to 3

Overall Mean Use Score

Subject	Pre-test	Post-test I	Post-test II
1	1.53	1.95	1.50
2	1.93	2.07	1.92
3	1.65	1.92	2.05
4	1.38	1.47	1.15
5	1.47	1.62	1.52
6	1.67	1.62	1.57
7	1.67	2.00	1.27
8	0.80	0.85	1.15

nal” coping strategies they had used prior to the intervention (Table II).

On the other hand, results on the BHS, taken six months later, were nearly identical to those scores obtained immediately after the intervention. This was irrespective of the child’s medical progress.

Another important observation at post-intervention and six-month follow-up was the bonding that had occurred among the group participants. The emotional support among them was extended to the point that some parents attended the funeral of one of the children from this group who died during the study period.

Discussion

The project team had some initial doubts as to the parents’ willingness or ability to fully utilise this Western-developed intervention model. The concern was that the parents would be uncomfortable with the requirement to disclose and share intimate family-related feelings and behaviours with strangers, and that they would be reluctant for their children to be “tested” or

seen by a psychologist. However, both parents and children surprised the hospital staff and the project team by responding enthusiastically to the programme.

Another area of concern was the anticipated disruption of hospital routine and procedures, and an elevated level of anxiety among children and parents as a direct result of the intervention. These fears, however, did not materialise. On the contrary, the intervention was perceived to be anxiety reducing by all parties involved (based on feedback questionnaires).

For the intervention with children, it was remarkable, given the severity of the illness and the trauma of repeated hospitalisations and the numerous diagnostic and therapeutic procedures these children would have been subjected to, all except for one child, were rated to be within normal behavioural/emotional levels on the Rutter Behaviour Problem Checklist. This finding is in line with many other study findings which have commented on the outstanding resilience Singapore children seem to have.^{21,22} The overall positive response of the children to problem-focused play and distraction methods is similar to observations made in Western countries utilising such interventions.^{23,24}

Interestingly, ethnic, language and socio-cultural differences in the group of parents (8 Chinese and 2 Malays) did not prove to be as big an obstacle as was initially feared. Another interesting feature that stood out in the analysis of the parents’ group sessions was the difference in coping strategy choices along gender lines. While the fathers in the study repeatedly sought medical information on the illness, and preferred self-reliant coping strategies over emotive ones, the mothers utilised support ant strategies (mutual emotional support offered within the group) more often than self-reliant ones. Thus it was observed that the subjects’ actual behaviour in the group matched their stated choices on the JCS. These findings are similar to gender differences found in Western families coping with the same illness¹⁹ and may therefore be more universal than culture-specific.

A finding with practice implications for parents of children with cancer was the predominance of guilt feelings and anger. These feelings were expressed mostly in the context of perceiving themselves as incompetent parents. Some anger was also expressed towards the medical profession in general for its inability to determine the cause of the illness. These findings correspond to similar themes of cancer support groups in the West.²⁴

Although the findings of this study are relevant to the specific needs of Singapore families coping with childhood leukaemia, they must be considered as preliminary. Some of the constraints of this study are: the small number of subjects, differing lengths of treatment due to varying duration of hospitalisation, differences in the medical condition and the length of illness of children in

the study group and the delegation of intervention with the children to a research assistant who was under training. Further studies on this population should attempt to overcome some of these limitations through more vigorous control and a longitudinal research design.

Conclusions

This intervention model, which was the first of its kind implemented in a Singapore hospital, has several implications for paediatric oncologists and related health care providers in Singapore.

We were able to demonstrate that in children with cancer, compliance with treatment regimes and parental co-operation could be improved by using this intervention model. This observation confirms similar findings in other Asian⁴ and Western countries.

Secondly, by establishing and encouraging parent support groups "on-site" at the hospital, the medical team can use this resource to refer newly diagnosed and relapsed cases. These support groups can greatly enhance and complement the medical team's efforts in providing comprehensive care to their patients.

Last but not least, it has been observed^{25,26} that paediatric oncology teams often experience frustration, burn out and grief reactions because of the nature of this particular sub-specialty. By integrating clinical social workers or psychologists into a hospital-based programme, the needs of the medical team may also be addressed and their coping repertoire further enhanced.

With respect to psychological intervention with the children, this study demonstrated that the problem-focused play sessions helped them to express fears surrounding pain and death, and to assimilate unpleasant experiences in a way that was beneficial to their coping reactions. As the computer-assisted play was found to be of limited usefulness, a subsequent study has been implemented in two hospitals to compare problem-focused play with cognitive-behavioural methods.

From the generally positive response to this study by patients, their parents and the hospital team, we have tentatively concluded that families facing childhood leukaemia in Singapore can indeed benefit from structured support groups and play intervention in terms of enhanced coping behaviour.

The study provides some evidence that a well coordinated and comprehensive programme can meet several of the multiple needs of such families. The receptiveness of the hospital team to this intervention programme indicates that it can be adapted to fit into a hospital setting without disrupting existing routines.

In light of these observations, we recommend that hospitals with oncology units should work towards developing an integrated psychosocial intervention pro-

gramme which will become an integral part of the total management strategy for children with cancer.

Acknowledgements

This study was funded by the National University of Singapore. The research assistance of Ms Janice Liow Siew Yong is deeply appreciated. Special thanks to the paediatric staff of Singapore General Hospital and to Dr Tan Hiang Khoon of the Children's Cancer Foundation, Singapore, who contributed to the study in so many ways.

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