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Psychosocial adjustment among pediatric cancer patients and their parents

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Abstract Children with cancer face both physical and psychosocial challenges. However, there is not enough empirical evidence in Taiwan regarding how they and their families cope with their illness. The purpose of the present study was to explore the psychosocial impact of cancer on target children and their families as well as the degree of depression experienced by these children. Twenty-four pediatric cancer patients, aged 8 through 17 years, completed the Chinese version of Children Depression Inventory (CDI). Both these patients and 18 parents completed questionnaires about their psychosocial adjustment since the diagnosis of cancer. The results showed: (i) patients did not perceive significant changes in their psychosocial adjustment, whereas parents indicated significantly lower mood of patients and a slight decrease in the number of friends; (ii) both parents and siblings showed positive adjustment; and (iii) there was neither significant difference on the CDI scores between the pediatric cancer patients and a normative group, nor significant relationships between patients' CDI scores and demographic characteristics of both patients and their parents, parenting attitudes, as well as variables related to the illness. Lastly, the results are discussed in terms of issues of methodology and instruments. Possible direction for further investigations is suggested.

Key words Children Depression Inventory (CDI), depression, parents, pediatric cancer patients, psychosocial adjustment.

INTRODUCTION

Childhood cancer affects about 500 children each year in Taiwan.[1] In the past, the prognosis for a child with cancer was almost invariably fatal. Parents could expect a few months or, at best, a year or two of remissions and relapses while preparing themselves for the inevitable death of their child.[2] More recently, there has been a dramatic improvement in treatment. There is still no certain cure, but more than 50% of children suffering from cancer now live for 5 years or more to reach adult life apparently cured.[3] Parents are given hope, yet must face the possibility that cancer may kill their child and so live in incomparable uncertainty and anxiety throughout the years of treatment and perhaps for years beyond the last check-up.[2,4]

It has been long recognized that in the early months after diagnosis, the parents of children with cancer often suffer a variety of psychosocial symptoms.[5–7] With children surviving longer, there is more recent evidence of psychological distress in the parents, persisting well after apparently successful treatment of the cancer.[8–11] In contrast, children with cancer and their healthy siblings have been found to have increased rates of externalizing/internalizing problems.[12,13] However, considerably inconsistent findings exist in research literature that has studied the depressive symptoms of children with chronic medical problems, in general, and cancer, in particular.[14] For example, some studies have found somewhat increased rates of child depressive symptoms reported by children with cancer or their parents.[15,16] In contrast, a majority of studies have found depressive symptoms no more common among children with than without cancer.[17–22]

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Moreover, a study even indicated significantly fewer depressive symptoms among adolescents with cancer compared to healthy controls.[23] With this inconsistent finding in the literature and growing concern about whether children with cancer and their families are at an increased risk for adjustment problems, several studies have been conducted in Taiwan to address such an issue.[24–27] Many factors have been identified in the literature that might have an impact on the adjustment process of patients and their parents. For example, in a recent study, it was found that Taiwanese parents of pediatric cancer patients tended to attribute their children's cancer to his/her wrongdoing in the past.[28] Such an explanation of illness could result in a punitive judgment on the parents and give rise to a guilty conscience. Similar guilt feelings have also been documented in cancer research on parental maladaptation.[29] These findings have implications for therapeutic intervention to patients and their families of childhood cancer. However, more studies are needed, given the complexity of this issue.

The present paper is part of a project that aimed at setting up a support system for pediatric cancer patients and their families. By examining psychosocial changes in both patients and parents since diagnosis, as well as patients' levels of depressive symptoms, we hope to learn more about the psychosocial stress or adjustment involved and to develop plausible ways to combat or facilitate it.

METHODS

Subjects

Twenty-five pairs of pediatric cancer patients and their parents from the ambulatory services of the Pediatric Hematology-Oncology Department at Chang Gung Children's Hospital were recruited for this study during the period from August to November 1997. Subjects were selected according to two criteria: (i) age range of 8–17 years; and (ii) exclusion of patients with mental retardation and/or language disorders. One patient and seven parents failed to complete the questionnaires due to the scheduling difficulty. Therefore, the final sample included 24 patients (14 boys and 10 girls) and 18 parents (6 fathers and 12 mothers). Demographic data of these pediatric cancer patients and their parents are presented in Table 1. Eighteen (75%) patients had diagnoses of leukemia or lymphoma. The mean duration since diagnosis was 14.5 months (SD = 11.48). The mean age of the patients was 12.7 years (SD = 3.02). The social economic status of the families in the present study ranged from low to medium. The majority of these parents (72% of parents) had less than high school education. Most patients lived with both parents (70%). The average number of children in a household was two, ranging from one to four. The primary caregivers for the patients were mothers (70%).

Table 1. Demographic data of pediatric cancer patients and their parents

	Patients ($n = 24$)		Parents ($n = 18$)	
Variable	Mean (SD)	Frequency (%)	Mean (SD)	Frequency (%)
Gender				
Male		14 (58%)		6 (33%)
Female		10 (42%)		12 (67%)
Age (in years)	12.7 (3.02)		38.8 (6.03)	
Diagnosis				
Leukemia (ALL + ANLL)		9 (37.5%)		
Lymphoma		9 (37.5%)		
Osteosarcoma		2 (8.3%)		
Other		4 (16.7%)		
Duration of illness (months)	14.5 (11.48)			
Education				
College				3 (17%)
High school				2 (11%)
Junior high school				7 (39%)
Elementary school				6 (33%)

ALL, acute lymphoblastic leukaemia; ANLL, acute non-lymphoblastic leukaemia.

Instruments

Psychosocial adjustment questionnaires

Two forms of psychosocial adjustment questionnaires were designed separately for patients and their parents. The patient questionnaire comprised four sections: (i) demographic characteristics; (ii) psychosocial health conditions; (iii) perception and attribution of the illness; and (iv) psychosocial changes of their families. The section on psychosocial health conditions consisted of paired items, rated on a five-point Likert scale, about the patient's subjective evaluation of their current and premorbid conditions of physical health, academic performance, number of friends, self-concept, temper and mood. On assessing temper, for example, patients were asked to rate from 1: always hot-tempered to 5: seldom hot-tempered on the paired questions of 'How is your temper currently?' and 'How was your temper before you became sick?'

The 12-item scale of perception and attribution of the illness was designed to assess their subjective thoughts of the cause of the particular illness, such as fate, environmental pollution, previous wrongdoing, unhealthy diet, heredity, gene mutation, stress, bad names, problems during pregnancy, evil *Feng-Shui*, infection and no particular reasons. Each item was rated on a four-point Likert scale, ranging from 1: fully disagree to 4: fully agree.

The section regarding psychosocial changes of their families consisted of: (i) two parallel sets of five questions about the patient's view of the changes in parental attitudes and behavior towards the patients themselves and towards their siblings since the onset of cancer; and (ii) seven questions about post-morbid changes of the patient's relationships with parents and siblings. All the questions were rated on a three-point Likert scale (i.e. 1: care less, 2: same as before and 3: care more). For example, patients were asked to rate their parents' attitudes and behavior towards themselves or their siblings on discipline, academic achievement, daily care, diet and household chore responsibilities with a comparison anchor (i.e. before the onset of the illness).

Parallel to the patient questionnaire, the parent questionnaire comprised four sections: (i) demographic characteristics; (ii) patient's psychosocial health conditions; (iii) perception and attribution of the illness; and (iv) psychosocial changes of their families. The content of items and construction of the rating scale in the parent questionnaire were similar to those in the patient questionnaire.

Children Depression Inventory

The Chinese version of the CDI[30,31] was used in the present study to assess commonly reported symptoms of depression that pediatric cancer patients might have experienced in the 2-week period prior to the testing. Using a self-report format, CDI is designed to be used for children aged 8 through 17 years. It consists of 27 items, each with three statements describing depression-related conditions. It takes about 20–40 min to complete and the total score a child can earn on CDI ranges from 0 to 54 points. As a tool used in many studies, CDI has shown satisfactory psychometric property.[32]

As to the Chinese version of the CDI, a preliminary report has provided a few small-scale local norms of third to eighth grades ($n = 1840$). Recent standardization and psychometric studies have been conducted with various groups of adolescents ranging from average junior and senior high schools to adolescents with conduct problems from corrective schools in Taiwan.[30,33] Preliminary results has yielded satisfactory internal consistency, Cronbach α ($n = 32 - 218$) = $0.82 - 0.84$, and 2-week test–retest reliability, Pearson r ($n = 32$) = 0.85.

Re-examination of the psychometric properties of the Chinese version of the CDI by using various samples of junior high school students yields satisfactory results with 3-week test–retest reliability ranging between 0.53 and 0.54, as well as internal consistency Cronbach's α equal to 0.84 and 0.81 for normal adolescents and adolescents with conduct problems, respectively.[33]

Procedure

Data collection was conducted in the chemotherapy room at the Pediatric Hematology-Oncology Department at Chang Gung Children's Hospital. Pediatric cancer patients who were receiving outpatient chemotherapy were screened for their inclusion in this study. Before approaching the target patients and their families, physicians and nurses were consulted in order to prevent any inadvertent harm to the subjects. Informed consent and assent forms were obtained.

Initially, a pilot study with a qualitative approach was employed to explore the perception and attribution of the illness and psychosocial changes in patients and their families. Based on the results of unstructured interviews with three patients and eight parents, the authors formulated two forms of structured questionnaires to assess the psychosocial adjustment of patients and their families after the diagnosis of cancer. These questionnaires were completed in structured interviews individually for each patient and their parents. It took approximately 40–60 min to complete the interview and questionnaire. Each patient was also individually instructed on how to fill out the Chinese version of the CDI. One of the researchers was always on site when the subjects were filling out the Chinese version of the CDI and help was provided immediately whenever needed.

Data analyses

Descriptive statistics was used to present the demographic data of the subjects and their families. The *t*-test was conducted to examine the difference in the perception of change since diagnosis between patients and their parents. Patients' CDI scores were first standardized against a normative group and then examined for any significant difference from normative data. Correlational analyses were also conducted to examine the relationships between patients' CDI scores and demographic characteristics of both patients and their parents, parenting attitudes, as well as variables related to the illness.

RESULTS

Perceptions and feelings regarding the illness

Almost all the patients, except two younger ones (both 8.8 years old), knew that they were sick and needed treatment. Thirteen (54.2%) children knew their exact diagnosis, which was mainly learned from their physicians (53.8%) or parents (23.1%). Nine (37.5%) had partial knowledge of their illness and the primary informants were their parents (44.4%) or physicians (33.3%). A majority of these children (67%) did not like to come to the hospital for treatment. The main reasons for these aversive reactions were: painful treatment procedure, side-effects, conditioned aversion, social isolation, boredom and deprivation of physical activities. In contrast, five (21%) children reported a fondness to visit the hospital because they had an opportunity to do things they enjoyed, such as reading comic books, participating in various activities, or just becoming accustomed to the procedures.

Table 2. Parents' self-report of change in attitudes and behavior towards patients and siblings since diagnosis of cancer ($n=18$)

Parental attitudes and behavior	Frequency (%)
Towards patients	
More careful about patient's diet	15 (83%)
More attentive to patient's daily care	15 (83%)
Fewer demands on household chore responsibility	12 (67%)
More lenient in discipline	11 (61%)
Lower academic expectation	9 (50%)
Towards siblings	
More careful about their diet	10 (56%)
More attentive to their daily care	9 (50%)
Favor patients more than siblings	8 (44%)

Most patients and their parents felt that their premorbid health conditions were at least as good as their peers. As to potential causes of cancer, most patients attributed their illness to fate and unhealthy diet, while their parents attributed the illness to environmental pollution and unhealthy diet. Both patients and their parents strongly disagreed that the illness was caused by infection, problems during pregnancy, heredity, previous wrongdoing, bad names or evil *Feng-Shui*.

Psychosocial changes since diagnosis

Although these patients reported no significant changes in their academic performance, friendship, character, temper and mood since diagnosis, their parents observed significantly lower mood ($t=3.4$, $P<0.01$) and a slight decrease in number of friends ($t=-2.1$, $P=0.056$). Parents also reported adjustments in their attitudes and behavior towards their child with cancer since diagnosis (Table 2). In general, they became more protective (more cautious about patient's diet and daily care), more lenient and less demanding (lower expectation on academic performance and household chore responsibility) towards the child. In addition, there seemed to be a spillover effect on parental attitudes and behavior towards the siblings with 50% or more parents reporting more cautiousness about siblings' diet and daily care. However, most parents still practiced the same discipline on siblings as they did before the diagnosis of the illness, regarding their behavior, school performance and household chore responsibility.

Both patients and their parents observed some positive changes in siblings' behaviors, such as more responsibility, more independence and greater closeness to the patient. Parents did not feel that their marital relationship had been jeopardized by the illness.

Depressive tendency of pediatric cancer patients

Cancer children's CDI scores were compared to grade- and gender-equivalent norms ($n=1840$, grade range = 3rd to 9th grade) and then transformed into Z scores. Although four children had a Z score greater than 1, the mean Z score was –0.25, indicating that the children with cancer did not differ significantly from

Table 3. Patients' Children Depression Inventory raw scores and standardized scores by grade and gender

			Current sample ($n = 24$)		Grade and gender norms	
Subject no.	Grade	Gender	Raw score	Z score	Mean	SD
1	2	M	18	1.015	12.60	5.32
2	3	M	6	−1.241		
3	3	M	19	1.203		
4	3	M	9	−0.677		
5	3	F	12	−0.454	15.32	7.32
6	3	F	3	−1.683		
7	5	M	25	2.021	12.21	6.33
8	5	F	4	−1.412	14.14	7.18
9	5	F	6	−1.149		
10	6	M	13	−0.064	13.42	6.57
11	7	M	13	−0.062	13.44	7.06
12	7	M	14	0.079		
13	8	M	16	0.363		
14	8	M	12	−0.204		
15	8	F	23	1.096	14.70	7.57
16	8	F	11	−0.489		
17	9	M	12	−0.476	15.39	7.12
18	9	M	9	−0.897		
19	9	M	4	−1.600		
20	9	M	16	0.086		
21	9	F	19	0.425	16.11	6.80
22	9	F	11	−0.751		
23	9	F	14	−0.310		
24	9	F	10	−0.899		

grade- and gender-equivalent norms on their CDI scores (Table 3). Analyses of the relationships between patient's depression and gender, age, birth order, diagnosis and duration of illness revealed insignificant results. Similarly, patient's depression score was unrelated to number of siblings, parent's age, education and parenting attitudes.

DISCUSSION

The results should be interpreted with caution given the lack of a control group for parents and the use of a normative instead of a community comparison group for patients. In addition, the heavy reliance on structured interviews as the only means of data collection as well as the lack of psychometric information on these interview questionnaires has also posed great concern. Despite the above-mentioned limitations, however, the present study has revealed some interesting findings.

First, the results of this study suggest that there was a positive change in the relationship of the child with their parents and siblings after diagnosis of cancer. Most studies in the literature have focused on the negative impact that such debilitating illness might have on children with cancer and their families.[34] Few studies have explored the positive changes that might occur in the families with cancer children. That is, a crisis can turn into an opportunity for the whole family to renew their relationship and to have a new perspective on life.

Second, our study did not find significant difference on depressive symptoms between children with cancer and a normative group. This finding is in general agreement with the majority of findings in the literature that children with cancer did not report more depressive tendency than healthy children.

However, this issue is more complicated than it appears. Many factors can affect a child's psychological well-being after diagnosis of cancer, such as age, gender, family/social support etc. More studies are needed in order to gain better understanding of this issue, and the mechanisms involved in the coping process should also be examined.

Third, parents in the present study tended to attribute their children's illness to scientific causes (i.e. environmental pollution and unhealthy diet) instead of their past wrongdoing as suggested in previous findings.[28] However, parental guilty feelings might arise from blaming themselves for not taking good care of their children and trying to make up for this by paying more attention to the diet and daily care of the cancer child and their siblings. Since the treatments for pediatric cancer patients tend to be a long process and require intensive parental involvement, it is very important to be aware of issues related to parental guilty feelings in designing and providing intervention for children with cancer and their parents.

Lastly, having cancer is likely to have a long-term impact on many aspects of a patient's development and psychosocial adaptation, such as educational achievements, employment and marriage.[11,35,36] Although this study has included a wide age range of patients, due to the small sample size, it is insufficient to address the psychosocial adjustment issue of pediatric cancer patients from a developmental perspective. Longitudinal studies with larger samples that collect data regarding patients' and families' experiences related to cancer diagnosis, treatment and long-term adjustment will improve our understanding of the problems and, hopefully, will help us identify any perceivable benefits that may result from having cancer.

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