

Hospitalization, Later Onset of the Disease, and Psychological Problems of Chronically Ill Children

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Abstract

This study examined disease-related variables that are thought to play some role in exacerbating psychological problems among chronically ill children. The participants included 63 parents of children suffering from cancer, epilepsy, and asthma. The parents rated their children's behavioral and emotional problems and provided information on the frequency of hospitalization, onset, and duration of the illness and the age of the child at the disease onset. The Child Behavior Checklist was used. Multiple-regression analysis and correlations were computed to determine the relationship of disease-related variables to the psychological problems of the children. One-way, between-subject ANOVA was used to analyze the psychological problems of children of different age groups. The results showed positive relationships between the frequency of hospitalization and the later onset of the illness and the psychological problems among children. It also showed that children in the age group of 7 to 11 years had the highest number of problems compared with other age groups. The psychological healing aspects of the family and the culture on the children's illnesses in the collectivist societies have been discussed.

Keywords

psychology, social sciences, health psychology, applied psychology, clinical psychology, developmental psychology, experimental psychology, personality

Disease Variables and Psychological Problems

Childhood chronic illness is any medical illness or disability that affects children for an extended period of time, often for life (Garrison & McQuiston, 1989). A chronic illness incapacitates or significantly impairs a child's sensory, physical, and mental aspects, interferes with his or her daily functioning, and is only manageable but seldom curable. Studies suggest that the family of a chronically ill child experiences denial, disbelief, distress, depression, guilt, "burden of responsibility," a "changed identity," family conflict and resentment in response to the child's illness (Coffey, 2006; Jusiene & Kuchinskis, 2004; Reiter-Purtill et al., 2008).

Prevalence studies suggest that 15% to 18% of all children in the United States suffer from a chronic health condition (Judson, 2004); about 33% of Medicaid children in the U.S. have a chronic health condition (Heflinger & Saunders, 2005).

Survey studies conducted in Malaysia indicate that approximately one child below 12 years is diagnosed with cancer per week (More Children Stricken by Cancer, 2002) and the National Cancer Registry records about 42,985 new cancer entries each year (Chye & Yahaya, 2004). The number of children suffering from asthma has increased from 10% to 13% between 1995 and 2002 (*Menangani masalah asma*, 2002; Othman, 2003) and prevalence of epilepsy among children is estimated at 0.5% (Guide for Nurses, 2003; Manonmani & Tan, 1999).

The results of a National Health and Morbidity Survey indicate a significant proportion of children suffering from asthma, cancer, and other physical disabilities also show psychological problems (Toh et al., 1999).

Other studies indicate that chronically ill children are at a greater risk of maladjustment, and mental health and psychological problems than children without such conditions (Caplan et al., 2005; Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003; Judson, 2004; Zeegers et al., 2010).

As regard the link between a chronic illness and specific psychological problems, studies have found emotional and psychological problems, such as anxiety and depression, among children and adolescents suffering from chronic illnesses (Caplan et al., 2005; Jaffee et al., 2005; Jusiene & Kuchinskis, 2004), difficulties in peer group relationships (Berge & Patterson, 2004; Parkes et al., 2008), behavior problems (Fagnano et al., 2009; Halterman et al., 2006), low social self-esteem and high social anxiety (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002), health risk behaviors (Suris, Michaud, Akre, & Sawyer, 2008), stronger beliefs

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in external control (Garrison & McQuiston, 1989), and internalizing problems (Alati et al., 2005). These broad findings show that chronic illnesses negatively affect the physical and psychological well-being of children. In addition, many “disease-related” variables related to the life circumstances of chronically ill children may also affect their psychological well-being.

Disease-related variables may include the frequency of hospitalization, the duration of illness, the age of the child at the onset of illness, the child’s age and the gender. Research shows that frequent hospital admissions, at least in the short term, cause adverse effects on the child’s well-being, and expose him or her to a number of stressors, which include stress of separation from the family, school and friends, pain of treatment, unfamiliarity of the surroundings, and fear of the unknown (Pao, Ballard, & Rosenstein, 2007). Studies also suggest that physical stressors experienced during the hospital stay are related to psychological distress among chronically ill children (Saylor et al., 1987). Other adverse hospitalization-related effects include trouble sleeping at night, bad food, lack of privacy, and experiencing medical procedures as more disturbing than the illness itself or the pain (Spirito, Stark, & Tyc, 1994). Recurrent hospitalization of chronically ill children is also associated with physical dysfunctions (Kelly & Hewson, 2001), and an increase in behavioral problems after being discharged from the hospital, regardless of age or medical condition (Thompson & Vernon, 1993).

Another factor related to the psychological problems among chronically ill children is the duration of disease. A number of studies of chronically ill children indicate severe adjustment problems with extended illness into adolescence (Jacobson et al., 1997; Tebbi, Bromberg, Sills, Cukierman, & Piedmonte, 1990).

The onset of illness at a specific age may also affect the physical, social, and cognitive development of a child and her or his well-being. Different studies show that children with later onset of illness compared with earlier onset show greater psychological problems (Johnson & Meltzer, 2002), have more difficulties in adjusting to their disease (Brown, Kaslow, Sansbury, Meacham, & Culler, 1991), and exhibit greater internalizing and externalizing problems (Schoenherr, Brown, Baldwin, & Kaslow, 1992).

Our study examined the impact of three factors, namely, the frequency of hospitalization, the duration of illness, and the age of the child at the onset of illness on the psychological problems among chronically ill children. We selected three medical categories of oncology, neurology, and respiratory problems because they differ on disease-related dimensions, including age of child at the onset of the disease, duration and severity of illness, perceived prognosis, course, and degree of interference with the daily living (Kelly & Hewson, 2001; Schoenherr et al., 1992; Spirito et al., 1994). However, examining the impact of these factors separately

on the three categories of disease was not possible because of small sample sizes in each category.

Culture plays a significant role in psychopathology; however, the research differs in describing its role. The cultural relativism perspective views culture and psychopathology as interlinked; a psychological problem can be understood within the framework of its culture. The opposing view acknowledges the impact of culture on psychological disorders but looks at the cross-cultural similarities in the psychological underpinnings and subjective experiences of these disorders (Matsumoto & Juang, 2013).

The issue is rather complex when it comes to the definition and the measurement of psychological problems across different cultures, especially, in the case of children. Children are more under the dictates of the cultural influences through their parents and other social institutions. Generally, researchers define and describe a disorder in a specific culture and then export their notions to the other cultures (Kirmayer, 2007). The opponents of this approach emphasize the cultural specificity of psychological problems (Marsella & Yamada, 2007), especially the problems with the reliability and validity of the diagnostic categories across different cultures. Some argue that even translation of some items of an assessment instrument to another culture might not make any sense as the language may be very culture specific (Kleinman, 1995). This suggests the complexity of the psychometric issues related to the assessment of psychopathology across cultures (Green, 2009).

There is ample evidence that sociocultural factors play a significant role in health and disease processes (Ahmad, 2000; Cheung, Nelson, Advincula, Cureton, & Canham, 2005; Matsumoto & Juang, 2013; McPherson, Smith-Lovin, & Brashears, 2006). Cross-cultural studies show that family and social support in collectivist culture buffer many types of stresses (Matsumoto & Fletcher, 1996; McPherson et al., 2006; Triandis, Bontempo, Villareal, Asaim, & Lucca, 1988). Studies also show that cultural beliefs (Gone, 2010) and religious and spiritual values and practices (Abu Raiya & Pargament, 2010) may be mitigating forces in illnesses and psychopathology to reckon with (Sue, Zane, Hall, & Berger, 2009).

In contrast to the Western studies, we believe that the family and the parent–child relationship in the Malaysian collectivist culture may, to some extent, mitigate the negative impact of disease-related variables (Berry & Hardman, 1998). However, we also feel that as the parent–child relationship and parental support in a collectivist culture is deep rooted (Ahmad, 2000; Cheung et al., 2005; Triandis et al., 1988), any short- or long-term separation of children from their families may negatively impact the physical and psychological health of the child. This may be, especially, applicable in the case of hospitalization of the child. The first hypothesis tested was that a greater frequency of hospitalizations is associated with more psychological problems.

Social contact and participation are part of the life of a child in Malaysia. Any inability of a child to participate in everyday social activities may affect the well-being of the child. The second hypothesis of the study postulates that the longer the duration of the illness, the children will face more psychological problems.

A child who has been healthy and enjoyed a carefree life for most of his or her childhood may react with utter disbelief and denial when diagnosed with a chronic illness compared with a child in his or her early childhood. The diagnosis of chronic illness in the later life compared with the earlier years of life may have more negative consequences for a child. The third hypothesis predicts that the later the onset of the illness, more psychological problems will be experienced by chronically ill children.

Method

Participants

The participants were 63 parents of chronically ill children including 51 mothers and 12 fathers in the age range of 20 to 51 years. Majority of the parents were housewives, others were working in the government or private sector. The parents were recruited from the outdoor pediatric clinics and wards of Kuala Lumpur General Hospital (GHKL) after they agreed to participate in the study.

The children were 39 males and 24 females in the age range of 4 to 17 years. There were 22 children suffering from cancer, 21 from epilepsy, and 20 from asthma. Twenty-nine children were the middle child, 15 were the eldest, 17 were the youngest, and 2 were the only child in the family. As regard their schooling, 25 children attended school for 1 to 3 years, 15 attended school for 4 to 6 years, 16 attended school for 7 to 9 years, 5 children attended school for 10 to 12 years, and 2 children did not yet attend any school. Thirty-four children came to the clinic for the follow-up while 29 were hospitalized for the treatment. There were 7 outpatient and 15 hospitalized cancer children. Among epilepsy children, 20 were outpatient and 1 was hospitalized. In the case of asthma children, 7 were outpatient and 13 were hospitalized. Detailed demographic characteristics of the respondents and the children are presented in Table 1.

Measures

A demographic questionnaire and the Child Behavior Checklist (CBCL) for the age range of 4 to 18 (Achenbach, 1991) were used in the study.

CBCL. CBCL (age 4-18; Achenbach, 1991) was used to assess the psychological problems of chronically ill children. The CBCL is a widely used measure to assess behavioral, emotional, and social problems of children cross-culturally. The checklist has 118 items and is used to obtain information

Table 1. Demographic Characteristics of the Parents and Their Chronically Ill Children.

Variable	Frequency (n)	Percentage (%)
1. Parents' characteristics		
Parenthood		
Mother	51	-81.0
Father	12	-19.0
Age (in years)		
20-30	4	-6.3
31-40	28	-44.4
41-50	21	-33.3
50 and above	10	-15.9
Occupation		
Housewife	37	58.7
Government servant	20	31.7
Private sector	5	-7.9
Others	1	-1.6
2. Children's characteristics		
Sex		
Male	39	61.9
Female	24	38.1
Age (in years)		
4-7	24	38.1
7-11	18	28.6
11-17	21	33.3
Number of siblings		
0-4	27	42.9
5-8	33	52.4
9 and above	3	-4.8
Order of birth		
First child	15	-23.8
Middle child	29	-46.0
Youngest child	17	-27.0
Only child	2	-3.2
Years of schooling		
No schooling	2	-3.2
1-3	25	39.7
4-6	15	23.8
7-9	16	25.3
10-12	5	-8.0
Type of visit		
Outpatient	34	54.0
Hospitalized	29	46.0

about children's competencies and problems from their parents or surrogate parents. Responses are scored on a 3-point rating scale ranging from "0" through "2" (0 = *not true of the child*; 1 = *sometimes true of the child*; and 2 = *very true or often true of the child*) during the past 6 months.

The profile of CBCL displays eight syndromes derived from the statistical analyses of the problems of 4,455 children referred to mental health services, such as withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behaviors,

and aggressive behaviors. The eight syndromes are categorized into two major groups of disorders, internalizing and externalizing problems. The externalizing problems involve children's conflicts with others and comprise of aggressive and delinquent behavior syndromes. The internalizing problems consist of disorders of emotion and subjective inner distress among children such as anxiety and depression, withdrawn, and somatic complaints (Achenbach, 1991).

The internal consistency of subscales of CBCL ranges from 0.54 to 0.96 (Achenbach, 1991). Content validity of CBCL is demonstrated by the ability of nearly all of its items to discriminate significantly between demographically matched referred and nonreferred children. Construct validity is supported by numerous correlates of CBCL scales, including significant associations with analogous scales on the Conner's (1996) Parents Questionnaires and the Quay-Peterson (1983) Revised Behavior Problem Checklist. Criterion validity is supported by the ability of the CBCL's quantitative scale scores to discriminate between referred and nonreferred children after demographic effects were partialled out. Clinical cutoff points on the scale were also shown to discriminate significantly between demographically matched referred and nonreferred children (Achenbach, 1991).

The major issues in the use of CBCL in other cultures pertain to its construct validity, in particular the wording and the interpretation of the items (Green, 2009; Kleinman, 1995; Marsella, 2009). However, some major reviews of the use of CBCL in different cultures show its reliability and validity (Crijnen, Achenbach, & Verhulst, 1999) but on the other hand, they also show the variability of its cutoff scores in different cultures.

Some large-scale studies conducted across 23 cultures have replicated the factor structure of CBCL (Ivanova et al., 2010); however, other studies suggest that the factors of CBCL may not be able to assess some culture-specific problematic behaviors (Weisz, Weisz, Suwanlert, & Chaiyasit, 2006), a fact which led to the inclusion of culture-specific behaviors on CBCL (Achenbach et al., 2008). Our earlier studies using more culture-specific scales to measure the psychological problem of individuals in the Asian countries show quite encouraging results (Siddiqi & Shah, 1997; Malik & Shah, 2007), however, to test the cultural suitability of CBCL for the Malaysian population was beyond the scope of this study. As we used the total scores on CBCL in our analyses, we did not replicate the factor structure for our sample. We only computed the internal consistency index of CBCL as the measure of its reliability for our sample.

Coefficient alpha was computed to determine the internal consistency reliability of CBCL for our sample after removing the following items that had zero variance: behave opposite sex (C5), sexual problem (C73), think about sex (C96), wish to be opposite (C100), and other problems (C113). The

internal consistency was .94. Interestingly, the authors of CBCL recommend removing these items when the study is conducted in Muslim respondents. Another Malaysian study obtained an average test-retest reliability of .95 after removing the sexual problem items (Teoh, 2010) from CBCL.

Demographic questionnaire. A demographic questionnaire was constructed to collect personal and clinical background data of children and their parents. Information obtained included children's age, gender, number of siblings, years of schooling, diagnosis of disease, age at the onset of illness, duration of illness, frequency of hospitalization, and current treatment. Demographic parental information obtained was the gender, age, occupation, and relationship with the child.

Procedure

Prior to conducting the study, the research proposal was reviewed and approved by International Islamic University Malaysia Postgraduate Research and Ethics Committee and Director of GHKL. The data were collected at the Paediatric Department, GHKL, which has five pediatric wards and three outpatient pediatric clinics for children suffering from medical illnesses. The researcher approached the parents whose children were either suffering from cancer, epilepsy, or asthma during their visits to the outpatient clinic or while accompanying their children in the wards. If both the parents were present, the mother was requested to fill out the questionnaire.

First, the researcher explained to the parents the purpose of the study, which was to know about the psychological and other problems of chronically ill children. Then, their consent to participate in the study was obtained. They were assured of the confidentiality of information and about the least likelihood of adverse effects on them as respondents and their children following research participation. The respondents were administered the CBCL and then the demographic questionnaire. Most of the parents preferred to be interviewed rather than completing the questionnaires themselves. The researcher administered the questionnaires individually. Each interview took 25 to 40 min. After the interview the researcher thanked the parents and briefed them on the purpose of the study.

Statistical Analyses

A multiple-regression analysis was used to assess the impact of disease-related variables (duration of illness, the frequency of hospitalization, and the age of the children at the onset of the illness) to the psychological problems of children.

The design also includes a one-way ANOVA on the psychological problems of children for the age of the children at the onset of the disease.

Table 2. Multiple-Regression Coefficients, *F* Value, Degrees of Freedom, and Significance of *F* for the Frequency of Hospitalization^a, Age at the Onset of Illness^a and Duration of Illness.^a

Model	<i>R</i>	<i>R</i> ²	Adjusted <i>R</i> ²	<i>F</i>	<i>df</i>	<i>p</i>
1	.89	.79	.78	56.18	(4, 58)	.001

Note. CBCL = Child Behavior Checklist.

^aPredictors: (Constant), Duration of illness, Frequency of hospitalization, Age on illness onset.

Results

Preliminary Analyses

A *t* test for independent samples performed on the psychological problem scores of outpatient and the hospitalized children showed a nonsignificant effect. The mean CBCL score of the outpatients was 59.8 (*SD* = 23.3) and the hospitalized children was 50.5 (*SD* = 32.3); *t* = 0.489; *ns*. This means that the outpatient and the hospitalized children do not differ on the psychological problems.

To examine the hospitalization effect for the similarity vis-à-vis differences in the behavioral problems for the three disease categories was not possible because of the considerable asymmetry in the number of hospitalized cancer, asthma, and epilepsy children.

Hypothesis Testing

A multiple-regression analysis was used to determine the significance of disease-related variables to the psychological problems of children. The duration of illness, the frequency of hospitalization, and the age of the children at the onset of the illness were entered as the predictors and the psychological problems as the criterion variables in the equation.

One-way, between-subject ANOVA was performed on the psychological problem scores of children in different age groups to analyze the differences in their psychological problems.

Table 2 shows a highly significant effect of multiple-regression analysis, $F(4, 58) = 56.18$, $p < .001$. The results show that the predictors significantly contribute toward the psychological problems of the chronically ill children, the criterion. The multiple correlation (*R*) was .89, the *R*² was .79, and the adjusted *R*² was .78. This shows that 79% of the variance of the criterion (psychological problems) was accounted by the predictors, namely frequency of hospitalization, age of the children at the onset of illness, and the duration of illness.

Results in Table 3 show a highly significant relationship between the frequency of hospitalization and the psychological problems ($r = .80$; $\beta = .61$; $t = 8.67$; $p < .001$), a significant relationship between the age at the onset of illness and

the psychological problems ($r = .21$; $\beta = .29$; $t = 4.21$; $p < .001$), and a nonsignificant relationship between the duration of illness and the psychological problems of chronically ill children. These results indicate that more frequently the children were hospitalized, and the older the children were when afflicted by the illness, the more psychological problems they experienced.

The beta coefficients in Table 3 show highest β -weight for the frequency of hospitalization followed by the age of the children at the onset of illness. This means that frequency of hospitalization was the most important predictor of the psychological problems among chronically ill children.

One-way, between-subject ANOVA on the psychological problem scores of the children for their age in Table 4 shows a significant difference in the psychological problems of children in different age groups, $F(2, 60) = 12.85$, $p < .001$. The mean psychological problem score of children in the age range of 7 to 11 years was the highest ($M = 73.2$; $SD = 23.28$), followed by the age ranges of 11 to 17 years ($M = 61.4$; $SD = 21.04$) and 4 to 7 ($M = 37.0$; $SD = 26.0$). These results indicate that children in the middle age range suffered from more psychological problems as compared with the children in the lower and upper age ranges. An effect size of $\eta^2 = .299$ (.3) or 30% shows that the independent variable of age explains a substantial portion of variance of the dependent variable. This means that the children's age at the onset of the disease plays a crucial role in their psychological problems later.

Discussion

This study examined the relationship of three disease-related variables, namely, frequency of hospitalization, duration of illness, and age of the children at the onset of illness to the psychological problems among chronically ill children. The results supported the first hypothesis of the study that postulated a relationship between the frequency of hospitalization and psychological problems of chronically ill children. This implies that frequency of hospital admission is strongly associated with the psychological problems among chronically ill children. Other studies show that frequent hospitalization of sick children causes psychological dysfunctions (Kelly & Hewson, 2001; Pao et al., 2007), specifically depression, emotional difficulties, anxiety, behavioral disturbances, and aggression (Alati et al., 2005; Kaplan et al., 1987). Repeated or prolonged hospitalization may put excessive demands on the children because of separation from the family and friends and restricting their participation in social activities (Haslum, 1988). This sense of deprivation may make the children feel inadequate, handicapped, inferior, and depressed.

A hospitalized child may face the dilemma of adjusting to an unfamiliar, regimented hospital environment, and painful medical procedures (Jones, Fiser, & Livingston, 1992). Exposure to unfamiliar nursing care in a hospital instead of caring by the parents may cause feelings of helplessness,

Table 3. Correlations, Unstandardized and Standardized Coefficients, and *t* Values for Multiple-Regression Analysis of Disease-Related Variables and the Psychological Problems of Children.

Variables	<i>r</i>	<i>B</i> (unstandardized coefficients)	β (standardized coefficients)	<i>t</i>
Constant		-8.80		1.28
Frequency of hospitalization	.80**	4.73	.61	8.67**
Age at illness onset	.21*	0.18	.29	4.21**
Duration of illness	.05	8.212E-02	.11	1.59

p* < .05. *p* < .001.

Table 4. One-Way, Between-Subject ANOVA on the Scores of Psychological Problems of Children in the Age Range of 4 to 7 Years, 7 to 11 Years, and 11 to 17 Years.

Source	Sum of squares	<i>df</i>	<i>M</i> ²	<i>F</i>	<i>p</i>
Between groups	14,531.62	2	7,265.813	12.85	.001
Within group	33,916.08	60	566.268		
Total	48,447.714	62			

embarrassment, and irritation among children. Evidence suggests that dependency and hopelessness result in the feelings of anxiety, humiliation, withdrawal, apathy, depressed mood, babyish behavior, throwing tantrums, anger, and aggressiveness (Alati et al., 2005; Caplan et al., 2005; Pao et al., 2007; Zeegers et al., 2010). A study of Malaysian mothers of children with cerebral palsy found that repeated or lengthy hospitalization put great demands on the child and the family, led to the deterioration of caregiver's health and morale, and, in few cases, to family disintegration (Ong, Afifah, Safiah, & Lye, 1998).

As mentioned earlier, we could not examine the hospitalization effects on the behavioral problems of children between the three disease categories. However, it is possible that the hospitalization effects might be very different for the three disease categories if a bigger sample was studied.

Similarly, big differences in the number of children in different categories of the variables on the "number of siblings" and the "year of schooling" was an obstacle to performing meaningful analyses to see their impact on the psychological problems of children suffering from chronic diseases. We assume that the number of siblings as well as the years of schooling might have some mitigating effect on the psychological problem of these children.

Malaysian children live in a diverse social circle as they socialize with their relatives and neighbors and visit their friends after the school. Hospitalization may make sick children feel lonely, bored, and predispose them to emotional and behavioral problems.

Furthermore, a positive relationship between the age of the children at the onset of illness and the psychological problems support our second hypothesis. A comparison of different age groups showed that children in the age of 7 to 11 years had the most psychological problems, followed by

the children in the age ranges of 11 to 17 and 4 to 7 years. A child who had been healthy for quite some time, the diagnosis of chronic illness may devastate the child and force her or him to adapt to this new unwelcome and unpleasant reality. Thus, the feelings of anxiety and aggression may be heightened during this particular time.

The results of a national survey of psychiatric morbidity among Malaysian children and adolescents indicated the highest number of mental health and psychological problems for 10- to 12-year-old children (15.5%) followed by 13- to 15-year-olds (14.4%) and 5- to 6-year-olds (9.7%), respectively (Toh et al., 1999).

Other findings also suggest that children in the middle childhood stage experience more problems in dealing with their illness because they are in the developmental stage of an increasing need for autonomy, initiative, and mastery of new skills (Garrison & McQuiston, 1989; Witt, Riley, & Coiro, 2003). Chronic illnesses that impose limitations on physical activity and social interaction restrict the children's freedom, deprive them of the experiences crucial to their development of self-esteem, sense of mastery and control over their environment (Meijer et al., 2002; Perrin & Gerrity, 1984). A sudden change from normal life to illness in the middle and later childhood takes its toll in the form of behavioral and emotional problems (Fagnano et al., 2009; Schoenherr et al., 1992; Suris et al., 2008); however, children may adjust to and overcome these difficulties, especially the feelings of depression and anxiety over time (Jusiene & Kuchinskis, 2004), if family support and good nurturing is available (Berge & Patterson, 2004).

Our study found no relationship between the duration of illness and the psychological problems of children in contrast to some Western studies (Jacobson et al., 1997; Matsumoto & Fletcher, 1996; McPherson et al., 2006; Tebbi et al., 1990). We believe that the collectivist Malaysian society with its well-established social support mechanism (Gone, 2010) may be a mitigating force on the long-term effects of a chronic illness as it provides opportunities to the sick children to participate in everyday activities and to be part of the main stream society (Matsumoto & Fletcher, 1996). The opportunities of social contact and interaction in extended families and participation in the religious and spiritual practices in the collectivist cultures may alleviate the

negative psychological and physical effects associated with the duration of sickness (Abu Raiya & Pargament, 2010; Berry & Hardman, 1998; Triandis et al., 1988).

Conclusion

The outcome of this study may be useful to improving the psychological well-being of chronically ill children by proposing a culturally relevant approach to taking care of chronically ill children which may have more promise of success (Gracia, 2006; Uziel-Miller, Lyons, Kissiel, & Love, 1998). Our study shows that recurrent hospitalization and the onset of disease in the middle childhood are the two factors contributing toward the psychological problems among chronically ill children. Obviously efforts need to be made to avoid repeated or prolonged hospitalization of children.

On the bases of the outcome of our research, especially the impact of hospitalization on the psychological well-being of the sick children, we would like to recommend to the Ministry of Health to develop a comprehensive and sustainable training program for the nurses, social workers, psychiatrists, clinical psychologists, child psychologists, and counselors to deliver mental health services to the chronically ill children and adolescents.

Childhood is a vital stage in human development. Chronically ill children, in particular, demand special care and attention, to ensure their well-being. Mental and psychological problems in childhood tend to continue into adulthood; hence, they require attention and management at the earlier stages of sickness.

Limitations

Our study has some limitations because of a small sample size and a lack of a thorough test of psychometric properties of CBCL for the Malaysian culture. The scope of the study did not permit gathering a larger sample size as it was time-consuming and costly. It took a couple of months to recruit a sample of 63 parents of chronically sick children as these childhood illnesses are not common.

As mentioned earlier, we did not test the factor structure of CBCL as we used only total scores on the scale and did not analyze differences between different disease categories on the internalizing and externalizing problems, and so on.

Some disease-specific analyses on some demographic variables could not be performed because of insufficient number of subjects in different categories of these variables such as the differences in the hospitalization effects for the three disease categories, the years of schooling, and the number of siblings.

It would be difficult to generalize our findings because of the small sample and the limited focus of the study; however, the outcome of this study could provide some useful directions for future research.

Suggestions for Future Research

The research in the future may focus on contributions of the Malaysian joint family system as a viable alternative to providing care to the sick children at home to avoid the adverse effects of hospitalization for the children. The grandparents and other family members can take care of sick children. Future research can also examine if the family members were trained to take care of a chronically ill child, whether they do it with more care, involvement, and passion and whether all this has a positive impact on the well-being of a child.

The future research may also focus on suggesting certain measures to lessen the impersonal impact of the hospital on the sick child if hospitalization were indispensable. The measure may include provision such as “live in” pediatric wards, that is, admitting the mother and the child, allowing visits at all times, and promoting home atmosphere in the ward through ingenious decoration, lively wall colors, toys, and books (Kornhauser, 1980).

Another future research focus may be on the role of continuation of education by sick children irrespective of their inpatient status. Any impediment of a child’s education because of hospitalization and its relation to the psychological problems of the children may suggest the positive impact of education on the children despite their sickness and hospitalization. Such findings serve as a catalyst for promoting an education friendly hospitalization atmosphere where the sick children have the opportunity to learn and to interact with their teachers and the class mates to enhance their development.

Future research may also examine the impact of improved mental health care facilities on the psychological and overall well-being of sick children. In this regard, it may be important to focus on increasing the awareness of the parents, family members, and the health care providers about the social impact of chronic illness on the family system. This will help the health caregivers to provide effective services and will empower families to increase their resources, coping behaviors, and problem-solving skills to deal with the stressors involved in caring for a family member with chronic illness (Coffey, 2006; Livneh & Antonak, 2005).

Authors’ Note

The first author was working at the Department of Psychology, International Islamic University, Malaysia, when the study was conducted.

Declaration of Conflicting Interests

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