

RELATED QUALITY OF LIFE AMONG PARENT WITH CHILDREN HAVING ACUTE LYMPHOBLASTIC LEUKEMIA

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ABSTRACT

A child who diagnosed as acute lymphoblastic leukemia (ALL) require prolonged care which has an impact on parent's health-related quality of life (HRQOL). The aim of the study was to assess the health-related quality of life of parents and determine the factors that correlate it. A cross-sectional study was conducted using self-administrated questionnaire and 293 parents were recruited. There were 50.9% of total respondents have perceived their quality of life as good and satisfied (51.9%). Mean WHOQOL-BREF scores were 14.54±s.d.2.20 for the physical health domain, 14.60±s.d.2.07 for the psychological domain, 15.03±s.d.2.68 for the social relationships domain, and 14.08±s.d.2.09 for the environmental domain; the mean overall HRQOL score was 14.53± s.d.1.96. Socio-demographic characteristics were found to be significantly associated with the parent's HRQOL (education level, ethnicity, family income, marital status and child age). Multivariate analysis showed that family income accounted for 30% of the variance in the overall HRQOL: 29.4 % of the variance in the psychological well-being domain, 38.5% of the variance in the social relationship domain and 31.4 % of the variance in the environmental domain. The study highlighted certain aspects in the parents' life that may help in improving their quality of life. It could be useful if the health care providers focused on these significant aspects and implant the programs accordingly.

Keywords: Childhood acute lymphoblastic leukemia, health-related quality of life, psychosocial aspect, WHOQOL BREF

Introduction

Parent play an important role in caring their sick child while continue dealing with their usual daily life responsibilities. Collision of caregiving roles and daily life responsibilities can often have an impact on their quality of life including physical, social, financial and psychological wellbeing. Specific interventions aimed at improving quality of life among parents of sick children are timely needed. Many forms of intervention can be carried out such as providing social support, psycho-education of parents and other family members which should go hand in hand with that of children. Besides educating them issues related to their illness, developing their parenting skills and their coping with stress of having a chronically ill child can be suggested.

Childhood cancer especially Acute Lymphoblastic Leukaemia (ALL) is one of commonest childhood cancer in Malaysia (NCR, 2007). Cancer incidence for age group of 10-19 years old was reported by Malaysia Cancer statistics that the male (13.4 per 100 000 population) has higher rate compared to girls (10.1 per 100 000 population). The incidence was also noted higher among the Malay ethnicity compared to others for age group of 10-19 years old. Leukemia was noted the highest incidence rate among type of childhood cancer for age group of 0-14 years old in Malaysia.

Globally childhood cancer is listed the 4th common causes of death in children less than 15 years old (Linett et al, 1999). Data reported globally on cancer incidence for year 2014, estimated that the annual incidence rate of cancer in children and adolescents is 186.6 per 1 million children aged birth to 19 years and approximately 1 in 530 young adults between the ages of 20 and 39 years is a childhood cancer survivor (Ward et al, 2014). The incidence of childhood cancer varies by countries. This could be due to risk exposure such as pediatric Burkitt lymphoma in sub-Saharan Africa is associated with Epstein-Barr virus infection in conjunction with malaria, whereas Burkitt lymphoma in industrialized countries is not associated with these

infectious conditions or varies by ethnic or racial population subgroups (Scott,2007). Childhood Leukemia has been noted higher in Finland (47.3), Denmark (47.2), Sweden (45.6), Norway (44.0) and Pakistan (40.5/100 000 population).

The multimodality treatments that combine surgery, radiation, chemotherapy or others have markedly improved the prognosis of many forms of cancer. Approximately 98% of acute lymphocytic leukemia (ALL) patients attain remission, 85% of patients aged 1 to 18 years with newly diagnosed ALL treated on current regimens are expected to be long-term event-free survivors, with over 90% surviving at 5 years (Pieters, 2016).

As the survival of ALL is higher in trend with better technology and medication, there has been recognition of the need to assess the quality of life of children survivors and their parents. Nevertheless, to date, few researchers have explored quality of life issues of family caregivers of patients with cancer. Caregiving is a normal part in parenting any child, but children with chronic diseases require high level of caring which impact the physical, psychological health and social well-being of the parents (Raina 2004). Caregiving is defined as "the frequency of task performed by the caregiver" (Hermanns & Mastel-Smith, 2012, Caregiving, 2010). Because parents involved in caring the child with the chronic disease they may have less chance for social activities and less time to do outside work and they may have physical disruption which will increase the caregiving burden. Caring a child with disability experience increased stress has been reported in many studies (Baird,2000, Lopez et al 2008) .

Health of the caregiver is other factor that affects the caregiver abilities of caregiving. Studies found that caregivers with poor health will experience high levels of caregiving burden compared with caregivers with good health (Talley 2014, Heykyung and Eun-Kyoung, 2009, Bauer & Alfonso, 2015). Family income play important role in determining the amount and type of health services that can be purchased to alleviate the caregiving burden, Fink stated that financial expenses is a predictor of caregiving burden (Abuosi et al 2015). The aim of this study is to assess the quality of life among parents of children with acute lymphoblastic leukemia in relation to their psychosocial aspects.

Methodology

A cross-sectional study design was conducted to determine general information about parent's health-related quality of life and factors affecting it. Present study was conducted in pediatric wards and clinics of Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and *Pediatric Institute Hospital Kuala Lumpur (IPHKL)*. The population of this study was the parents of children diagnosed with ALL and attended pediatric hematology and oncology UKMMC and IPHKL as inpatients and outpatients. Data collection was based on the list of children aged from newborn to 18 years who diagnosed by specialist as ALL and is on treatment or follow up in UKMMC and IPHKL in the period from 2006 to 2011. This will cover patients in different stages of treatment.

The inclusion criteria set as:

- Parents of children aged from newborn -18 years old and medically diagnosed with ALL.
- Resides with the child since diagnosis.
- Able to understand English or Bahasa Malayu.

Only one either the mother/father who is the prime caregiver were included for each child (one child one respondent)

Exclusion criteria set as:

- Parents of children at the end stage or with serious complications (such as bleeding, severe infection involvement of other organs or disseminated intravascular coagulation) as determined by the child oncologist.
- Refusal to participate in the study.

For the sample size calculation prevalence and means of some of the variables in the current study were used for sample size calculation using PS2 and Epi Info version 3.5.3. The precision was set at 5% and confidence interval at 95%. Based on calculation minimum sample size were 288 parents with adding of the 70 % respondents for reject samples due to exclusion criteria, the minimum final sample size was 490 caregivers. Self-administered questionnaire was used in this study which covered the socio demographic information and the WHOQOL-BREF. The child card information was used to assess on the child's factor. Approval from the Research Ethics Committee of University Kebangsaan Malaysia and Pediatric Institute Hospital Kuala Lumpur under the National Medical Research Ethic Committee Ministry of Health was obtained. All participants were given briefing on the purpose of the study before taking their written consent. The dependent variable was the caregiver health-related quality of life. The psychosocial aspect factors and child factors that affect or predict the caregiver health-related quality of life are considered independent variables. The Caregiver health-related quality of life was measure using the WHOQOL BREF which consists of 26 items. Each item uses a Likert-type five-point scale. There are two items that are examined separately and the other 24 items are distributed in four domains namely: a) Physical domain, b) Psychological domain, c) Social Relationships domain, and) Environment domain. Domain scores for the WHOQOL-BREF are calculated by taking the mean of all items included in each domain and multiplying by a factor of four. These scores are then transformed to a 0-100 scale. Where more than 20% of data are missing from an assessment, the assessment should be discarded. Where up to two items are missing, the mean of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if < 1 item is missing). Data entry and analysis were performed utilizing the Statistical Package for the Social Sciences (SPSS), Version 20. The data was analyzed using descriptive statistics, bivariate comparison and correlations and multiple regression.

Result

A total of 293 parents of children with ALL participated in the study. Respondent's age ranged from 23 to 54 years old and the mean age was 37.7 ± s.d.6.67 years. The largest age group represented was 30-45 years old (70.6%) while the smallest age group represented was below 30 years old (12.0%). The sample (n=293) consisted of 75.1 % Malay, 15.4% Chinese, 8.9% Indians and only two mothers who were foreigners (one from India and the other from Burma) but married to Malay men. There were females 72.7% and 27.3% males. The majority of the respondents were biological parents (98.6%), out of the non-biological parents (1.4%), in which 0.7% was adoptive parents and 0.7% step parents. Most of the respondents were married (94.5%), 2.7% were divorced, 0.7% were separated, 0.3% widowed and 1.7% stated themselves as single. Majority of the parents obtained education till the secondary school level (76.8%), 20.1 % had university degrees. The others, 2.4 % were primary school level and 2 respondents (0.7%) got master's degree. Almost half of the respondents were employed (52.2%), of them 41.6% were full time, 3.8% part time, 6.8% were on leave to take care of their ill child. About 47.8% of the respondents were not employed. The age of children with ALL in this study ranged from almost 0.5 year to 18 years with mean of 7.7 years ±s.d.4.3. The largest age group represented was 6-12 years old (n=145) 49.5%. About 60.8% of the children diagnosed with ALL were boys and 39.2% were girls. The ages of children when diagnosed with ALL ranged from 0.08 year (1 month) month to 14 years with a mean of 4.5 years. The majority of the children (70.3%) were diagnosed between 0 and 6 years.

For the over-all perceived HRQOL question, the mean score was 3.57 ± s.d. 0.73 which indicated that the respondents moderately felt good about their quality of life. Half of the respondents (50.9%) perceived their overall quality of life (WHOQOL- BREF item 1) as good, 39.2% as neither poor nor good and only 2% reported to have poor quality of life (Table1). The mean score of the second question, which asked about how the respondents satisfied with their lives in general, was 3.69 ± s.d. 0.72. Again the majority of the respondents were satisfied (51.5%), 34.8% were neither satisfied nor dissatisfied and only 2.4% dissatisfied.

The means of the four domains and the total of HRQOL, which represent the sum of the domains, of the WHOQOL-BREF were used to describe the HRQOL among the respondents. The mean scores of the total of HRQOL (Physical domain, Psychological domain, Social relationships domain and Environment domain) are presented in Table 1.

The results of the study revealed that the quality of life to be poorest in the environment domain (mean14.08± s.d.2.11) and best in social relationship domain (mean 15.09 ±s.d.2.63). However, much difference was not found among the mean scores of the psychological and physical domains suggesting that they were all affected equally. Among the items of physical health domain the lowest score was found with the question "How satisfied are you with sleep?" (Mean =3.4) while the highest was with "How much do you need any medical treatment to function in your daily life?" (Mean =3.9).

The psychological domain has 6 items the highest score was found with "How satisfied are you with yourself?" (Mean =3.8) in which the majority were satisfied, the lowest score was found with "how much you enjoy your life?"(Mean= 3.4) indicating that they were moderately enjoying their lives. The social relationship domains assessed by three items, the mean scores of them were close to each other indicating that the respondents were satisfied with their social relationships. The means scores were 3.8 for the first item 3.8 for the second and 3.7 for the third item. The environment domain, which had the lowest scores compared to the other domains, consists of eight items. The highest scores were "How satisfied are you with your access to health services?"(Mean= 3.9) and "How satisfied are you with the conditions of your living place?" The two lowest scores were "To what extent do you have the opportunity for leisure activities?"(Mean= 3.0) and "Have you enough money to meet your needs?"(Mean= 3.0).

Table 1: Correlates Health Related Quality Of Life and Psychosocial aspects of parent with Acute Lymphoblastic leukemia children

Variables	Total QOL	PC	PW	SR	EN
Parental's gender					
Male	58.74±8.05	14.74±2.16	14.63±2.09	15.2±20.75	14.18±2.09
Female	57.91±7.76	14.47±2.21	14.59±2.06	14.80±2.77	14.05±2.09
t(df)	0.81(291)	0.93(291)	0.12(291)	1.11(291)	0.64(291)
p-value	0.42	0.35	0.90	0.27	0.47
Ethnicity					
Malay	59.10±7.35	14.82±2.05	14.80±2.08	15.35±2.50	14.25±2.05
Non-Malay	55.21±8.55	13.70±2.41	14.00±1.98	14.07±3.01	13.56±2.17
t(df)	3.77(291)	3.57(108.6) ^a	2.90(291)	3.28(106.8) ^a	2.48(291)
p-value	<0 .001*	<0 .001*	< 0.001*	0.001*	<0 .01*
Marital status					
Married	58.38±7.70	14.59±2.14	14.62±2.06	15.13±2.64	14.14±2.07
Not married	53.88±9.21	13.75±3.02	14.25±2.21	13.19±2.79	13.13±2.28
t(df)	2.25(291)	1.09(15.89) ^a	0.70(291)	2.86(291)	3.26(291)
p-value	0.03*	0.29	0.49	0.005*	0.06
Education level					
Secondary	57.56±8.04	14.38±2.20	14.45±2.07	14.94±2.74	13.94±2.11
Higher level	60.31±6.65	15.18±2.09	15.16±1.97	15.36±2.46	14.61±1.93
t(df)	-2.46(291)	-2.57(291)	-2 .41(291)	-1.09 (291)	-2.22(291)

Variables	Total QOL	PC	PW	SR	EN
<i>p</i> -value	0.01*	0.01*	0.02*	0.28	0.03*
Employment status					
Employed	57.32±7.87	14.42±2.12	14.44±2.10	14.71±2.58	13.90±2.12
Not employed	59.02±7.73	14.68±2.28	14.78±2.02	15.38±2.76	14.28±2.04
<i>t</i> (df)	-1.86(291)	-1.01(291)	-1.41(291)	-2.58(291)	-1.55(291)
<i>p</i> -value	0.06	0.31	0.16	0.03*	0.12
Parental's age					
< 30 years	59.56±7.40	15.0±2.09	15.0±1.93	15.4±2.66	14.1±1.84
30-45 years	57.65±8.10	14.39±2.23	14.6±2.20	14.9±2.74	14.0±2.20
> 45 years	59.18±6.87	14.88±2.08	14.9±1.76	15.5±2.43	14.6±1.92
<i>F</i> (df)	1.41(2,291)	1.86 (2,290)	0.75 (2,290)	1.50(2,290)	1.85(2,290)
<i>p</i> -value	0.25	0.16	0.47	0.23	0.16
Monthly income					
< 1000 RM	55.80±8.10	14.15±2.19	13.9±1.97	14.40±2.88	13.47±2.15
1000-2500 RM	59.39±7.03	14.71±2.16	14.94±1.99	15.48±2.37	14.32±1.87
> 2500 RM	59.85±7.78	14.89±2.21	15.11±2.07	15.32±2.66	14.66±2.10
<i>F</i> (df)	8.50(2,290)	3.06(2,290)	10.07(2,290)	5.56(2,290)	8.69(2,290)
<i>p</i> -value	<0.001*	0.049*	<0.001*	<0.001*	<0.001*
Age of the ill child					
0-6 years	60.17±7.70	14.89±2.11	15.03±2.18	15.72±2.64	14.54±2.02
6-12 years	56.71±7.93	14.16±2.28	14.34±2.06	14.52±2.62	13.80±2.19
>12 years	58.17±7.00	14.98±1.93	14.47±1.68	15.11±2.68	13.96±1.74
<i>F</i> (df)	5.99(2,290)	4.52(2,290)	3.44(2,290)	6.26(2,290)	3.96(2,290)
<i>p</i> -value	0.003*	0.01*	0.03*	0.002*	0.02*
Child's gender					
Boys	58.72±7.65	14.68±2.06	14.62±2.04	15.26±2.73	14.21±2.05
girls	57.23±8.06	14.33±2.38	14.57±2.12	14.66±2.57	13.89±2.14
<i>t</i> (df)	1.60(291)	1.33(291)	0.24(291)	1.89(291)	1.29(291)
<i>p</i> -value	0.11	0.18	0.81	0.06	0.20
Child's age at the time of diagnosis					
0-6 years	58.70±7.56	14.73±2.06	14.74±2.09	15.08±2.59	14.16±2.03
6-12 years	56.53±8.42	14.03±2.42	14.23±2.03	14.54±2.84	13.89±2.28
>12 years	59.38±7.60	14.88±2.80	14.63±1.19	15.88±3.18	14.00±1.60
<i>F</i> (df)	2.31(2,290)	3.06(2,290)	1.78(2,290)	2.03(2,290)	0.50(2,290)
<i>p</i> -value	0.10	0.048*	0.17	0.13	0.61
Duration of the disease					
< 1 year	58.10±8.58	14.14±2.41	14.65±2.18	15.28±2.81	14.06±2.29
1-3 years	57.07±8.04	14.34±2.29	14.29±2.16	14.70±2.74	13.81±2.07
> 3 years	59.12±7.01	15.00±1.88	14.84±1.87	15.15±2.53	14.34±1.95
<i>F</i> (df)	1.84(2,290)	4.27(2,290)	1.92(2,290)	1.14(2,290)	1.25(2,290)
<i>p</i> -value	0.16	0.01*	0.15	0.32	0.29
Stage of treatment					
Active	58.02±8.33	14.44±2.36	14.57±2.22	15.09±2.75	13.98±2.18
Follow up	58.31±7.03	14.70±1.92	14.65±1.80	14.93±2.58	14.24±1.94
<i>t</i> (df)	-3.15(291)	1.00(274.8) ^a	0.36(276.4) ^a	0.50(291)	1.06(291)
<i>p</i> -value	0.002*	0.32	0.72	0.62	0.29

PC=Physical capacity, PW=psychological well-being, SR=Social relationships and EN=Environment well-being.
Not married = (Single/divorced/widowed) ^a Assumption of homogeneity of variance violated

Bivariate analysis was conducted to determine if any of the factors studied were related to the health-related quality of life of the parents. Unpaired t-test was performed to compare means of the dependent (WHOQOL) variable with dichotomous level independent variables. One way Analysis of Variance (ANOVA) was performed for all ordinal level variables to compare means. There was no significant difference in total QOL scores or by domain scores with gender, parental's age, child's gender, child's age, and stages of treatment. Selected domains were noted significant for some variables. The physical domain was significantly reported for education level and duration of disease. The psychological and environmental domains were significantly for education level. While, the social relationships domain showed significant for marital status and employment status.

Multivariate analysis using linear regression was conducted to determine if any of the independent variables explained parents HRQOL by specific domain. Socio-demographic and disease related factors found to be significantly correlated with physical health were entered in this regression. The variables included were educational level, ethnicity, monthly income, and duration of the disease (time elapsed since diagnosis). Socio-demographic and disease-related factors explained 29.1% of the variance (adjusted R² =0.291, F (6,286) = 6.135, p < 0.001). The determinant factors found were education level (β=-0.778, p=0.015) ethnicity (β=3.25, p=0.002), monthly income (β=-2.97, p=0.004), child's age (β=2.88, p=0.004) and duration of disease (β=1.109, p<0.001). Other factors studied were not significantly found after adjusted.

Table 2: Multivariate Analysis of total score Health Related Quality Of Life and Psychosocial aspects of parent with Acute Lymphoblastic leukemia children

Variables	B	Std. E	β	P value
Constant	54.355	2.272		<0.001
Education level	-0.778	0.319	-0.144	0.015*
Ethnicity	3.249	1.031	0.180	0.002*
Income RM 1000-2500 vs.< RM 1000	-2.970	1.013	-0.184	0.004*
RM 1000-2500 vs.> RM 2500	0.356	1.137	0.020	0.754
Child age 6-12 yrs. vs. < 6 yrs.	2.883	0.991	0.175	0.004*
6-12 yrs. vs.>12 yrs.	1.393	1.258	0.065	0.269
Duration	1.109	0.236	-0.246	<0.001*

R₂=0.291**Discussion**

The childhood cancer incidence is much less than the incidence of cancer among adults, however, the diagnosis of a cancer in a child is disastrous news for the parents. It constitutes a major challenge for the whole family due to the nature of the disease and the new tasks which must be performed by the family. The shift of the patient care from the hospital to home necessitates change in the family roles and the preparedness to control their social activities, job commitments and all aspects of life which will have great impact on their health and well-being. Understanding the challenges faced by the parents of ill child and the impact of these on their HRQOL will help the health care providers in identification of priorities and assist them in planning for the appropriate interventions required the most by the parents.

Parents participated in this study were mostly mothers, which is in agreement with other studies where the mother considered as the primary caregiver (Litzelman et al., 2011). With the presence of ill child in the family, the mothers play other roles like monitoring and observing the child's condition, support him, protect and prioritize his interests (Moreira and Angelo, 2008).

The average age of parents ranged from 23 years to 54 years with mean age of 37.7 years consistent with other studies (Litzelman et al., 2011; Zarina et al., 2012). Most of the parents were Malay, married and were high school graduates and all of them but 4 were biologic parents. Over half of the parents were employed and most of them had monthly income of RM 2500 or less. This is consistent with other studies carried on parents of children with chronic diseases in Malaysia (Zarina et al., 2012). In this study children with ALL showed male predominance which is corroborating with the national data with age mean 7.7 years (NCR, 2011). Most of the children were less than 6 years when diagnosed with ALL which is compatible with ALL statistics (American Cancer Society, 2015). More than half of the children in this study still under active treatment and less than three years had passed since they diagnosed with ALL.

In a study conducted in Canada 411 parents of children with cancer compared with population norms found that parents of children with cancer reported lower scores of QOL than population norms (Klassen et al., 2008). Other study assessed QOL among mothers of children with cancers had poorer compared to population norms (Eiser et al, 2005) which is comparable with a study done in Japan which comparing QOL of mothers of children with leukemia and QOL of mothers of healthy children (Yamazaki et al, 2005). The present study found relatively high perception of overall QOL of life can be explained by the adaptation model which suggests that negative feelings and caregiving burden declines over time due to the development of new adaptation capacities (Townsend et al, 1989). In a study among 42 couples of children with cancer, emotional distress was evaluated 2 months after the diagnosis and again 20 months later, significantly lower scores of anxiety was found among mothers which was explained by the parental adaptation to the situation (Dahlquist et al, 1996). A study assessing the psychological distress among parents of children diagnosed with cancer at time of diagnosis, 6 months, 12 months, and 5 years later, were found that both fathers and mothers reported significantly less psychological distress over the 5 years (Wijnberg-Williams et al, 2006).

Among the quality of life assessment domains in the present study, the participants' WHOQOL-BREF scores were found to be highest in social relationship domain and lowest in the environmental domain. This result is against the study done in Sri Lanka which found about 47.1% of the parents of children with leukemia had low social quality QOL (Pathirana et al, 2014), other study in Japan mothers reported low social QOL (Yamazaki et al, 2005). The social relationships domain contains questions on personal relationships, social support and sex life. High scores in this domain indicate that parents were satisfied with their personal relationships and social support which have positive effect in their well-being and adjustment to the situation. Litzelman and colleague suggested that the protective effects associated with social support explained why better mental health among parent associated with being married or partnered (Litzelman et al, 2011). Satisfaction with social support and family cohesion resulted in better mental health in mothers of children with cerebral palsy (Glenn et al., 2009).

Environmental domain had the lowest scores among other domains which is consistent with the results of other studies concerning the parents of children with chronic diseases like Down syndrome, cerebral palsy and osteogenesis imperfecta (Geok et al., 2013). The physical well-being domain among parents in this study found to be affected but it is better when compared with other environmental domain. In the Sri Lanka study aimed was to assess the QOL of caregiver of children with leukemia found that 75.7 of the caregivers reported to have low to moderate physical QOL (Pathirana et al., 2014). Physical domain items assessed sleep quality, impact of pain on daily activities, need for medical treatment to function, amount of energy for everyday life, ability to get around, and satisfaction with work.

Psychological domain score was closer to the Physical domain scores. In present study it was found to be affected but better when compared with study from Sri Lanka who found that about 83 % of parents of children with ALL had moderate to low psychological QOL (Pathirana et al., 2014). This domain measures self-image, negative thoughts, positive attitudes, self-esteem, mentality, learning ability, memory and concentration, religion and mental status. The most affect item was "How much do you enjoy life?" This may be due to less time for the parent to perform own activities and due to high commitment toward their children.

Conclusion

Two hundred and ninety three parents were included in the present study, half of them (50.9%) perceived their quality of life as good and satisfied with their health (51.9%). The mean overall HRQOL score was 14.53 ± 1.96 . The highest scores were found in the social relationships domain (15.03 ± 2.68), and the lowest were in the environmental domain (14.08 ± 2.09). Ethnicity, education, family income, marital status and child age were found to be significantly correlated with their parents HRQOL. Provision of medical social support in each hospital should focus more on parent with leukemic children, who are at higher risk of developing poor health related quality of life: Malays, lower educational level, low income, single, and younger age children.

References

- Abuosi AA, Francis AA, Anarfi J, Badasu DM, Atobrah D, Yawson A (2015). Investigating parents/caregivers financial burden of care for children with non communicable diseases in Ghana. *BMC Pediatrics* (2015) 15:185 DOI 10.1186/s12887-015-0504-7.
- American Cancer Society (2012). *Cancer Treatment and Survivorship Facts & Figures 2014-2015*. Atlanta: American Cancer Society; 2014.
- Bauer JM, Sousa-Poza A (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family, IZA DP No. 8851, <http://ftp.iza.org/dp8851.pdf>
- Caregiving. (2010). In Oxford English Dictionary. Retrieved from <http://dictionary.oed.com>
- Geok CK, Abdullah KL, Kee LH (2013). Quality of life among Malaysian mothers with a child with Down syndrome. *International Journal of Nursing Practice*, 19(4), 381-389.
- Glenn, S, Cunningham, C, Poole H, Reeves D, Weindling, M (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: care, health and development*, 35(1), 71-78.
- Dahlquist LM, Czyzewski DI, Jones CL (1996). Parents of children with cancer: a longitudinal study of emotional distress, coping style, and marital adjustment two and twenty months after diagnosis. *J Pediatr Psychol*, 21(4), 541-554.
- Eiser C, Eiser JR, Stride CB (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and quality of life outcomes*, 3, 29.
- Hermanns M, Mastel-Smith B (2012). Caregiving: A qualitative concept analysis. *The Qualitative Report*, 17(Art. 75), 1-18. Retrieved from <http://www.nova.edu/ssss/QR/QR17/hermanns.pdf>
- Heykyung OH, Othelia Lee EK (2009). Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea, *International Journal of Disability, Development and Education*, 56:2, 149-167, DOI: 10.1080/10349120902868624
- Klassen AF, Klaassen R, Dix D, Pritchard S, Yanofsky R, O'Donnell M, Sung L. (2008). Impact of caring for a child with cancer on parents' health-related quality of life. *J Clin Oncol*, 26(36), 5884-5889
- Linnet MS et al. Cancer Surveillance Series: recent trends in childhood cancer incidence and mortality in the United States. *J Natl Cancer Inst*, 1999; 91(12):1052
- Litzelman K, Catrine K, Gangnon R, Witt WP (2011). Quality of Life among Parents of Children with Cancer or Brain Tumors: The Impact of Child Characteristics and Parental Psychosocial Factors. *Quality of Life Research*, 20(8).
- Lopez V, Clifford T, Minnes P, Ouellette-Kuntz H (2008). Parental Stress and Coping in Families of Children With and Without Developmental Delays, *Journal of developmental disabilities*, Volume 14, Number 2
- Moreira PL, Angelo M (2008). Becoming a mother of a child with cancer: building motherhood. *Revista Latino-Americana de Enfermagem*, 16, 355-361.
- National Cancer Registry, Malaysia (2007). *Malaysian Cancer Statistics - Data and figure Peninsular Malaysia*, ISBN 978- ISBN 978-983-3433-51-3
- Pathirana TI, Goonawardena C, Wijesiriwardane I (2014). Quality of life of caregivers and impact on the nuclear family of children with leukaemia in the National Cancer Institute of Sri Lanka. *Journal of the Postgraduate Institute of Medicine*, 2, E18
- Pieters R, de Groot-Kruseman H, Van der Velden V, et al (2016). Successful Therapy Reduction and Intensification for Childhood Acute Lymphoblastic Leukemia Based on Minimal Residual Disease Monitoring: Study ALL10 From the Dutch Childhood Oncology Group. *J Clin Oncol* 34 (22): 2591-601
- Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, Russell D,
- Scott CH. Childhood cancer epidemiology in low-income countries. *Cancer*, 2007, 112; 3:461-472
- Swinton M, King S, Wong M, D Walter S, Wood E (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice , *BMC Pediatrics* 2004, 4:1, <http://www.biomedcentral.com/1471-2431/4/1>
- Talley RC et al. (eds.), *The Challenges of Mental Health Caregiving*, Caregiving: Research Practice Policy, DOI 10.1007/978-1-4614-8791-3_2, © Springer Science Business Media, New York 2014
- Townsend A, Noelker L, Deimling G, Bass D (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and aging*, 4(4), 393.

- Yamazaki S, Sokejima S, Mizoue T, Eboshida A, Fukuhara S (2005). Health-related quality of life of mothers of children with leukemia in Japan. *Quality of Life Research*, 14(4), 1079-1085.
- Ward E, De Santis C, Robbins A, Kohler B, Jemal A (2014). Childhood and Adolescent Cancer Statistics, 2014. *CA Cancer J Clin* 2014;64:83-103
- Wijnberg-Williams BJ, Kamps WA, Klip EC, Hoekstra-Weebers JE (2006). Psychological adjustment of parents of pediatric cancer patients revisited: five years later. *Psycho-oncology*, 15(1), 1-8.
- Zarina A, Radhiyah R, Hamidah A, Zakaria SZS, Jamal R (2012). Parenting stress in childhood leukaemia. *Medicine & Health*, 7(2), 73-83.