

Coping Strategies among Caregivers of Children with Acute Leukemia at Nanakali Hospital in Erbil City

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ABSTRACT

Background and objective: Childhood with leukemia is one of the developing global health issues, which has negative psychological, social, and physical consequences on caregivers, and affects the quality of long-term care of leukemic children. The current study aimed to assess coping strategies among caregivers of children with acute leukemia in Erbil City in the Kurdistan Region of Iraq.

Methods: A descriptive study was carried out at the Nanakali Hospital for Blood Diseases and cancer in Erbil City from 10th October 2018 to 10th June 2019. The research sample involved 54 caregivers of leukemic children undergoing chemotherapy that were purposively recruited for the study. The researchers used a standard tool of "Coping Health Inventory for Parents" after verifying its validity and reliability. The data were collected by interviewing the participants and analyzed using frequency, percentage, mean, chi-square, and Fisher's exact test.

Results: More than half, 28 (52%) of the children were female and the majority, 48 (88.9%) of them were diagnosed with acute lymphoblastic leukemia. The mean age of caregivers was 36.53 ± 7.53 years, and the majority of chief caregivers (87%) were mothers, mainly illiterate and secondary school graduates. Regarding the overall levels of coping patterns scores among caregivers, the highest percentage (61.1%) of them were at the medium level. Concerning each of the three levels of coping patterns score; for 87% of caregivers, maintaining family integration was within the medium level, while social support and self-esteem and an understanding medical situation, had lower percentages of 59.3% and 63% retrospectively. The results of the study revealed that there is a significant relationship between levels of coping and caregiver's education.

Conclusion: According to the findings of the study, the majority of caregivers of children with leukemia undergoing chemotherapy treatment had a low level of coping in most of the coping patterns domains.

Keywords: Caregivers, Leukemia

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INTRODUCTION

Childhood cancer is an increasing and prevalent type of chronic disease worldwide. Leukemia represents 25% of all cancers in children under the age of 15 years and is the most common type of cancer in this age group [1]. Acute leukemia is the most common malignancy that affects children. In 2018, leukemia accounted for 6.6%

of 25,320 new cases of cancers in the Iraqi population [2]. In Erbil, during 2016-2018, there were more than 120 cases of children with leukemia registered at the Nanakali Hospital for Blood Diseases and Cancer. Like other chronic diseases, the situation causes many physical and psychosocial problems for a person who gives care for the children having cancer.

Caregivers, who are mainly parents, during the early stages of their child's diagnosis show various levels of psychological problems [1]. Families of the children with cancer face significant stress as they conform to demanding treatment regimens, potential side effects of medical treatment, daily activities changes, interruption in roles, and the threat of death [4]. A caregiver is an individual who helps a person during physical and psychosocial care in need. Usually, most of the caregivers are family members that support the patient to do daily living activities without remuneration [5]. Coping is defined as cognitive and behavioral effort to manage demands perceived as taxing or exceeding the resources of an individual. Coping is classified into two types including problem-focused coping and emotion-focused coping. The first one is oriented toward resolving challenges, while the second type is connected to managing emotions [6]. Coping can be difficult for all family members especially caregivers of children with the physical and emotional challenges of a cancer diagnosis and its treatment. This is especially true of pediatric cancer patients, with extensive research documenting the psychosocial consequences experienced by the parents and siblings of patients [7]. Leukemic children can affect social well-being of caregivers, especially changing the family roles and can also affect the physical well-being of a parent during the care for the patient. Although the health status of caregiver is initially similar to that of the normal population, caregivers often report more problems with fatigue, sleep disturbances, and impaired cognitive function than non-caregivers. Nurses are in a unique position to identify stress and the psychological burden of caregivers [8]. Furthermore, they can identify the possible negative effects of cancer such as decreased familial coping and adaptation, increasing hospitalization,

abilities, and increased family stress levels. Nurses who understand the characteristics of caregivers' coping responses and how different coping strategies affect their adjustment can plan appropriate interventions. This study aimed to assess coping strategies among caregivers of children with acute leukemia in Erbil City and identify an association between some of the socio-demographic characteristics with the overall level of coping patterns. To the best of the researchers' knowledge, this is one of the first studies on the coping patterns among the caregivers of children with leukemia in Erbil City.

METHODS

A descriptive study was conducted among the caregivers having leukemic children undergoing chemotherapy treatment in Erbil City from 10th October in 2018 to 10th June in 2019. The sample of the study was chosen from the outpatient department of the pediatric unit at the Nanakali Hospital for Blood Diseases and Cancer in Erbil City and included 54 caregivers of children, medically diagnosed with acute leukemia and undergoing chemotherapeutic treatment. The caregivers had to be able to communicate clearly in Kurdish language to be included. The caregivers having a chronic disability such as inability to speak or difficulty of listening, psychologically not comfortable, and the caregivers who refused to participate in the study were excluded. The researchers obtained official permission for conducting the study from both the Erbil General Directorate of Health and the Nanakali Hospital for Blood Diseases and Cancer. The informed consent was obtained from all the study participants and the ethical approval was obtained from the Research Ethics Committee at the College of Nursing of Hawler Medical

University, dated 25th June 2019 with serial number 76. In order to achieve the aim of the study, the researchers prepared a questionnaire consisting two parts. The first part was divided in to two sections, the first section was to assess the socio-demographic data of the caregivers (main caregiver, age, level of education, occupation and place of residence), and the second section was to gather the socio-demographic data of the leukemic child (age, gender, order of the child, medical diagnosis and family history of cancer). The second part of the questionnaire contained the Coping Health Inventory for Parents (CHIP) to assess the caregiver's coping strategies, which was developed by McCubbin et al, in 1981 [9]. The CHIP consisted of a checklist of 42 specific behaviors divided into three domains that represented different positive coping patterns. The Pattern I was identified as maintaining family integration, cooperation and an optimistic view of the situation, the Pattern II was identified as maintaining social support, self-esteem and psychological stability, and the Pattern III was identified as understanding the medical situation through communication with other parents and consultation with medical staff. This validated instrument was designed to assess parents' or caregivers' appraisal of behaviors currently in use to manage family life when they have chronically ill children. The tool was previously modified by El-Malky in 2016 [10]. The tool was submitted to a panel of eleven experts in different fields of nursing and medicine to assess the content of the questionnaire for its clarity, relevance, and adequacy. After the approval, the researchers translated the instrument into the Kurdish language. A total score ranging from 0 to 84, was used, and the scoring was modified to the 3-point Likert scale instead of 5-point Likert scale as

follows: never used (0), sometimes used (1), and always used (2). The total of scores gained by the caregivers was arranged as the following grades: a low coping level (0-28), a medium coping level (29-55), and a high coping level (56-84). The pilot study was carried out in February 2018 on ten caregivers who were excluded from the study and the results were analyzed to find out the reliability by calculating Cronbach's Coefficient Correlation, which was 0.78. The data were collected through direct interviews with caregivers by researchers and lasted approximately 20-25 minutes. Data were organized and coded using Statistical Package for Social Sciences (SPSS) Version 25, in addition to using Excel program for Graphic Descriptive Statistical Analysis (Frequency, Percentage, Mean and Standard deviation). The inferential statistical analysis (Chi-Square test or Fisher's Exact Test) for categorical variables was used to measure the significant association between different variables p-value measured form ≤ 0.05 .

RESULTS

Fifty-four caregivers participated in the study. Their mean age and standard deviation were 36.53 ± 7.53 years old. The result of the study shows that the majority (87%) of caregivers were mothers and 29.6% of them were between 31-35 years old. Approximately half of the caregivers were either illiterate or secondary school graduates. The highest proportion of the respondents were unemployed (77.8%), and 48.1% of them were living in urban areas (Table 1). The results of the study showed that more than half (51.9%) of children were females, 31.5% of children's age was between 1-4 years old and 31.5% of children were the second-order child in the family. The majority (88.9%) of children had acute lymphoblastic leukemia,

and 79.6% of children had no family history of cancer (Table 2).

The study illustrated that the caregivers had a low level of coping related to the understanding the medical situation, maintaining social support and self-esteem (63%, and 59.3% respectively), and the majority (87%) of caregivers had a medium level of coping regarding maintaining family integration (Figure 1).

Table 1: Demographic characteristics of caregivers of children with leukemia

Demographic characteristics	F (%)
Mean age ± Standard deviation	36.54 ± 7.53
The person responsible for caring	
Father	6 (11.1)
Mother	47 (87)
Grandparent	1 (1.9)
Caregiver age (years)	
21-25	2 (3.7)
26-30	11 (20.4)
31-35	16 (29.6)
36-40	11 (20.4)
41 and above	14(25.9)
Level of education	
Illiterate	14 (25.9)
Read and write	10 (18.5)
Primary school graduate	12 (22.2)
Secondary school graduate	14 (25.9)
Graduated institute and college	4 (7.5)
Occupation	
Employed	12 (22.2)
Unemployed	42 (77.8)
Place of residence	
Rural	11 (20.4)
Suburban	17 (31.5)
Urban	26 (48.1)
Total	54 (100)

Table 2: Demographic characteristics of children with leukemia

Demographic characteristics	F (%)
Sex	
Male	26 (48.1)
Female	28 (51.9)
Age groups (years)	
1- 4	17 (31.5)
4.1-8	14 (25.9)
8.1-12	15 (27.8)
12.1-16	8 (14.8)
Child's order in the family	
1 st	12 (22.2)
2 nd	17 (31.5)
3 rd	9 (16.72)
4 th and above	16 (29.6)
The medical diagnosis of children	
AML	6 (11.1)
ALL	48 (88.9)
Family history of cancer	
Yes	11 (20.4)
No	43 (79.6)
Total	54 (100)

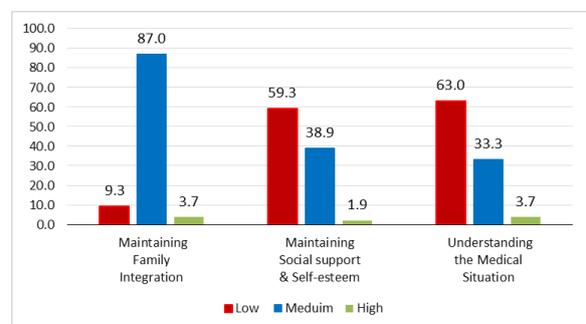


Figure 1: Distribution of caregivers coping patterns levels (low, medium and high) among three coping patterns domains

The study showed that the majority (61.1%) of caregivers' overall level of coping was within the medium level, 37% of caregivers have had a low level, and only 9.1% were within a high level of coping (Figure 2). Table 3 shows the association between some of the socio-demographic and overall level of caregivers' coping and indicates the presence of highly significant

Results also reveal a statistically significant association with the caregiver's occupation, the residency area and the child's family history of cancer (P-value 0.012, P-value 0.05, and P-value 0.024 respectively), while the association between the overall level of coping and the age of the caregivers was statistically non-significant (P-value = 0.348).

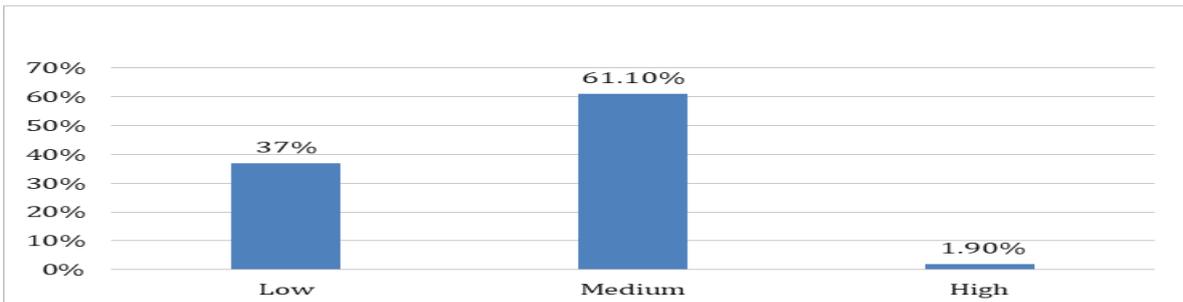


Figure 2: Distribution of caregivers of children with Leukemia among overall levels of coping pattern

Table 3: Association between socio-demographic characteristics of caregivers with an overall level of coping pattern

Demographic characteristics (n=54)	Low	Medium	High	Total	P-value*
	F (%)	F (%)	F (%)	F (%)	
Caregiver age (years)					
20-25	1(50)	1(50)	0(0)	2(100)	0.348****
26-30	3(27.3)	8(72.7)	0(0)	11(100)	
31-35	6(37.5)	10(62.5)	0(0)	16(100)	
36-40	2(18.2)	8(72.7)	1(9.1)	11(100)	
41 and above	8(57.1)	6(42.9)	0(0)	14(100)	
Level of education					
Illiterate	11(78.6)	3(21.4)	0(0)	14(100)	0.001**
Read and write	4(40)	6(60)	0(0)	10(100)	
Primary school graduate	3(25)	9(75)	0(0)	12(100)	
Secondary school graduate	2(14.3)	12(85.7)	0(0)	14(100)	
Graduated institute and college	0(0)	3(75)	1(20)	4(100)	
Occupation					
Employed	1(8.3)	10(83.3)	1(8.3)	12(100)	0.012***
Unemployed	19(45.2)	23(54.8)	0(0)	42(100)	
Residency area					
Rural	3(27.3)	8(72.7)	0(0)	11(100)	0.050***
Suburban	3(17.6)	14(82.4)	0(0)	17(100)	
Urban	14(53.8)	11(42.3)	1(3.8)	26(100)	
(Children) Family history of cancer					
Yes	1(9.1)	9(81.8)	1(9.1)	11(100)	0.024***
No	19(44.2)	24(55.8)	0(0)	43(100)	
Total	54(100)				

* Fisher's Exact test, ** highly significant, ***significant, **** non-significant.

DISCUSSION

Acute leukemia in children like other chronic diseases has a significant physical and psychosocial effect on the family members and caregivers leading to poor coping with this condition. Regarding the socio-demographic characteristics, the highest percentage of the study caregivers were in their thirties (the mean age of 36.53 ± 7.53 years), which agrees with the result of a previous, quasi-experimental study conducted in Egypt with 80 caregivers' of children with epilepsy that found the mean age score was 37.21 ± 5.22 years [10]. The result of this study indicated that the highest percentage of caregivers caring for leukemic children were mothers, which is consistent with the result of a descriptive study conducted by Hasan et al in Erbil (2012), which assessed the caregivers' home care for adolescent leukemia patients and found that most of the caregivers (71.3%) were the patients' mothers [3]. Furthermore, the study found that the caregivers of leukemic children were mostly secondary school graduates or illiterate and the majority were living in urban areas. These results are similar to the findings of a quasi-experimental study conducted in Egypt by El-Abbassy et al in 2015 who studied the effectiveness of practical guides on burden's coping strategies among the 50 caregivers of children undergoing hemodialysis [11]. The present study found that the majority of the children were diagnosed with acute lymphocytic leukemia. This result is congruent with the finding of a descriptive study conducted in Erbil by Hasan et al, among 80 adolescents from the period of 2010 to 2011, which aimed to assess the common physical problems among leukemic adolescent patients undergoing chemotherapy. They also found that 77.5% of cases had acute lymphoblastic leukemia and a lower percentage of cases had acute myelocytic leukemia (22.5%) [12].

Concerning the age groups of children, the age range of 1-4 years had the highest percentage. This agrees with a longitudinal prospective study finding which was carried out in the Netherlands among 115 parents and found that most of the children age were less than four years old [13]. Regarding the Coping Pattern I (maintaining family integration, cooperation and an optimistic of the situation), the majority of caregivers had a medium level of coping. The researchers believe that during the stress situations all the relatives and family members help and support each other following their Muslim culture and recommendations, and therefore express a medium level of coping. Concerning the Coping Pattern II (maintaining social support, self-esteem and psychological stability) and III (understanding the medical situation through communication with other parents and consultation with medical staff), the current study demonstrated that the majority of participants had low levels of coping compared to the Coping Pattern I (maintaining family integration, cooperation and an optimistic of the situation). This finding is supported by a study carried out among 200 Korean mothers of children with cancer, which found that mothers had a low rate of coping behaviors of the support subscale (coping pattern II) comparing with the other clusters of coping strategies measured by the CHIP [14]. The researchers believe that because most of available educating sources about leukemia are in English or other foreign languages and the caregivers have low educational level, they are not able to gain information from such sources or understand the medical staff explanation. Consequently, caregivers demonstrate a low level of coping in the coping pattern III (understanding the medical situation through communication with other parents and consultation with medical staff).

Regarding the overall level of coping patterns of caregiver having children with acute leukemia in the present study, the majority of caregivers showed a medium level of coping. This finding is in concurrence with a quasi study conducted by Hassan and Ibrahim (2018) in Egypt among 60 caregivers, which showed that most of the caregivers of cancer children had a moderate level of coping patterns [15]. In addition, the results of the current study show that in terms of the relationship between the total scores of overall coping level and some chosen parameters, as shown in Table 3, there was no statistically significant association between the age of caregivers and coping patterns level. This finding is consistent with the results of a study conducted by Hassan and Mohamed in 2011 for the assessment of burden and coping strategies in 100 caregivers of schizophrenic patients at Assiut University Hospital, Egypt, which reported that there was a significant negative correlation between the mean score of coping strategies and age of caregivers [16]. The current study revealed that there was a statistically significant association between the overall level of coping with caregivers' education level, and residence. This is in line with the findings of the study conducted by El-Abbassy et al in 2015, which found statistically significant differences between total scores of coping patterns with the father's education and residence [11]. Their study found no significant association between the total scores of coping strategies and the occupation of participants, which is in contrast with the present study that demonstrated a significant association between the overall score of coping patterns and the occupation of caregivers.

CONCLUSION

Researchers concluded that the highest percentage of the caregivers with leukemic

children had a low level of coping in two domains of coping (Pattern II; maintaining social support, self-esteem and psychological stability and Pattern III; understanding the medical situation through communication with other parents and consultation with medical staff). Furthermore, a highly significant association was found between the levels of education and overall coping patterns level. Finally, the researchers recommend further studies with a larger sample size.

CONFLICTS OF INTEREST

The authors Reported no conflict of interest.

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