

How to Cite:

Abbas, Z. K., & AL-Doori, N. M. (2022). Mother's burden form caring of their children with leukemia in Al-Basrah Province/ Iraq. *International Journal of Health Sciences*, 6(S4), 5153–5162. <https://doi.org/10.53730/ijhs.v6nS4.9285>

Mother's burden form caring of their children with leukemia in Al-Basrah Province/ Iraq

Zahraa Kadhum Abbas

PhD student Child Health Nursing, Faculty of Nursing, University of Babylon
Corresponding author email: zahraakadhum90@gmail.com

Nuhad Mohammed AL-Doori

Assist. Professor of Child Health nursing, Faculty of Nursing, University of Babylon
Email: nuhad64@yahoo.com

Abstract---Objectives: to assess the severity of the burdens practiced by Mothers for their children with leukemia in Al-Basrah Province and find out the association between severity of the burden and demographic characteristics. Methodology: A cross-sectional descriptive study consisting of (105) mothers who have children under eighteen years were selected in oncology & hematology clinic and leukemia ward (B) were interviewed at Al.Basrah children specialist hospital from 9 July 2021 to 20 October 2021. Result: Findings of the study revealed that (85.1 %) of the mothers expressed sever care burden. Conclusion: The study concluded that mothers overall responses were sever at care burden.

Keywords---care burden, mothers, leukemia, children.

Introduction

Leukemia is the general name for a group of cancers that affect the bone marrow and lymphatic system. It is a multifaceted illness with varying degrees of heterogeneity. As a result, categorization has become more complicated, sophisticated, and important, as determining, the subtype of leukemia has therapeutic and prognostic ramifications (1). Myeloblasts, lymphoblasts, and monoblasts, which are frequently referred to as "blasts," are immature white blood cells that cannot function efficiently in leukemia. An abnormal number of immature white blood cells reduces the amount of space available in the bone marrow for the formation of other healthy blood cells. The blast cells could then penetrate the bloodstream and infiltrate the brain (CNS) (1).

Acute Lymphocytic Leukemia (ALL) and acute myelogenous leukemia (AML) are the two most common kinds of childhood leukemia (AML). When a child has ALL, completely formed white blood cells are unable to form properly, and as a result, the patient is unable to fight off diseases (such as the common cold) effectively, and may succumb to the sickness. White blood cells aid in the fight against infection. In leukemia patients, white blood cells form improperly in leukemia patients, and stem cells transform into lymphoblasts (leukemia cells). This has a negative impact on the body because the number of red blood cells and platelets produced by the bones is reduced. Blood coagulation, infection resistance, and iron retention are all dependent on red blood cells. Heavy bleeding from a small incision or anemia is possible without healthy red blood cells (2).

Childhood leukemia is a kind of childhood cancer that affects children aged 0 to 14. In 2018, it accounted for 29 percent of cancers in children aged 0–14. In children, there are several types of leukemia, the most prevalent of which is acute lymphoblastic leukemia (ALL), followed by acute myeloid leukemia (AML) (Howlader et al., 2018). Survival rates vary depending on the type of leukemia, but with ALL, they can be as high as 90% (3). Leukemia is a type of hematological cancer that develops in the bone marrow, the soft interior part of the bone where new blood cells are produced. Normal healthy cells, on the other hand, only proliferate when there is enough room for them. The body will control cell production by sending out signals when it is time to cease. The cells of a child with leukemia do not respond to the signals that instruct them when to cease producing cells and when to stop producing them. When the bone marrow becomes overcrowded, it has difficulty creating other blood cells (4).

The signs and symptoms of childhood leukemia can be caused by other diseases or internal disorders. Anemia, weakness, feeling cold, pale skin, and shortness of breath are among the symptoms of childhood leukemia. Low white blood cell counts, which can cause infections, fevers, and a lack of immunity, cause the most noticeable symptoms. In addition, encourage the child to get more infected and inflamed. The accumulation of leukemia cells along the surface causes joint discomfort and swelling on the outside of the stomach. Gradual inflammation in many places of the body might potentially indicate the presence of cancer. Extreme weariness and weakness are the final symptoms of pediatric leukemia (5 and 6).

When parents learn that their children have lymphoma, leukemia, or another type of cancer, they are filled with fear. It's a period of new people and situations, as well as fears and change. It may be comforting to know that children's cancer survival statistics have improved dramatically over the past several decades. Around the world, doctors, nurses, and scientists are collaborating to improve outcomes for children diagnosed with pediatric cancers—experts are still looking for causes, developing better treatments, and reducing long-term impacts. psychologists, social workers, psychiatrists, and other health experts are also trying to figure out ways to help children and families cope with cancer and its treatment while also maintaining a high quality of life during their treatment (7).

There are two categories of caregivers: formal and informal. Formal carers are professionals who are paid to provide all forms of care (Rohani et al., 2014).

Individuals who provide unpaid, continuing support with activities of daily living or instrumental activities of daily living for people with a chronic disease or handicap are known as informal caregivers. Informal, or at-home, caregivers are the backbone of the long-term care system, and they are frequently made up of family, friends, and relatives (8).

Burden is a multifaceted notion with objective and subjective components that can be described. The term "objective burden" refers to specific events and activities associated with caregiving, such as financial difficulties or personal activity constraints. On the other hand, "subjective burden" refers to subjective reactions to the caregiver experience, such as anxiety, pressure, and guilt (9). The caregiver burden is described as a subjective experience that the carer considers to be particularly burdensome. Caregivers' physical and psychological well-being, as well as their personal and social relationships, are all affected by caregiver burden. In the survey, 60.6 percent of carers claimed they didn't have time to devote to their caregiving tasks, 78.8% said they were exhausted, 84.9 percent said they had communication issues with the patient, and 56.9% said they were having financial troubles (10). Caregiver burden is defined by Ahmadi et al. (11) as the physical, social, emotional, or economic challenges that a person who cares for a chronically ill or disabled family member can endure and is characterized by the caregiver's negative reaction.

Subjects and Methods

Cross-sectional description was approved throughout the present study aimed to care burdens and coping strategies practiced by mothers for their children with leukemia in Al-Basrah province from the period 1st October/2020 to 1st March/2022. Non Probability "convenient" sample of (105) mothers who have children under eighteen years were selected in oncology & hematology clinic and leukemia ward (B) at Al.Basrah children specialist hospital. Data were obtained through face-to-face interview techniques as means of data collection. The period from 9 July 2021 to 20 October 2021, interviews were achieved with mothers who were attended the setting of the study to complete the questionnaire, permission was arranged from the training and development center in the health directorate and an agreement of participation was obtained from the mothers to the interview. The researcher collected these data in oncology & hematology clinic and leukemia ward (B) at morning and evening, through average time required for each respondent has taken nearly 35 - 45 minutes to complete the questionnaire for assessing care burden practiced by mothers for their children with leukemia through the interview. The ZBI questionnaire was used for measuring mother burden in caring of child with leukemia. This part consisted of (22) items (Bédard et al., 2001). The responses for these items are rated and scored on 3-level type Likert scale as; always=3, sometime=2 and never=1. Data were analyzed through using the Statistical Package of Social Sciences (SPSS, version 24) performed with descriptive and inferential statistical data analysis approach.

Results

Table (1a): Distribution of mother's demographic data (n=105)

Demographical data	Ranking And Intervals	Frequency	Percentage %
Age of mother/ year	19-26	24	22.9
	27-33	31	29.5
	34-40	36	34.3
	41-47	14	13.3
	Total	105	100.0
	Mean $\pm$ (SD)	33.74 $\pm$ (7.85)	
Level of education	Unable to read and write	22	21.0
	Only read	6	5.7
	Read and write	15	14.3
	Primary	33	31.4
	Intermediate	14	13.3
	Secondary	3	2.9
	Institute	5	4.8
	College	7	6.7
	Total	105	100.0
Occupation	Unemployed	103	98.1
	Employed	2	1.9
	Total	105	100.0
Economic status	Unsatisfied	54	51.4
	Satisfied to some extent	37	35.2
	Satisfied	14	13.3
	Total	105	100.0

Table (1a) the mean age and standard deviation (SD) for mothers in the study was (33.74 $\pm$ (7.85)); one third of the mother were 36(34.3%) reported at age (34-40) years; the highest percentage 33(31.4%) were from primary school education; majority percentage of the study mothers 103 (98.1%) were unemployed; vast majority of mother 97 (92.4%) were married and more than half of mother 54 (51.4%) unsatisfied with their income.

Table 1b: Distribution of Child's Demographical data (N=105)

Demographical data	Ranking And Intervals	Frequency	Percentage%
Child age	Early childhood	70	66.7
	Middle childhood	25	23.8
	Late childhood	10	9.5
	Total	105	100.0

Child gender	Male	65	61.9
	Female	40	38.1
	Total	105	100.0
Child order in the family	1 st	22	21.0
	2 nd	20	19.0
	3 rd	26	24.8
	4 th and above	37	35.2
	Total	105	100.0

Table (1b) shows the observed frequencies, percent of children demographical characteristics variables that the child age were represented in early childhood as 70(66.7%) and the lowest as in late childhood 10(9.5%), while more than half of them 65 (61.9%) were male, while 40 (38.1%) were female. In relation to their orders among siblings revealed that 37 (35.2%) were 4th and above as highest but the lowest who are 2nd order among them 20 (19.0%).

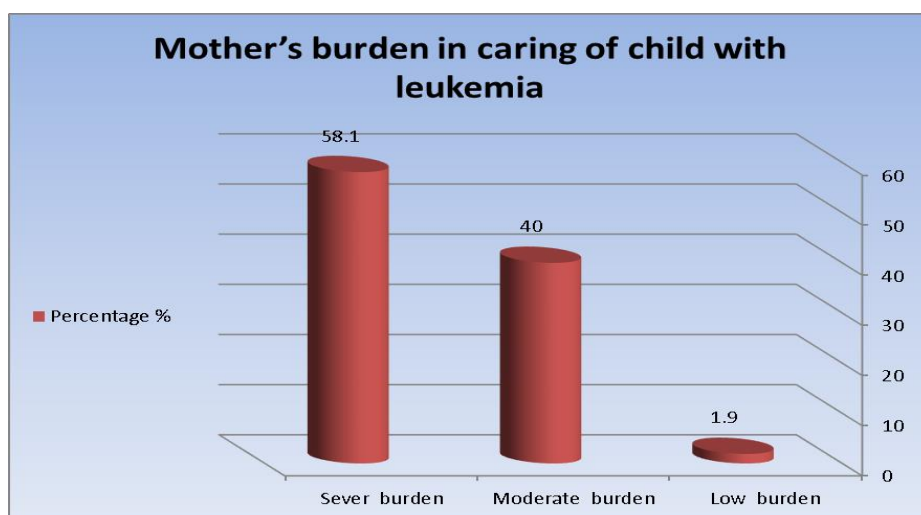


Figure (1): Overall assessment level of mother's burden in caring of child with leukemia.

Figure (1): show that more than half (58.1%) of the mothers expressed sever care burden.

Table (2): Relationship between mother's care burden and their Demographic Characteristics

Characteristics		Rating		Chi-square test x ² obs.= 4.052 d.f = 6 p-value = 0.670 Sig.=N.S
Age	Low burden	Moderate burden	Sever burden	
19-26	0	11	13	
27-33	0	11	20	
34-40	1	14	21	
41-47	1	6	7	

Total	2	42	61	
Level of education				
Unable to read and write	0	8	14	x^2 obs.= 20.455 d.f = 14 p-value = 0. 116 Sig. = N.S
Only read	0	3	3	
Read and write	0	7	8	
Primary	0	15	18	
Intermediate	2	2	10	
Secondary	0	1	2	
Institute	0	1	4	
College	0	5	2	
Total	2	42	61	
Occupation				
Unemployed	2	40	61	χ ² obs. = 3.058 d.f = 2 p-value = 0.217 Sig.= N.S
Employed	0	2	0	
Total	2	42	61	
Economic status				
Unsatisfied	0	17	37	x^2 obs.= 8.011 d.f = 4 p-value= 0.091 Sig.= N.S
Satisfied to some extent	1	17	19	
Satisfied	1	8	5	
Total	2	42	61	

χ^2 : chi-square, D.F: Degree of freedom, p-value: probability value, Sig: significant at $p \leq 0.05$, NS: Not significant at $p > 0.05$, n: sample size

Table (2): This table indicates, at a p-value of >0.05 , that there was no significant relationship between mothers care burden and their age groups, level of education, occupation and Economic status.

Table (3): Relationship between mother's care burden and child Demographic Characteristics

Characteristics	Rating			Chi-square test
Child age	low burden	moderate burden	sever burden	χ^2 obs.= 2.709 $d.f$ = 4 p -value = 0.608 Sig.=N.S
Early childhood	1	26	43	
Middle childhood	1	10	14	
Late childhood	0	6	4	
Total	2	42	61	
Gender				
Male	1	24	40	χ^2 obs.= .872 $d.f$ = 2 p -value= 0.647 Sig.=N.S
Female	1	18	21	
Total	2	42	61	

Child order				χ^2 obs.= 5.094 d.f = 6 p-value = 0.532 Sig.=N.S
1st	0	9	13	
2nd	0	6	14	
3rd	0	11	15	
4th and above	2	16	19	
Total	2	42	61	

" χ^2 : chi-square, D.F: Degree of freedom, p-value: probability value, Sig: significant at $p \leq 0.05$, NS: Not significant at $p > 0.05$, n: sample size

Table (3): This table indicates, at a p-value of >0.05 , that there was no significant relationship between mothers care burden and child age groups, gender and child order.

Discussion

Table (1a): the outcomes of the research underhand showed that the mean age and standard deviation (SD) for mothers in the study was $(33.74 \pm (7.85))$; one third of the mother were one third reported at age group (34-40) years, concerning to educational level, the less than one-third percent of mothers were primary school level, most percentage of the study mothers were unemployed, while the lowest percentage were employed and regarding to economic status, more than half of mother were unsatisfied with their income.

The findings of this study disagree with the study done by Sharma et al., (12) was the mean age of the studied sample was the average age of the parents was (38.76) SD-3.58 years. The outcomes of this result agree with the study done by Hashemi, et al., (13) on (72) parents included in the study, mention that the participants in this study was primary to high school education (69.4%). Another study with a convenience sample of 80 caregivers conducted by El Malky et al., (14) at the outpatient department at the health insurance institute in Shebin El-Kom district, Menoufia Governorate in Egypt. The finding of this study represent that the majority of participants (75%) was not working. The results of this research approved with the study done by Mahmoud, Elaziz, (15) in Egypt, that included a purposive sample of 60 parents, and their children attended Ain Shams University's pediatric hospital offers day care and outpatient clinics, which discovered that the majority of them (93.3%) with insufficient monthly income for their needs.

Table (1b), the current study discloses that more than two thirds of children as majority were within early childhood, regarding child gender, the study represent that less than two thirds were male and concerning child order in the family, one third were 4th and above. The result agree with study conducted by Al-Mutlaq et al., (16) aims to describe throughout a ten-year period the patterns of childhood malignancies in Saudi Arabia (1999-2008). The findings from this study indicate that the birth to age 4 years group had the greatest incidence rate in the surveyed years. The result agree with study done by Ma'arefvand and Khatamsaz, (17) in Iran about A convenience sampling of 991 parents of children with cancer was used to choose coping techniques of parents of children with cancer for a survey of 200 participants. Shows that most of the children (127) were male.

This result is slightly different from Hassan and Ibrahim, (18) who mentioned in their study about the impact of supportive nursing intervention on caregivers' stress and coping methods for children with cancer in a specialized pediatric hospital in Benha in Egypt that, the highest percent of children was late rank in the family. Figure (1) the present results were shown that the mothers burden related to caring of child with leukemia was demonstrated that the mothers expressed sever care burden ($n = 61$; $\% = 58.1$). According to researcher opinion, this indicate that mothers of children with leukemia have a higher care burden due to variables such as a lower probability of recovery, worsening of the child's condition as the disease progresses, lack of response to treatment, and more reliance on mothers for everyday activities.

In a similar way, in Texas a study conducted by Palos et al., (19) on Symptom burden on caregivers: the dangers of caring for an underserved patient with advanced cancer among 85 caregivers , which determined that the caregiving burden of the caregivers was high. Table (2): the findings presented that non-significant relationship between mother's care burden of children with leukemia and their age groups, level of education, occupation and economic status at p -value >0.05 . In a similar way, in Texas a study conducted by Palos et al., (19) on Symptom burden on caregivers: the dangers of caring for an underserved patient with advanced cancer among 85 caregivers ,establish that there was no significant variance among caregivers burden and age groups.

This outcome agree with descriptive research in turkey done by GÜR and ERSİN, (20) about the study of carers' burdens and quality of life while caring for cancer patients. There was no statistically significant variance among the mean scores of the whole burden interview according to education level ($p = .788$). The result agree with study conducted by Şahin and Ergüney, (21) about evaluating the emotions and gestures of family members who are caring for someone who is having chemotherapy. The finding represent that no significant association between the employment and caregivers burden. A cross-sectional study among 170 patients and their relatives who were treated in a chemotherapy unit of a hospital directed by Zeliha et al., (22) in Turkey aimed to determining the care load of caregivers caring for cancer patients. It was similarly, stated that showed that non-significant relationship between caregivers burden of and economic status at p -value >0.05 .

Table (3) this table indicate that there was no significant association among mother's care burden of kids with leukemia and kid age, gender and child order at p -value >0.05 . In turkey, a study directed by Baran, (10) aimed to establishing the link between caregiver load and life satisfaction among Turkish moms of cancer-stricken children. The finding of this study disagree with present result reveals that there was a negative association among the mean score of caregiver load and the age of the kid at (P value <0.01). A cross-sectional research on 209 parents of children with leukemia was conducted by Motlagh et al., (23). The finding agree with present result reveals that no significant correlation between care burden and child gender at p -value $=0.671$.

Conclusion

The study concludes that after assessing the mother's burden related to caring of child with leukemia, the findings indicated that the mothers expressed severe care burden.

Acknowledgments

I would like to express my thanks to the Ministry of Health, and Ministry of Higher Education and Scientific Research. Our sincere thanks go to the University of Babylon, College of Nursing. My sincere thanks to Prof. Dr. Ameen A.Yasir, Ph.D. Dean of College of Nursing/ Babylon University.. Sincerely thanks and appreciation to my supervisor Assist. Professor Dr. Nuhad AL-Doori. Sincerely thanks to the mothers at Al.Basrah children specialist hospital who consented to participate in this study.

References

1. Hockenberry, M.J., Wilson, D., and Rodgers, C.C., (2017). Wong's Essentials of Pediatric Nursing, 10th edition. USA: Elsevier, P.1616-973.
2. Bernard, S.C., Abdelsamad, E.H., Johnson, P.A., Chapman, D.L. and Parvathaneni, M., 2017. Pediatric leukemia-A review. *Journal of Cancer Clinical trials*, 2(131).
3. Hunger, S.P. and Mullighan, C.G., 2015. Acute lymphoblastic leukemia in children. *New England Journal of Medicine*, 373(16), pp.1541-1552.
4. Pui, C.H., Yang, J.J., Hunger, S.P., Pieters, R., Schrappe, M., Biondi, A., Vora, A., Baruchel, A., Silverman, L.B., Schmiegelow, K. and Escherich, G., 2015. Childhood acute lymphoblastic leukemia: progress through collaboration. *Journal of Clinical Oncology*, 33(27), p.2938.
5. Metayer, C., Dahl, G., Wiemels, J. and Miller, M., 2016. Childhood leukemia: a preventable disease. *Pediatrics*, 138(Supplement_1), pp.S45-S55.
6. Metayer, C., Dahl, G., Wiemels, J. and Miller, M., 2016. Childhood leukemia: a preventable disease. *Pediatrics*, 138(Supplement_1), pp.S45-S55.
7. DeGennaro, L. J., 2012. Coping with Childhood Leukemia and Lymphoma.
8. Plöthner, M., Schmidt, K., de Jong, L., Zeidler, J. and Damm, K., 2019. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. *BMC geriatrics*, 19(1), pp.1-22.
9. Ahmad, A.S., 2020. Psychological Burden of Caregivers of Children with Cancer at AL-Amal Hospital in Baghdad City. *Medico-legal Update*, 20(4), p.1747.
10. Baran, G., 2018. The burden of care and life satisfaction of the Turkish mothers of children with cancer. *Journal of Client-Centered Nursing Care*, 4(4), pp.175-184.
11. Ahmadi, M., Rassouli, M., Gheibizadeh, M., Karami, M. and Poormansouri, S., 2019. Predictors of caregiver burden among parents of children with cancer. *Iranian Journal of Pediatric Hematology & Oncology*.
12. Sharma, R., Shyam, R. and Grover, S., 2018. Coping strategies used by parents of children diagnosed with cancer. *Indian journal of social psychiatry*, 34(3), p.249.

13. Hashemi, F., Razavi, S., Sharif, F. and Shahriari, M.M., 2007. Coping strategies used by parents of children with cancer in Shiraz, Southern Iran.
14. El Malky, M.I., Mohsen, M.M. and Amer, H.M., 2016. The effectiveness of the nursing intervention program on feeling of burden and coping among caregivers of children with epilepsy. *International Journal of Advanced Nursing Studies*, 5(1), p.87.
15. Mahmoud, S. and Elaziz, N.A.A., 2015. Effect of Psycho-Educational Training Program for Parent's Having Child with Leukemia on Their Experience and Psychological Wellbeing. *Journal of Education and Practice*, 6(12), pp.13-29.
16. Al-Mutlaq, H.M., Bawazir, A.A., Jradi, H., Al-Dhalaan, Z.A. and Al-Shehri, A., 2015. Patterns of childhood cancer incidence in Saudi Arabia (1999-2008). *Asian Pacific Journal of Cancer Prevention*, 16(2), pp.431-435.
17. Ma'arefvand, M. and Khatamsaz, Z., 2014. Coping strategies of the parents of the children with cancer. *Quarterly journal of social work*, 3(3), pp.3-9.
18. Hassan, G.A. and Ibrahim, H.S., 2018. The effect of supportive nursing intervention on the burden and coping strategies of caregivers of children with cancer. *Journal of Nursing Education and Practice*, 8(7), p.125.
19. Palos, G.R., Mendoza, T.R., Liao, K.P., Anderson, K.O., Garcia-Gonzalez, A., Hahn, K., Nazario, A., Ramondetta, L.M., Valero, V., Lynch, G.R. and Jibaja-Weiss, M.L., 2011. Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. *Cancer*, 117(5), pp.1070-1079.
20. GÜR, S.C. and ERSİN, F., 2021. The Investigation of Caregiving Burden and Life Quality of Caregivers Who Care for Cancered Patients. *Harran Üniversitesi Tıp Fakültesi Dergisi*, 18(1), pp.88-94.
21. Şahin, Z.A. and Ergüney, E., 2015. Determining reactions and anger expressions of family members giving care for receiving chemotherapy. *Chemo Open Access*, 4, pp.1-6.
22. Zeliha, K.O.Ç., Sağlam, Z. and ÇINARLI, T., 2016. Determination of Caring Burden and Factors Affecting Relatives of Patients Caring for Individuals Diagnosed with Cancer. *Samsun Journal of Health Sciences*, 1(1), pp.99-116.
23. Motlagh, M.E., Mirzaei-Alavijeh, M. and Hosseini, S.N., 2019. Care Burden in Parents of Children with Leukemia: A Cross-Sectional Study in the West of Iran. *International Journal of Pediatrics*, 7(6), pp.9541-9548.
24. Eviasty, N., Daud, N. A., Hidayanty, H., Hadju, V., Maddeppungeng, M., & Bahar, B. (2021). The effect of personal coaching on increasing knowledge, attitudes, and actions about lactation nutrition, uterine involution, and lochia in public mothers. *International Journal of Health & Medical Sciences*, 4(1), 155-163. <https://doi.org/10.31295/ijhms.v4n1.1669>
25. Widana, I.K., Dewi, G.A.O.C., Suryasa, W. (2020). Ergonomics approach to improve student concentration on learning process of professional ethics. *Journal of Advanced Research in Dynamical and Control Systems*, 12(7), 429-445.
26. Widana, I.K., Sumetri, N.W., Sutapa, I.K., Suryasa, W. (2021). Anthropometric measures for better cardiovascular and musculoskeletal health. *Computer Applications in Engineering Education*, 29(3), 550-561. <https://doi.org/10.1002/cae.22202>