

Psychological Burdens and Challenges among Parents of Children Undergoing Chemotherapy

Dr. Wameedh Hamid Shakir

Assistant Professor, University of Kufa, faculty of Nursing, Pediatric Nursing Branch. Iraq

Annotation: Background: A cancer diagnosis and subsequent chemotherapy treatment have significant physical and psychological impacts on both the child and family members. Cancer is recorded as the second leading cause of death in the United States and the third in Iran, further intensifying the situation. Along with emotional and physical challenges, families also face substantial financial burdens to cover the costs of treatment and care. **Methodology:** This descriptive study used a non-probability sample of 95 families with a child undergoing chemotherapy, conducted from October 9, 2023, to April 10, 2024, at the AL-Najaf Health Directorate / National Oncology Teaching Hospital. The research tool assessed psychological burdens through interviews with one or both parents. Findings revealed that 73.91% of parents experienced moderate burden levels. Contributing factors to higher burden included extended caregiving duration, late-stage diagnosis, multiple chemotherapy courses, large extended family, financial challenges, and high anxiety and depression. The study concluded that most child patients suffered from Acute Myelogenous Leukemia, non-Hodgkin's Lymphoma, and Acute Lymphoblastic Leukemia, with parents experiencing moderate psychological burdens.

Methodology

Study Design

A descriptive study was carried out through the present study in order to achieve the early stated objectives. The study was beginning from October, 9th, 2023 to April, 10th, 2024.

Setting of the study: The study was conducted in the city of Najaf Al-Ashraf/Najaf Health Directorate/National Oncology Teaching Hospital.

The study sample: A convenience sample of (97) parents having children undergone chemotherapy

The Study Instrument: The research tool was used to assess the psychological burdens of families of children who underwent chemotherapy. It consists of two parts, Part One: A: Demographic data for the parents, including (age, gender, level of education, profession, number of children, monthly income, family type, and Family history).

Part One: B: Demographic data for the child, including (age, gender, sequence of the child in the family, type of disease, duration of care, stage of discovery of the disease, number of chemotherapy cycle

Part Two: This part consists of 23 questions to assess the psychological burdens and Challenges of the parents, which is measured on a three-point scale (Always, sometimes, never).

Data collection: Data were collected on a performance system specially designed for this study and using a structured interview technique with one or both parents who were interviewed at the National Oncology Teaching Hospital using the Arabic version of the questionnaire. The data collection process started from February 2024 to March 2024

Statistical analysis: Descriptive data analysis involves the following: Frequency and percentage tables, mean of score. Inferential data analysis: ANOVA: Repeated measures of ANOVA were used to find the relationship between socio-demographics and complications.

Keyword: Psychological; Burdens Challenges; Children; Chemotherapy.

Introduction

Cancer is among the most prevalent diseases and has been increasing in incidence among children. Each year, approximately 300,000 children aged 0 to 19 are diagnosed with cancer worldwide. According to American Cancer Society data, 10,590 children under the age of 15 were diagnosed with cancer in the United States in 2018. Cancer ranks as the second leading cause of death among children aged 5 to 14 in the U.S. and the third leading cause of death among children aged 1 to 14 in Iran (1)

A child's cancer diagnosis profoundly influences not only the child but also their entire family. During treatment, children endure symptoms, side effects, frequent hospital visits, and cycles of remission and relapse, all of which contribute to heightened stress and burden on parents. Additionally, the shift towards providing healthcare at home places more caregiving responsibilities on family members. This caregiving role can also strain the family's financial resources. However, the level of burden perceived by parents can vary based on factors such as their age, gender, economic status, the type of cancer, and their health. Without adequate support, parents may feel overwhelmed, experiencing heightened psychological stress and health-related issues (2)

In 2014, the American Cancer Society projected that nearly 16,000 children, ranging from birth to 19 years, would be diagnosed with cancer in the United States. Thankfully, advancements in treatment have led to a high survival rate among pediatric cancer patients, with over 80% living more than five years post-diagnosis. However, the costs associated with life-saving cancer therapies can impose a significant financial strain on families. In 2009, the average hospitalization cost for pediatric cancer patients in the U.S. was approximately \$40,400, almost five times higher than the average for other pediatric conditions (\$8,100). The most substantial expenses were related to leukemia (\$55,700) and non-Hodgkin lymphoma (\$46,900). These elevated costs are often attributed to unforeseen procedures during treatment, such as managing infections, pain, septicemia, and dehydration, which may necessitate additional hospital stays (3)

Mothers and fathers of children with complex conditions often respond to their circumstances in different ways. Typically, mothers take on the role of primary caregivers and are more likely to leave their jobs to care for their children, which can lead to social isolation. They frequently have a greater need for social support and positive reinforcement regarding their situation compared to fathers. Conversely, fathers face challenges that may differ from those experienced by mothers. They often feel their role as protectors is compromised when they struggle to find ways to help and are unable to shield their families from the overwhelming recurring difficulties. The considerable stress within the family can result in feelings of depression, weakness, guilt, powerlessness, isolation, embarrassment, and anger among fathers. Concerned about appearing weak or losing control, fathers may suppress their emotions and project an outward sense of confidence, leading others to believe they are managing well. They also grapple with worries about their children's future, the growing financial pressures, and the daily upheaval experienced by the entire family (4)

Parental psychological distress can significantly affect the well-being of children with cancer and their siblings. Identifying and addressing the factors contributing to this distress may enhance the overall family survivorship experience after a childhood cancer diagnosis. Cancer is among the most prevalent diseases affecting children, and it creates numerous challenges for parents, often leading to a substantial caregiving burden that can result in adverse health effects. This study aims to assess the caregiving burden and identify the factors that influence it among parents of children with cancer (5)

Results and Findings

Table 1: Socio-demographic Characteristics of the studied sample

Socio-demographic		Frequency	Percent
Age	<= 20	1	1.1
	21 – 26	4	4.2
	27 – 32	17	17.9
	33 – 38	20	21.1

	39 – 44	27	28.4
	45 – 50	6	6.3
	51+	20	21.1
	Total	95	100.0
Type of caregiver	Fathers	39	41.1
	mothers	56	58.9
	Total	95	100.0
Level of Education	Read and Write	18	18.9
	Primary School	26	27.4
	Secondary School	34	35.8
	Institute	8	8.4
	College	9	9.5
	Total	95	100.0
Occupation	Employee	18	18.9
	Free Work	28	29.5
	Housewife	49	51.6
	Total	95	100.0
Monthly income	Satisfied	19	20.0
	Satisfied to Some Extent	47	49.5
	Unsatisfied	29	30.5
	Total	95	100.0
Family History	Yes	32	33.7
	No	63	66.3
	Total	95	100.0

This table showed the socio-demographic data for fathers, the most frequent age group (39-44) at 28.4%. The study showed that most of the caregivers were mothers, at 58.9%. In related level of education, 35.8% of parents graduated from secondary school. In addition, occupation was 51.6% housewife. The study showed that 49.5% of parents' monthly income was sufficient to some extent. Finally, the results indicated that more than half of the families did not have previous history.

Table 2: Socio-Demographic Characteristic of the Children

Socio-Demographic		Frequency	Percent
Age	<= 2	1	1.1
	3 – 6	18	18.9
	7 – 10	37	38.9
	11 – 14	29	30.5
	15+	10	10.5
Sex	Male	53	55.8
	Female	42	44.2
Duration Care	3 Months	9	9.5
	3-6 Months	22	23.2
	7-12 Months	30	31.6
	More than one year	34	35.8
Disease Stage	Second Stage	53	55.8
	Third Stage	37	38.9
	Late Stage	5	5.3
Course of Chemotherapy	Two courses	29	30.5
	Three courses	28	29.5
	Four courses	38	40.0

This table shows the child socio-demographic data, most child age between (7-10) years of age. In addition, the study result shows that the majority of children are male (53) and the remaining are female. In related to the duration of disease most of child have more than one year. Additionally, majority of child within second stage in related to the disease duration. Finally, the study result shows that the most child received four courses of chemotherapy.

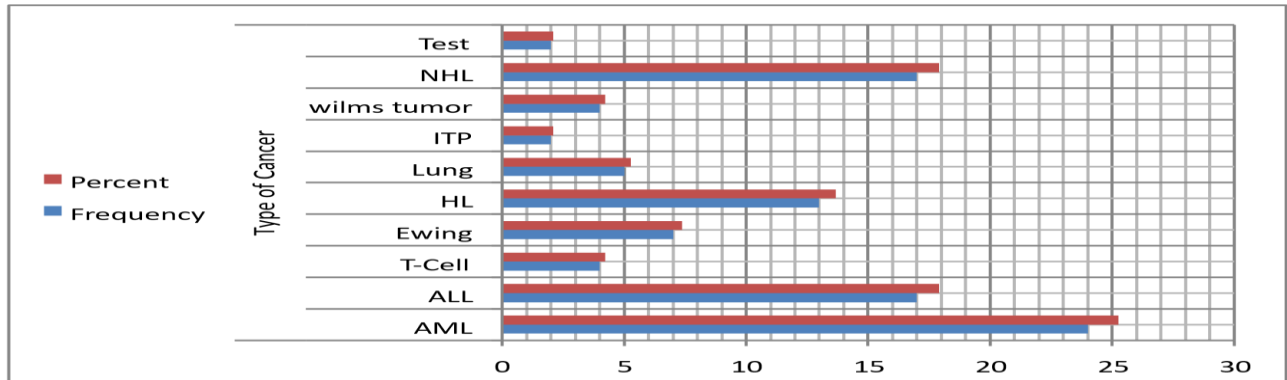


Figure-1: shows the type of cancer that child suffers from

Table 3: Statistical distribution of Parents Psychological burden with child undergoing chemotherapy

Questions	Mean	Response
Q1 Stressed about caring for your child and trying to meet other responsibilities for your family or work?	2.75	Always
Q2 Embarrassed you're your child's behavior?	1.89	Some time
Q3 Angry when you are around your child?	2.17	Some time
Q4 Your child's currently affects your relationship with other family members or friends in a negative way?	2.43	Always
Q5 Are you afraid of what the future holds for your child?	2.79	Always
Q6 Strained when you are around your child?	2.58	Always
Q7 You do not have as much privacy as you would like because of your child?	2.12	Some time
Q8 Your social life has suffered because you are caring for your child?	2.61	Always
Q9 Uncomfortable about having friends over because of your child?	1.96	Some time
Q10 You have lost control of your life since your child's illness?	2.43	Always
Q11 Wish you could just leave the care of your child to someone else?	1.11	Never
Q12 uncertain about what to do about your child?	1.21	Never
Q13 You should be doing more for your child?	2.11	Some time
Q14 You could do a better job in caring for your child?	1.64	Never
Q15 Overall, burdened do you feel in caring for your child?	1.82	Some time
Q16 That your child asks for more help than he needs?	2.40	Always
Q17 you don't have enough time for yourself because of the time you spend with your child	2.39	Always
Q18 Your child is dependent upon you?	1.56	Never
Q19 Does your health have suffered because of your	2.20	Some time

involvement with your child?		
Q20 Your child seems to expect you to take care of him/her as you only person can depend on?	2.58	Always
Q21 You will be unable to take care of your child much longer?	1.13	Never
Q22 Don't have enough money to care for your child in addition to the rest of your expenses?	2.07	Some time
Q23 Do you have complete knowledge about the disease.	1.82	Some time

Cut-off point (>=2.34=Always/ >=1.67=Some time/ >=1=Never)

Table (3) shows that the majority of Parents having children undergoing chemotherapy having psychological burden is distributed between sometime and always.

Table 5: Relationship between psychological burden and child Socio-demographic data:

	Sum of Squares	Df	Mean Square	F	Sig.
Age	365.718	22	16.624	1.327	0.185
Sex	4.551	22	0.207	0.789	0.728
Childe sequence	73.035	22	3.320	1.193	0.281
Type of Cancer	271.957	22	12.362	1.442	0.125
Duration Care	43.454	22	1.975	2.953	0.000
Disease Stage	10.869	22	0.494	1.704	0.048
Course of Chemotherapy	31.975	22	1.453	3.062	0.000

Table (5) reveals that there is a significant relationship between psychological burden and some demographic data for children such as duration of disease, disease stage, and course of chemotherapy at (p-value > 0.05), while there is a non-significant with remaining demographic data.

Table 6: Relationship between Parents psychological burden and Socio-demographic data

	Sum of Squares	Df	Mean Square	F	Sig.
Age	73.104	22	3.323	1.629	0.063
Sex	7.067	22	0.321	1.453	0.120
Level of Education	40.946	22	1.861	1.151	0.318
Occupation	17.593	22	0.800	1.465	0.115
Number of Children	68.786	22	3.127	1.213	0.265
Monthly income	22.339	22	1.015	2.971	0.000
Family Type	5.984	22	0.272	1.997	0.015
Family History	6.679	22	0.304	1.503	0.101

Table (6) reveals that there is a significant relationship between psychological burden and their demographic data such as monthly income at (p-value > 0.05), while there is a non-significant with the remaining demographic data.

Discussion

The study indicated that the majority of parents were aged between 39 and 44 years, which represented the largest percentage of the sample collected. This finding aligns which reported that the average age of parents was 41.1 years. The research highlighted that most caregivers in families with children undergoing treatment were women. This is attributed to the emotional challenges associated with caring for a child, as women are generally more adept at providing emotional support. Additionally, fathers often have other responsibilities that limit their ability to be involved. also found that the

proportion of female caregivers was significantly higher than that of males, with women comprising 87.5% of the caregivers (6)

The study found that most parents had completed secondary school, which influences their level of cultural understanding and their ability to care for their child appropriately, as well as their comprehension of medical instructions. This finding is supported by Kahriman, which reported that 60% of parents had education levels below high school. In terms of parents' occupations, the highest percentage identified as housewives, reflecting the earlier observation that caregivers are predominantly women. This aligns with the results of Barbosa, which indicated that 65.6% of participants were housewives (7)

Regarding monthly income, half of the families with children diagnosed with cancer struggle to cover their various needs, including often exorbitant treatment costs, which can place a significant burden on the family over time, along with the expenses associated with home care. The concern of one or both parents about maintaining employment to save money is a major contributing factor to this situation. In terms of family cancer history, most families of children with cancer did not report having a history of the disease. This finding is consistent which found that 56% of their study sample also had no family history of cancer(8)

The study highlighted a significant prevalence of nuclear families compared to a decline in the proportion of extended families, attributed to cultural shifts, economic changes, and individuals' preferences for independence. Reported that 87.7% of families were nuclear. Regarding the number of children, 24% of parents had four children, while the distribution of the remaining family sizes was uneven. Overall, families did not have many children, which can be linked to various social, economic, and cultural factors. This aligns which noted that 87.7% of families had two or more children (9)

The majority of children were between 7 and 10 years old, representing 38.9% of the total sample. This is expected, as this age group is often targeted in research involving children with cancer, consistent with findings from the average age of children was 7.9 years. Regarding gender, most of the children in the study were male, corroborating the findings of indicated that 52.8% the children were male. The duration of care varied among children due to the different types of cancer and individual responses to treatment, with the most common care period exceeding one year (10)

Concerning the stage of the disease, the majority of children were diagnosed at stage two, a result confirmed by reported a 42% diagnosis rate at this stage. Additionally, the study found that most children (40%) required four treatment courses per month, which negatively impacts the financial, psychological, and physical well-being of both the families and the children involved (11)

Conclusions

1. Most children in the sample are diagnosed with cancers such as Acute Myelogenous Leukemia, Non-Hodgkin's Lymphoma and Acute Lymphoblastic Leukemia in that order.
2. Most parents of children undergoing chemotherapy experience psychological burdens, with these challenges ranging from occasional to constant.

Recommendations

1-Support for Parents

Develop tailored support programs and resources specifically designed for parents, Offer emotional support through counseling services and support groups. Provide educational materials to help parents understand the treatment process, manage side effects, and handle challenges they may encounter

2- Financial Assistance

Create financial assistance programs to cover medical, transportation, and other related expenses. Partner with government agencies, non-profit organizations, and community initiatives to offer financial aid and resources for families in need

3-Psychosocial Support for Children

Implement child life programs in healthcare facilities, offering activities, play therapy, and educational resources to help children manage their diagnosis and treatment. Build a supportive, child-friendly environment in hospitals and treatment centers, including playrooms, child-centered decor, and age-appropriate activities to improve the treatment experience for children.

References

1. Ahmadi, M., Rassouli, M., Gheibizadeh, M., Karami, M., & Poormansouri, S. (2019). Predictors of caregiver burden among parents of children with cancer. *Iranian Journal of Pediatric Hematology & Oncology*.
2. Castle, P. E. (2024). Looking Back, Moving Forward: Challenges and Opportunities for Global Cervical Cancer Prevention and Control. *Viruses*, 16(9), 1357.
3. Warner, E. L., Kirchoff, A. C., Nam, G. E., & Fluchel, M. (2015). Financial burden of pediatric cancer for patients and their families. *Journal of oncology practice*, 11(1), 12-18.
4. Franklin, Q. M. (2020). Utilizing the psychosocial risk assessment in pediatrics to inform child life prioritization for children with cancer undergoing lumbar punctures with nitrous oxide sedation. Texas Woman's University.
5. Tan, X. W. I., Mordiffi, S. Z., Lopez, V., & Leong, K. (2021). Psychological distress in parents of children with cancer: a descriptive correlational study. *Asia-Pacific journal of oncology nursing*, 8(1), 94-102.
6. Fisher, R. S., Perez, M. N., Basile, N. L., Pepper, M., Gamwell, K. L., McNall-Knapp, R., ... & Mullins, L. L. (2021). Childhood cancer physical symptom burden and parent distress: The role of parent rumination. *Clinical Practice in Pediatric Psychology*, 9(3), 251.
7. Cheng, L., Reeve, B. B., Withycombe, J. S., Jacobs, S. S., Mack, J. W., Weaver, M., ... & Hinds, P. S. (2023). Profiles of symptom suffering and functioning in children and adolescents receiving chemotherapy. *Cancer nursing*, 46(2), E129-E137.
8. Cajete, G. (1999). *Native science: Natural laws of interdependence*. Clear Light Publishers.
9. O'Keeffe, N. (2022). *The Effect of Attending a Virtual Oncology Camp on Childhood Cancer Patient's Psychosocial Functioning and Parental Stress: A Pilot Study* (Master's thesis, Trent University (Canada)).
10. MacDonald, J. J. (2022). *Psychosocial contributors to psychological and physical health-related outcomes in adults with poor prognosis cancer and their caregivers*. University of California, Los Angeles.
11. Ha, L. (2022). *A patient-centred approach to engage childhood cancer survivors in health behaviours using novel digital technologies* (Doctoral dissertation, UNSW Sydney).
11. Shokri, M., Tarjoman, A., Borji, M., & Solaimanizadeh, L. (2020). Investigating psychological problems in caregiver of pediatrics with cancer: A systematic review. *Journal of Child and Adolescent Psychiatric Nursing*, 33(4), 229-238.