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Research Article

Examining Caregiving Burden in Mothers of Children With Newly Diagnosed Leukemia: The Role of Information Needs

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Background: This study aimed to identify the information needs of mothers of children diagnosed with leukemia and to examine the relationship between these needs and the care burden.
Methods: This longitudinal descriptive study, conducted in 2022, involved 110 mothers of children and adolescents aged 6 to 18 with leukemia. Data were collected at two points: upon admission and before discharge. The study utilized a 13-item information needs scale and a 22-item Caregiver Burden Scale (CBS) to gather data. The multivariable linear regression analyses were employed to identify predictors of caregiver burden, including variables that were significant in the bivariate analyses (p values < 0.05) as independent variables in the multivariate model.
Results: In the first week, the mean score for the overall information needs scale was 2.19 ± 0.54, which significantly increased to 2.99 ± 0.34 by the fourth week. The mean score for the overall CBS was 2.97 ± 0.41 (out of 4) in the first week, rising significantly to 3.34 ± 0.34 by the fourth week ($p < 0.001$). There was a significant inverse correlation between overall information needs and overall CBS both in the first week ($r = -0.415$, $p < 0.01$) and in the fourth week ($r = -0.224$, $p < 0.05$).
Conclusions: This study highlights the evolving information needs and increasing caregiver burden among mothers of children and adolescents with leukemia during their initial round of chemotherapy. Although increasing information helps alleviate the caregiver burden, the upward trend in perceived caregiver burden from the first suggests the need for additional supportive interventions.

Keywords: caregiver burden; health information needs; leukemia; neoplasms; pediatrics

1. Introduction

Cancer is the second leading cause of death from non-communicable diseases in individuals under 20, with an estimated 13.7 million new cases of childhood cancer expected globally between 2020 and 2050 [1–3]. In 2016, cancer accounted for 1853 of the 20,360 deaths of children and adolescents in the United States [4]. It is also a leading cause of death in Middle Eastern countries such as Jordan, Egypt, Lebanon, and Iran, where the incidence rate is

particularly high [5]. In Iran, the crude incidence rate of cancer in children aged 0–14 is 16.8 per 100,000 for boys and 16.56 per 100,000 for girls, making it the highest in Asia [6]. According to data from the Society for the Support of Children with Cancer (MAHAK Charity) covering the past decade, 19,973 children in Iran have been diagnosed with cancer, highlighting the increasing prevalence of this disease [7]. Following a diagnosis, families are plunged into a difficult and uncontrollable situation. Within this family unit, mothers most frequently assume the primary responsibility for their child's care and treatment, a role that can often feel overwhelming and is associated with unique burdens [8, 9].

The challenges associated with cancer, as well as the uncertain prognosis of this disease, distinguish it from other chronic illnesses in children [9]. Caring for children with cancer greatly impacts the physical, psychological, social, and economic well-being of family caregivers, often diminishing their quality of life [10]. Mothers, in particular, face immense stress and challenges, frequently exacerbated by a lack of awareness about cancer causes and treatment methods, as well as anxiety regarding the numerous precautions and restrictions involved in the care of the child [11]. While they act as crucial mediators between their child and the treatment team, helping to reduce the child's anxiety, this essential role can lead to significant caregiver burden, encompassing physical, psychological, and economic stress [4, 12]. Identifying and addressing this maternal caregiver burden is therefore crucial for improving outcomes for both the child and the family [13].

A key factor in mitigating this burden is information. Having sufficient and clear information about the child's illness helps maintain good relationships with healthcare providers and reduces parents' frustration and stress [14, 15]. For mothers, who are typically on the front lines of care, being empowered with information is critical to advocating for their child, making informed decisions, and managing home care [8, 16, 17]. However, the inadequate provision of information during treatment remains a significant concern [18]. Studies consistently show that mothers seek detailed information to cope with the illness and continue treatment [19, 20]. Person-centered informational interventions can help parents, and especially mothers, gain a deeper understanding and a sense of control [21].

The needs of mothers require special attention, particularly those with limited social support and long-term caregiving responsibilities, with information and emotional support being crucial [22–24]. These needs are dynamic and are often most pronounced during the first stressful weeks and months after diagnosis [25]. Given that mothers are the constant caregivers during intensive treatments like chemotherapy, this longitudinal descriptive study aimed to capture the trajectory of care burden and information needs specifically in mothers.

In this study, patients with leukemia were specifically selected because leukemia accounts for the largest proportion of childhood [26]. Also, its treatment period is longer than that of many other cancers, increasing the physical and psychological burden on the family, especially mothers [27]. In addition, the drugs used in the treatment of leukemia have unique side effects, including constipation, muscle weakness, neuropathy, and chronic fatigue, which affect the child's daily activities and quality of life [28]. In such situations, the knowledge and awareness of caregivers, especially mothers, plays a decisive role in managing complications, reducing anxiety, and improving the quality of child care [29].

We hypothesized that the burden on mothers would intensify over a 4-week chemotherapy period due to mounting complications and stress, necessitating continuous information exchange with healthcare providers. The study sought to examine the caregiver burden in mothers of newly diagnosed cancer patients and its relationship with their informational needs in the first and fourth weeks of chemotherapy.

2. Methods

2.1. Aim. This study aimed to determine the caregiver burden experienced by mothers of children newly diagnosed with leukemia and to examine its relationship with their information needs.

2.2. Study Design. A longitudinal descriptive design was employed to explore the relationship between the informational needs and caregiver burden of mothers of children undergoing chemotherapy. This design was essential to address the challenges of integrating results from cross-sectional studies involving different individuals and time points [30].

This study focused on mothers' experiences of caregiver burden and their evolving information needs. The primary objective of this study was to assess the self-reported caregiver burden of these mothers throughout their children's chemotherapy, examining how their understanding of their child's cancer evolved from the first week to the last week of treatment. The initial cycle of chemotherapy for these patients lasts 1 month, during which they are hospitalized and receive the chemotherapy protocol.

Sociodemographic and medical information of the children and participating mothers was collected. The participating mothers' information needs and caregiver burden scores were assessed twice: once at admission (Week 1) and again at the completion of chemotherapy (Week 4) prior to discharge.

The informational resources typically made available to mothers in the oncology wards of the studied hospitals included verbal explanations from physicians and nurses regarding the diagnosis, chemotherapy protocol, potential side effects, and their management; educational brochures in Persian prepared by the nursing unit; and access to nurses and physicians for inquiries during the hospitalization. No intervention was administered by the research team to provide additional information, as this was an observational longitudinal study. Consequently, the study solely assessed the mothers' informational needs and their caregiver burden in response to these standard, routinely available resources.

2.3. Setting and Participants. The study was conducted in the oncology wards of Tabriz Teaching Hospitals in Northwest Iran. This study was conducted in the oncology departments of the teaching hospitals in Tabriz, northwestern Iran. These hospitals are government-run institutions. Treatment costs at these centers are covered through a mixed payment system, in which a portion of the expenses is paid by the patient and the majority is covered by health insurance. Study inclusion criteria were as follows:

- Mothers of children with a diagnosis of acute lymphoblastic leukemia (ALL) or acute myelotrophic leukemia (AML)
- Mothers of children in the age range of 6 years–18 years who had been hospitalized for a first course of chemotherapy
- Mothers without a prior history of a child having cancer besides the penultimate child
- No history of psychiatric disorders in the mother, based on self-report

The presence of any serious chronic condition, such as a major congenital anomaly, metabolic disease, or severe developmental or neurological disability, was an exclusion criterion. This information was obtained through a review of the child's medical records and direct questioning of the mother.

2.4. Recruitment. Participants for this research were selected using a convenience sampling method between March 2022 and February 2023. This approach was adopted due to the challenge of limited access to children with newly diagnosed leukemia, which made it impractical to establish a comprehensive sampling frame for random selection. Consequently, inviting all eligible patients who visited the hospital during the study period was deemed the most practical and ethically appropriate recruitment strategy for this specific population. All new cases were evaluated against the study's inclusion and exclusion criteria. A total of 110 eligible mothers were identified and invited to participate.

Since the samples were selected through convenience sampling, all eligible mothers were included in the study according to the inclusion and exclusion criteria. Due to the lack of previous similar studies in this specific field, a pilot study was conducted before the main study to obtain baseline data, estimate the effect size, and determine the sample size. In this pilot study, 15 mothers participated, and the effect size was 0.30. The participants in the pilot study did not participate in the main study to avoid bias due to prior familiarity with the instrument. Based on the effect size of 0.30 obtained from the pilot study, the sample size was calculated using G∗Power software. With a 95% confidence level, 80% statistical power, and a two-sided test, the minimum required sample size was determined to be 110. In total, 110 mothers were included, and there were no missing data.

2.5. Measures. The data collection tool used in this study comprised three questionnaires. The first was a sociodemographic and medical information questionnaire, which gathered data on age, marital status, education, number of family members, income, and the child's information, including age, gender, and type of cancer.

The Information Needs Scale, designed by Motlagh et al. (2019b) [17], included 13 items on a 5-point Likert scale, ranging from 1 (*very low*) to 5 (*very much*), across four constructs: (a) medical information; (b) physical care information; (c) mental care information; and (d) lifestyle information. Medical information was assessed with three items (e.g., "How much do you know about treatment methods for your child's disease?"). Physical care information was measured with three items (e.g., "How much do you know about pain relief management methods for your child?"). Mental care information included four items (e.g., "How much do you know about coping methods with fear and anxiety in your child?"). Lifestyle information was evaluated with three items (e.g., "How much do you know about the needs of having relatives after your child's illness?"). A higher score on this scale indicated greater knowledge about the medical, physical, mental, and lifestyle aspects of the child's illness, implying fewer information needs. The alpha Cronbach coefficient for the entire scale in the study by Motlagh et al. (2019b) was 0.92, with subscale reliabilities as follows: medical information ($\alpha = 0.81$), physical care information ($\alpha = 0.88$), mental care information ($\alpha = 0.89$), and lifestyle information ($\alpha = 0.85$). In the current study, the scale's reliability, measured using Cronbach's alpha coefficient, was 0.96 for the whole scale and ranged from 0.92 to 0.99 for the subscales.

The Caregiver Burden Scale (CBS) is a multifaceted tool designed to assess the burden experienced by caregivers of patients with chronic illnesses [31]. We utilized the Persian version of the CBS. This scale comprises 22 items across five dimensions: 1. General Strain (8 items), 2. Isolation (3 items), 3. Disappointment (5 items), 4. Emotional Involvement (3 items), and 5. Environment (3 items). Each item is rated on a scale from 1 to 4 (1: *not at all*, 2: *seldom*, 3: *sometimes*, 4: *often*), with higher scores indicating greater perceived burden. Scores can be calculated separately for each domain or combined for a total score, reported either as a raw total or a mean score. The reliability coefficient for the Persian version of the CBS, as reported by Farajzadeh et al., ranged from 0.698 to 0.740 [32]. In this study, the scale's reliability, determined using Cronbach's alpha, was 0.93 for the entire scale and ranged from 0.70 to 0.95 for the subscales.

2.6. Data Analysis. The statistical analyses were performed using SPSS software, Version 24. Bivariate correlations were computed to determine the associations between information needs and CBS scores. Independent samples *t*-tests and one-way ANOVA were conducted to explore the relationship between background variables and both information needs and CBS scores. Additionally, multivariable linear regression analyses were employed to identify

predictors of caregiver burden, including variables that were significant in the bivariate analyses (p values < 0.05) as independent variables in the multivariate model. Categorical variables were converted into dummy variables before regression analysis. Assessment of skewness (within ±1.5) and kurtosis (within ±2) indicated that the caregiver burden data followed a normal distribution. The validity of the regression analysis was confirmed by verifying assumptions, including normality of residuals, homoscedasticity, and linearity of the variable relationships [33]. Cronbach's alpha coefficient was used to estimate the internal consistency of the various measures.

3. Results

The mean age of the mothers was 37.83 ± 6.51 years, with approximately 43.6% having a diploma-level education. The mean age of their children was determined to be 3.53 ± 11.73 years, with 77.3% diagnosed with ALL. Table 1 also highlights a significant correlation between mothers' education and their information needs; mothers with academic backgrounds demonstrated significantly higher knowledge and lower information needs compared to other groups in both the first and fourth weeks ($p < 0.05$). Moreover, mothers of children with ALL exhibited significantly greater information needs compared to those with children diagnosed with AML. There was a significant negative relationship between maternal age and information needs, meaning that younger mothers had a higher information need. Similarly, mothers of younger children had a higher information need than mothers of older children. Also, families with fewer members showed a higher information need. These patterns remained consistent in both the first and fourth weeks of chemotherapy. Caregiver burden was notably higher among mothers with education levels below a diploma than among others during both the first and fourth weeks ($p < 0.05$).

Table 2 illustrates that the overall mean of mothers' information needs at baseline (the first week) was 2.19 ± 0.54, which escalated to 2.99 ± 0.34 by the fourth week. Although the least amount of information needed was observed in the dimensions of medical care and physical care, the most substantial increase in information needs from the first to the fourth week, with an average difference of 0.97 and 0.90, respectively, occurred within these dimensions. Comparison of the average scores of total information needs and subscales between the first and fourth weeks using the paired t-test yielded significant results, indicating an increase in information ($p < 0.001$).

Table 3 reveals that the highest caregiver burden perceived in the first week was associated with the dimensions of Isolation, Disappointment, and General Strain, with averages of 3.34 ± 0.55, 3.14 ± 0.51, and 3.09 ± 0.53, respectively. These three dimensions experienced the most significant increase by the fourth week ($p < 0.001$). The lowest care burden in the first week was in the Emotional dimension with an average of 2.06 ± 0.50, which increased insignificantly by the fourth week. The average total CBS score in the first week was 2.97 ± 0.41, which increased significantly by the fourth week and reached 3.34 ± 0.34 ($p < 0.001$).

The results regarding the relationship between mothers' CBS and their information needs scores, as presented in Table 4, revealed significant inverse correlations. Specifically, there were inverse significant correlations between overall information needs and overall CBS scores ($r = -0.415$, $p < 0.01$), as well as between information needs and certain dimensions of CBS: General Strain ($r = -0.38$, $p < 0.01$), Disappointment ($r = -0.416$, $p < 0.01$), and Environment ($r = -0.414$, $p < 0.01$). Furthermore, the total CBS score exhibited a significant inverse relationship with the dimensions of medical care ($r = -0.366$, $p < 0.01$), mental care ($r = -0.415$, $p < 0.01$), and lifestyle ($r = -0.424$, $p < 0.01$) on the information needs scale.

The findings presented in Table 5 indicate a significant inverse relationship between mothers' overall information needs and overall CBS ($r = -0.224$, $p < 0.05$), as well as with the Environment subscale ($r = -0.317$, $p < 0.01$), during the fourth week. Moreover, the overall CBS score demonstrated a significant inverse relationship with the lifestyle dimension ($r = -0.21$, $p < 0.05$). Additionally, a significant inverse relationship was noted between caregiver burden in the environment dimension and mothers' information needs in the dimensions of medical care ($r = -0.333$, $p < 0.01$) and physical care ($r = -0.317$, $p < 0.01$).

In the multivariable linear regression analysis, mothers' information needs in the first week exhibited a negative association with their caregiver burden during the same week ($p < 0.001$). However, in the fourth week, information needs were not associated with caregiver burden ($p > 0.05$). Instead, the mother's education significantly predicted the caregiver burden in the fourth week. Specifically, mothers with a diploma degree displayed approximately 1.7 points lower caregiver burden scores compared to those with subdiploma education (Table 6).

4. Discussion

This longitudinal study assessed the information needs and caregiver burden among mothers of children with leukemia during the initial chemotherapy cycle. Findings indicate that although mothers had moderate information levels in the first week, scores were lowest in the domains of medical and physical care. By the fourth week, information levels increased most significantly in these areas—reflecting active efforts by both families and healthcare providers to address knowledge gaps. Nevertheless, absolute scores in medical and physical care remained relatively low, suggesting persistent unmet needs.

Consistent with studies from South Africa, Japan, and Iran, mothers expressed a strong desire for detailed medical information regarding their child's illness, treatment, and hospital care [8, 19, 20]. Acquiring such information is crucial—it enhances parents' understanding of the treatment process, supports their involvement in decision-making, and may ultimately alleviate caregiver burden.

The study found that although mothers' knowledge of physical care for children with leukemia has improved, it

Table 1: Demographic and clinical variables of mothers of children with leukemia ($N = 110$).

Variables	Frequency (%)	Information needs score		Caregiver burden score	
		Week 1 Mean (SD)	Week 4 Mean (SD)	Week 1 Mean (SD)	Week 4 Mean (SD)
Child gender					
Girl	56 (50.9)	2.15 (0.48)	3.03 (0.35)	2.96 (0.45)	3.27 (0.38)
Boy	54 (49.1)	2.23 (0.60)	2.94 (0.33)	2.97 (0.37)	3.40 (0.28)
Education level of mothers					
Under diploma	43 (39.1)	1.89 (0.50)	2.82 (0.26)	3.12 (0.41)*	3.46 (0.31)*
Diploma	48 (43.6)	2.30 (0.41)	3.02 (0.29)	2.88 (0.37)	3.23 (0.32)
Academic	19 (17.3)	2.64 (0.53)*	3.30 (0.39)*	2.82 (0.42)	3.28 (0.37)
Marital status					
Married	93 (84.5)	2.22 (0.55)	3.00 (0.34)	2.95 (0.39)	3.31 (0.33)
Divorce	9 (8.2)	2.07 (0.44)	2.94 (0.34)	3.09 (0.71)	3.46 (0.50)
Widow	8 (7.3)	1.89 (0.58)	2.92 (0.34)	3.11 (0.34)	3.56 (0.16)
Type of leukemia					
ALL	85 (77.3)	2.25 (0.56)*	3.03 (0.35)*	2.98 (0.41)	3.35 (0.33)
AML	25 (22.7)	2.00 (0.42)	2.85 (0.24)	2.93 (0.43)	3.30 (0.35)
	Mean (SD)	Correlation coefficient with information		Correlation coefficient with care burden	
		Week 1	Week 4	Week 1	Week 4
Mother's age (years)	37.83 (6.51)	−0.38*	−0.39*	0.14	0.18
Child age (years)	11.73 (3.53)	−0.34*	−0.28*	0.05	0.03
Family member size	4.16 (0.97)	−0.32*	−0.33*	0.06	0.02
Average family income in a month (IRR) per 100,000 T	122.27 (95.84)	0.002	0.155	−0.149	−0.179

Note: The independent samples t-test was used for two-group comparisons, one-way ANOVA for comparisons among three or more groups, and Pearson correlation for continuous variables (e.g., mother's age).
* $p < 0.05$, significantly different from other categories, or the correlation is significant.

Table 2: Mean difference of scale and subscales of mothers' information needs scale in the first and fourth weeks.

Scale and subscales	Mean (SD)		Mean difference	p value
	The first week	The fourth week		
Information needs scale	2.19 (0.54)	2.99 (0.34)	−0.79 (0.40)	< 0.001
Medical care subscale	1.70 (0.64)	2.67 (0.51)	−0.97 (0.49)	< 0.001
Physical care subscale	2.03 (0.66)	2.93 (0.33)	−0.90 (0.59)	< 0.001
Mental care subscale	2.44 (0.67)	3.15 (0.45)	−0.70 (0.61)	< 0.001
Lifestyle subscale	2.51 (0.60)	3.15 (0.43)	−0.64 (0.53)	< 0.001

Note: A paired t-test was used to compare means between the first and fourth weeks.
Statistical significance was set at $p < 0.05$.

Table 3: Mean difference of scale and subscales of mothers' CBS in the first and fourth weeks.

Scale and subscales	Mean (SD)		Mean difference	p value
	Week 1	Week 4		
Care Burden Scale	2.97 (0.41)	3.34 (0.34)	−0.36 (0.38)	< 0.001
General Strain subscale	3.09 (0.53)	3.62 (0.46)	−0.52 (0.54)	< 0.001
Isolation subscale	3.34 (0.55)	3.72 (0.42)	−0.38 (0.50)	< 0.001
Disappointment subscale	3.14 (0.51)	3.57 (0.47)	−0.043 (0.51)	< 0.001
Emotional subscale	2.06 (0.50)	2.17 (0.51)	−0.11 (0.31)	0.001
Environment subscale	2.90 (0.62)	2.98 (0.59)	−0.07 (0.25)	0.007

Note: A paired t-test was used to compare means between the first and fourth weeks.
Statistical significance was set at $p < 0.05$.

remains at a moderate level and is not sufficient to manage the complex complications of chemotherapy, such as pain, nausea, and malnutrition. This gap is of great importance because it directly affects the child's quality of life and treatment outcomes, as confirmed by Borgelillo et al. [8]. Understanding these important but often overlooked areas has a direct impact on treatment outcomes. When mothers are well informed about potential complications such as

Table 4: Correlation of mothers' caregiver burden with their information needs in the first week.

Scales and subscales	Caregiver Burden Scale	General Strain	Isolation	Disappointment	Emotional	Environment
Information needs scale	−0.415**	−0.380**	−0.070	−0.416**	−0.142	−0.414**
Medical care	−0.366**	−0.306**	−0.067	−0.335**	−0.281**	−0.345**
Physical care	−0.177	−0.182	0.118	−0.252*	0.137	−0.324**
Mental care	−0.415**	−0.396**	−0.124	−0.390**	−0.134	−0.370**
Lifestyle	−0.424**	−0.375**	−0.149	−0.415**	−0.205	−0.348**

Note: Pearson correlation coefficients were calculated to explore associations between caregiver burden and information needs in the first week.
*$p < 0.05$.
**$p < 0.01$.

Table 5: Correlation of mothers' caregiver burden with their information needs in the fourth week.

Scales and subscales	Caregiver Burden Scale	General Strain	Isolation	Disappointment	Emotional	Environment
Information needs scale	−0.224*	−0.146	0.112	−0.184	−0.181	−0.317**
Medical care	−0.172	−0.082	0.085	−0.146	−0.100	−0.333**
Physical care	−0.139	−0.043	0.086	−0.094	−0.136	−0.317**
Mental care	−0.177	−0.149	0.133	−0.146	−0.186	−0.175
Lifestyle	−0.210*	−0.164	0.033	−0.183	−0.138	−0.205

Note: Pearson correlation coefficients were calculated to explore associations between caregiver burden and information needs in the fourth week.
*$p < 0.05$.
**$p < 0.01$.

Table 6: Multivariable linear regression results of factors affecting mothers' caregiver burden.

Dependent variable ⟶⟶	Care burden in the first week				Care burden in the fourth week			
Predictors ↓↓	Adjusted B	95% CI lower	95% CI upper	p value	Adjusted B	95% CI lower	95% CI upper	p value
Information needs	−0.308	−0.459	−0.157	**< 0.001**	−0.081	−0.261	0.099	0.373
Subdiploma (reference)	—	—	—	—	—	—	—	—
Diploma	−0.128	−0.288	0.032	0.116	−0.172	−0.303	−0.041	**0.011**
Academic	−0.087	−0.307	0.133	0.435	−0.117	−0.301	0.067	0.209
	$R^2 = 0.216$, p value < 0.001				$R^2 = 0.086$, p value = 0.022			

Note: Multivariable linear regression analysis was used to identify predictors of mothers' caregiver burden at weeks one and four. Statistical significance was set at $p < 0.05$. Bolded values indicate statistically significant coefficients ($p < 0.05$).

infection or neutropenic fever in leukemia, they are more likely to recognize early warning signs and seek medical attention promptly [29, 34]. This awareness can significantly influence time-sensitive indicators such as the "time from fever to antibiotic initiation," a critical measure in pediatric oncology that substantially reduces both mortality and morbidity [35]. Consequently, moving beyond generic information delivery, the implementation of structured, practical training programs is proposed. Such programs should integrate cognitive-behavioral techniques—demonstrated by Shojaei et al. [30] and Melesse et al. [36] to reduce pain and distress—to equip mothers with actionable skills. This initiative should be coupled with dedicated nutritional counseling and ongoing support to effectively translate knowledge into confident home-based care.

This study revealed a significant increase in mothers' information needs regarding the mental care of their children with cancer, with scores rising from 2.44 to 3.15, highlighting the critical need for integrated psychosocial support alongside medical treatment. This finding aligns with the work of Motlagh et al. [12] and Borjalilu et al. [8], who emphasized parents' need for practical strategies to address their child's fear, anxiety, and anger. Given that children face psychological challenges due to repeated hospitalizations and observing parental distress, incorporating psychological interventions into care plans is essential [33, 37]. Furthermore, although lifestyle needs were initially a lower priority, cancer's impact on marital interactions and family cohesion [36, 38, 39], coupled with feelings of loneliness in siblings [40], underscores the necessity for counseling and training in interpersonal skills and anger management to enhance hope and mitigate parental stress [41]. Therefore, designing comprehensive care programs that focus on providing psychological information and supporting the entire family system is strongly recommended.

The findings indicate a significant increase in caregiver burden among mothers from the first to the fourth week, with the dimension of despair being the most pronounced. This aligns with established literature confirming that caring for a child with cancer is a profound source of stress and

pressure for parents. [19, 42, 43]. The experience of a high burden, as demonstrated in this study and others [19, 43] is multifaceted. Caregivers often face challenges such as constant worry about the child's prognosis, feelings of inadequacy, confusion, and profound fatigue, which collectively contribute to significant emotional stress [44]. This burden is not merely psychological; it has direct practical implications. A high caregiver burden can compromise the quality of care provided to the child and lead to adverse health outcomes for both the caregiver and the patient [42, 44, 45].

This study identified a significant inverse relationship between mothers' information needs and their perceived caregiver burden, both at one and 4 weeks postdiagnosis. Specifically, higher levels of information in the medical, mental, and lifestyle dimensions were associated with lower burden. Findings of this study align with existing literature on the mediating role of burden. Salvador et al. demonstrated that parental perceptions of illness severity negatively impact their quality of life through increased caregiver burden [46]. Furthermore, Crespo et al. established that providing diagnostic and treatment information as a family-centered intervention effectively reduces parental burden. They emphasize that the parental perception of care and the quality of interaction with healthcare systems are critical for adjusting to the caregiving role [47].

This study identifies key sociodemographic predictors of information needs among mothers of children with specific diseases. Findings of this study offer practical insights for tailoring clinical communication. Mothers with higher education levels demonstrated consistently greater information needs. Contrary to some studies [12, 17, 48], but aligning with Knijnangen et al. [49], this suggests that higher education may foster a proactive approach to information-seeking for managing a child's condition. Practically, a mother's educational level can serve as a useful indicator for healthcare providers to identify parents who may desire more in-depth information and detailed discussions. Conversely, information needs decreased with increasing maternal age and a larger number of family members. This is consistent with patterns where younger mothers and those from larger families may experience greater psychosocial stress, limiting their capacity for information-seeking [50]. A larger family likely acts as an internal information-sharing and support network, reducing the mother's perceived need for external information [12]. This highlights that providers should be especially attentive to the information needs of younger mothers and those with smaller family support systems, as they may be more vulnerable to gaps in knowledge. While this relationship can be influenced by cultural and socioeconomic contexts [17], findings of this study strongly support the buffering effect of family support.

Caregiver burden was significantly higher among mothers with an education level below a diploma. This finding aligns with existing literature, which suggests that lower educational attainment is often linked to a higher perceived burden [19]. This correlation may be explained by several factors: caregivers with higher education may possess more advanced stress management and problem-solving skills [21], while those with lower education often face associated socioeconomic challenges, limiting their access to essential resources and support systems [51].

5. Study Limitations

This small-scale survey investigated the information needs and caregiver burden among mothers of children diagnosed with leukemia at hospitals affiliated with Tabriz University of Medical Sciences. The specific needs and experiences of these participants may not be representative of parental caregivers in other settings, particularly private hospitals; therefore, the findings should be generalized with caution.

The study was conducted during a period of significant challenges within Iran's healthcare system due to international sanctions, which impacted access to resources, medications, and support services. These external factors likely exacerbated the caregiving burden. Future research should involve larger, more diverse populations to better understand the causal relationships between the variables. It should also examine the specific challenges faced by parents in similar sociopolitical contexts to comprehensively understand the interplay between information needs, care burden, and external influences. Any interpretation of this study's findings must account for these sociopolitical constraints.

6. Conclusion

This study uniquely examines the evolving dynamics between information needs, caregiver burden, and specific care dimensions for mothers of children undergoing leukemia treatment. It highlights the changing information needs and caregiver burden over the course of chemotherapy, stressing the importance of tailored supportive interventions beyond just providing information. To effectively support parents, healthcare providers—including doctors, nurses, psychologists, and social workers—should be accessible and equipped to meet the diverse needs of these families. Interdisciplinary collaboration should be encouraged to utilize all available resources. Additionally, this study underscores the significance of addressing contextual and psychosocial factors in caregiver burden. Developing comprehensive support programs and fostering collaborative care can significantly improve the well-being of families with children diagnosed with leukemia.

Data Availability Statement

The datasets used and/or analyzed in the current study are available from the corresponding author upon reasonable request.

Ethics Statement

This study was approved by the Medical Ethics Committee of Tabriz University of Medical Sciences (ethics code: IR.TBZMED.REC.1400.1179). The study followed accepted ethical standards, as outlined in the Declaration of Helsinki. All participants were provided with a comprehensive

description of the study aims, and their informed written consent was duly procured. Participants were additionally provided with an assurance regarding information confidentiality, as well as the option to voluntarily withdraw from the study at any point of the research.

Disclosure

All authors approved the final version. The funder had no role in the design of the study, the collection, analysis, and interpretation of the data, or in writing the manuscript.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

Hosna Ghorbani, Arefeh Davoodi, and Akram Ghahramanian conceived and designed the study and prepared the study protocol. Hosna Ghorbani and Sana Mojtahedy assisted with data collection. Akram Ghahramanian, Farzaneh Bagheriyeh, and Arefeh Davoodi supervised all data collection and study procedures. Akram Ghahramanian and Tonia C. Onyeka analyzed the study data. Akram Ghahramanian and Tonia C. Onyeka interpreted study findings. while all authors contributed to the preparation of the manuscript.

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