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The relationship between caregiver burden and hope in leukemia patients: a cross-sectional study in selected referral hospitals in Tehran, Iran

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Abstract

Background Leukemia is a life-threatening condition that imposes significant challenges not only on patients but also on their caregivers. Caregiver burden, a multidimensional concept encompassing physical, psychological, and emotional strain, often impacts the quality of care provided to patients. Conversely, hope, a critical psychological resource, plays a pivotal role in patient well-being and coping. Understanding the relationship between caregiver burden and patient hope is essential for improving holistic cancer care.

Methods This descriptive correlational study was conducted at the Cancer Institute and Valiasr Hospital, affiliated with Tehran University of Medical Sciences, between May and November 2024. A total of 400 participants, including 200 leukemia patients and their 200 primary caregivers, were recruited using convenience sampling. Data were collected using the Zarit Caregiver Burden Interview (ZBI) and Snyder's Adult Hope Scale (AHS). Descriptive statistics and Pearson's correlation coefficient were used to analyze the data in SPSS version 16, with a significance level of $P < 0.05$.

Results The mean caregiver burden score was 37.69 ± 7.12, indicating a moderate level of burden, while the mean hope score among leukemia patients was 32.19 ± 1.88, reflecting relatively high levels of hope. A weak but statistically significant negative correlation was found between caregiver burden and overall hope scores ($r = -0.164$, $P = 0.02$). However, no significant correlations were observed between caregiver burden and the subscales of hope, namely Pathway Thinking ($r = -0.127$, $P = 0.073$) and Agency Thinking ($r = -0.126$, $P = 0.076$).

Conclusion The study highlights a significant inverse relationship between caregiver burden and patient hope, underscoring the interconnected dynamics between caregiver well-being and patient psychological resilience. Interventions aimed at reducing caregiver burden and fostering hope in patients are essential for enhancing the overall quality of care in leukemia.

Clinical trial number Not applicable.

Keywords Caregiver burden, Hope, Leukemia, Holistic nursing

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Introduction

Leukemia is a group of cancers that affect the blood and bone marrow, characterized by the uncontrolled production of abnormal blood cells [1]. In 2020, leukemia contributed to around 2.5% of all newly diagnosed cancer cases worldwide and was responsible for approximately 3.1% of cancer-related deaths globally [2]. Leukemia is classified into four major types: acute lymphoblastic leukemia (ALL), acute myeloid leukemia (AML), chronic lymphocytic leukemia (CLL), and chronic myeloid leukemia (CML), each of which has distinct clinical features, treatment regimens, and prognoses [3].

The diagnosis of leukemia often comes with significant psychological and physical challenges for patients [4, 5]. Patients typically undergo intensive treatments, including chemotherapy, radiation, and bone marrow transplants, all of which can cause a range of side effects such as fatigue, pain, nausea, and emotional distress. In addition to the physical toll, leukemia patients experience profound emotional challenges, including fear, anxiety, and depression, due to the uncertainty of their diagnosis and treatment outcomes [5–7]. As a result, they require ongoing medical, emotional, and social support, much of which is provided by caregivers.

Leukemia patients frequently rely on caregivers to assist them in navigating the complexities of their illness. Caregivers play a pivotal role in managing patients' treatment schedules, providing physical care and offering emotional support [8, 9]. While caregiving is a vital component of cancer care, it is also a role that comes with significant personal costs. The demands of caregiving can lead to what is commonly referred to as caregiver burden [10].

Caregiver burden is a multidimensional concept that encompasses the physical, psychological, emotional, and financial strains experienced by individuals who care for chronically ill patients [11]. Physically, caregivers may endure exhaustion from managing the day-to-day needs of patients, often neglecting their own health in the process. Psychologically, caregivers frequently experience heightened levels of stress, anxiety, and depression. Emotionally, they may grapple with feelings of helplessness, grief, and frustration, particularly when witnessing the suffering of their loved ones. Financially, caregiving can result in significant economic strain, especially when caregivers reduce their work hours or leave their jobs to accommodate their caregiving responsibilities [12–16]. Collectively, these challenges not only affect the well-being of caregivers but may also have indirect implications for the patients they support.

For leukemia patients, maintaining hope is a crucial psychological resource that significantly influences their ability to cope with the disease and adhere to treatment [17, 18]. Hope, broadly defined as the ability to envision a positive future despite current adversities, plays a critical role in promoting emotional resilience and improving quality of life [19]. Hope has been associated with better psychological outcomes, increased motivation for self-care, and enhanced treatment compliance in cancer patients [18, 20].

Studies suggest that various factors can influence hope, including social support, coping strategies, psychological resilience, and religious or spiritual beliefs [21–23]. Importantly, hope is often shaped by the social and emotional environment in which the patient resides. In this context, the caregiver's mental and emotional state becomes particularly relevant.

Patient psychological outcomes can significantly influence various aspects of caregiver well-being. When patients demonstrate positive psychological states, such as hope and effective coping mechanisms, caregivers often experience reduced stress and an enhanced sense of efficacy in their role. Conversely, negative psychological outcomes in patients, such as anxiety, or depression, can exacerbate caregiver burden, leading to emotional exhaustion and feelings of helplessness [24–26]. Understanding and addressing these relationships is crucial for fostering a supportive care environment that benefits both patients and caregivers.

Investigating the relationship between caregiver burden and hope in leukemia patients, provides a deeper understanding of how caregiver well-being impacts patient psychological outcomes and to identify potential avenues for intervention. Insights gained from such research could guide the development of caregiver-focused support programs that alleviate burden and, in turn, positively influence patient outcomes. Therefore, this study aimed to investigate the correlation between caregiver burden and hope in leukemia patients.

Methods

Design and aim

This descriptive correlational study was designed to investigate the relationship between caregiver burden and hope in leukemia patients. The research was carried out at the Cancer Institute and Valiasr Hospital, affiliated with Tehran University of Medical Sciences, in Tehran, Iran, between May and November 2024.

Study setting and participants

The study population comprised leukemia patients who referred to the Cancer Institute and Valiasr Hospital, affiliated with Tehran University of Medical Sciences, along with their primary caregivers. Participants were selected using a convenience sampling method. The inclusion criteria for leukemia patients were as follows: being 18 years of age or older, having been diagnosed with leukemia for at least two months, being aware of their diagnosis, having the ability to read and write, and having no history of psychological disorders. For caregivers, the inclusion criteria included being the primary caregiver for a leukemia patient (defined as the individual who provides the majority of unpaid, daily care and emotional support to the patient), aged 18 years or older, having the ability to read and write, and free from psychological disorders. Exclusion criteria included participants who did not respond to more than 10% of the questionnaire items.

Sample size and power

The sample size was calculated based on a 95% confidence level and 80% statistical power, with an assumed correlation coefficient of 0.2 between caregiver burden and hope. According to the following formula, the minimum required sample size was estimated to be 194 participants. In this study, we recruited a total of 400 participants, consisting of 200 leukemia patients and 200 caregivers. The data of the patients and their caregivers were paired to assess the relationship between caregiver burden and the hope of patients.

$$\mathrm{n} = \frac{\left(\mathrm{z}_{1-\frac{\alpha}{2}} + \mathrm{z}_{1-\beta}\right)^2}{\mathrm{w}^2} + 3$$

$$w = \frac{1}{2} ln \frac{1+r}{1-r}$$

$$w = \frac{1}{2} ln \frac{1+0/20}{1-0/20} = 0/20$$

$$\mathrm{n} = \frac{(1/96+0/84)^2}{0/20^2} + 3 = 194$$

Data collection instruments

Data collection was carried out using the following instruments:

Demographic information questionnaire This questionnaire collected demographic details from both patients and caregivers, such as age, gender, marital status, and educational level.

The Zarit caregiver burden interview (ZBI) This tool was developed by Zarit et al. in 1980, is a widely used self-administered instrument designed to assess caregiver burden. It consists of 22 items, each scored on a Likert-type scale with five response options from never (0 points) to almost always (4 points). The minimum and maximum scores ranged from 0 to 88. Higher scores indicate greater caregiver burden. A score below 20 was categorized as mild psychological stress, 21 to 40 as moderate, 41 to 60 as severe caregiving burden, and 61 to 88 as very severe caregiving burden. Higher scores on the ZBI correspond to greater levels of caregiver burden, reflecting the increasing psychological, emotional, and physical strain experienced by caregivers [27].

In this study, the Persian version of the ZBI was used, which was psychometrically tested and validated in Iran by Novidian and Bahari Zaheden (2008) [28]. Additionally, Mollai et al. (2019) reported a Cronbach's alpha of 0.83 for the scale in cancer patients in Iran [29]. In the current study, the Cronbach's alpha of this tool was found to be 0.88, confirming its reliability.

Snyder's Adult Hope Scale (AHS) This questionnaire was designed in 1991 by Snyder et al. This scale consists of 12 items, 8 of which are scored, while the remaining 4 serve as lie detectors and are not included in the total score. The scale has two subscales: agency thinking and pathways thinking. Pathways thinking refers to an individual's understanding that they can create viable paths to achieve their goals, while agency thinking reflects the belief in their ability to use these paths effectively. Each subscale contains four items. The items are rated using a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The total score is calculated by summing the scores for each item. Higher scores indicate greater levels of hope [30].

Vakili et al. (2021) validated the Persian version of this scale. They reported a Cronbach's alpha of 0.65 for the Pathways Thinking subscale and 0.61 for the Agency Thinking subscale, indicating acceptable internal consistency for both dimensions. The overall Cronbach's alpha for the entire scale was 0.75, further confirming its reliability [31]. In the current study, the Cronbach's alpha for the Pathways Thinking subscale, the Agency Thinking subscale, and the overall scale were 0.77, 0.72, and 0.75, respectively, confirming its reliability.

Data collection procedure

After receiving ethical approval from the Ethics Committee of Tehran University of Medical Sciences, the research team approached leukemia patients and their caregivers in the research setting. The purpose and objectives of the study were thoroughly explained, and informed consent was obtained from all participants. The questionnaires were distributed in person, and participants completed them within the hospital setting. The completed questionnaires from each patient and their respective caregiver were paired and entered into the SPSS software simultaneously to ensure accurate data linkage and analysis. The researcher remained available throughout the completion of the questionnaires to address any questions or concerns and to assist with clarifying or answering items.

Table 1 Demographic characteristics of patients

Demographic information		Frequency	percent
Age (year)	< 30	76	38
	30–39	47	23/5
	40–49	49	24/5
	> 50	28	14
Gender	Female	76	38
	Male	124	62
Marital status	Single	67	33/5
	Married	133	66/5
Education level	Below diploma	73	36/5
	Diploma	98	49
	Above Diploma	29	14/5

Table 2 Demographic characteristics of caregivers

Demographic information		Frequency	percent
Gender	Female	108	54
	Male	92	46
Marital status	Single	33	16/5
	Married	167	83/5
Education level	Below Diploma	66	35
	Diploma	91	45/5
	Above Diploma	39	19/5

Ethical considerations

The study received approval from the Ethics Committee of Tehran University of Medical Sciences (IR.TUMS.IKHC.REC.1402.293). All patients and caregivers were provided written informed consent. Participants were informed about the study's purpose. They were assured that their participation was entirely voluntary, with the right to withdraw at any time without any negative consequences. Confidentiality of their responses was guaranteed and the research team ensured that no identifying information was shared.

Statistical analysis

Data were analyzed using SPSS version 16. Descriptive statistics, including frequencies, means, and standard deviations, were employed to summarize and report the demographic characteristics of the participants. The normal distribution of the data was assessed and confirmed using the Kolmogorov-Smirnov test. To examine the relationship between caregiver burden and hope in leukemia patients, Pearson's correlation coefficient was used. The significance level for statistical tests was established at $P < 0.05$.

Results

Participant demographics

A total of 200 leukemia patients and their primary caregivers participated in the study. Among the patients, 38% were female, and 62% were male. The majority of patients were married (66.5%), and the most common age group was under 30 years (38%). Regarding education levels, 49% of patients had completed a diploma, while 36.5% had education below the diploma level, and 14.5% had pursued education above the diploma level (Table 1).

The caregiver group comprised 54% females and 46% males. Most caregivers were married (83.5%), and the largest proportion had attained a diploma-level education (45.5%). Approximately 35% had education below the diploma level, and 19.5% had education above the diploma level (Table 2).

Table 3 Despritvie statistics of patents' hope and caregivers' burden care

Variable	Minimum	Maximum	Mean	Standard Deviation
Burden Care	15	68	37.69	7.12
Pathway Thinking	13	18	16.04	0.87
Agency Thinking	11	20	16.16	1.58
Hope	27	38	32.19	1.88

Table 4 Correlation between patents' hope and caregivers' burden care

	Burden Care	
	Correlation Coefficient	*P* Value
Pathway Thinking	-0.127	0.073
Agency Thinking	-0.126	0.076
Hope	-0.164	**0.02**

Descriptive statistics

The mean caregiver burden score was 37.69 ± 7.12, with scores ranging from 15 to 68. For leukemia patients, the mean hope score was 32.19 ± 1.88, with a range of 27 to 38. The mean scores for Pathway Thinking and Agency Thinking were 16.04 ± 0.87 and 16.16 ± 1.58, respectively (Table 3).

Correlation analysis

Results indicated a weak but statistically significant negative correlation between caregiver burden and overall hope scores (r=-0.164, $P = 0.02$). However, no significant correlations were found between caregiver burden and the subscales of hope, namely Pathway Thinking (r=-0.127, $P = 0.073$) and Agency Thinking (r=-0.126, $P = 0.076$) (Table 4).

Discussion

This study explored the relationship between caregiver burden and hope in leukemia patients, highlighting the psychological dynamics between patients and caregivers. The mean caregiver burden score in this study reflected a moderate level of burden. This suggests that while caregivers of leukemia patients faced many challenges, their burden score was not high, indicating that they had successfully adapted to the difficult circumstances. Our results are consistent with previous studies in Egypt [32] and Turkey [33]. However, some studies in Iran [34] and Ethiopia [35] reported higher levels of caregiver burden. The differences observed between studies may be attributed to various factors influencing caregiver burden, including the emotional strain of caregiving, the physical demands of providing care, the psychological toll of witnessing a loved one's illness, and the financial challenges. Additionally, access to support systems and effective coping strategies may have helped mitigate the overall perceived burden [36–39].

The mean score for hope among leukemia patients reflected a relatively high level of hope. This finding underscores the psychological resilience of patients despite the challenges posed by their condition. A study conducted on Iranian cancer patients, utilizing a different scale to measure hope, reported that 61.1% of participants exhibited high levels of hope, a finding consistent with the results of the present study [40]. Similarly, another investigation observed moderate to high levels of hope among Iranian cancer patients, further supporting the alignment with our findings [41]. Maintaining a high level of hope is crucial in cancer care, as it fosters better emotional well-being, enhances adherence to treatment, and improves overall quality of life [19, 42]. The high level of hope observed in this study may be attributed to effective communication with healthcare providers, robust social and familial support, or individual psychological coping mechanisms.

The findings of this study highlight a significant negative correlation between caregiver burden and patient hope in leukemia patients, illustrating the interconnected dynamics between caregiver and patient well-being. Consistent with our findings, Krug et al. (2016) reported that patients' dyspnea, along with feelings of depression and anxiety, significantly contribute to an increased perception of burden among caregivers [26]. Similarly, Götze et al. (2014) demonstrated that anxiety and depression frequently occur concurrently in both caregivers and patients, highlighting the interdependence of their emotional states [24]. Further evidence comes from a study on caregivers of patients with lung cancer and heart failure experiencing breathlessness, which found that higher caregiver burden was associated with poorer quality of care provided to patients. Moreover, caregiver depression was linked to fewer positive caregiving experiences, suggesting that caregivers' psychological well-being directly influences the quality of care patients receive and, ultimately, their outcomes [43]. Another study revealed that caregivers of patients with depressive symptoms experienced higher levels of burden [25]. Additionally, Grunfeld et al. (2004) noted that as the functional status of breast cancer patients declined, caregivers experienced increased levels of depression and perceived burden, further underscoring the connection between patient functional status and caregiver well-being [44]. Our findings underscore the bidirectional relationship between patient and caregiver well-being, where the psychological state of one significantly impacts the other. Addressing patient hope through targeted interventions, such as psychological counseling and resilience training, may help reduce caregiver burden. Similarly, supporting caregivers' and reducing their caregiving burden can create a more positive environment that enhances patients' hope and overall outcomes.

Implications for practice

The results emphasize the need for holistic interventions that address both caregiver burden and patient hope. Programs designed to reduce caregiver strain, such as counseling, respite care, and peer support groups, may indirectly enhance patient hope by fostering a more supportive and less stressful caregiving environment. Also, initiatives aimed at increasing patient hope—such as positive psychology interventions and goal-setting strategies—could alleviate caregiver burden by creating a more optimistic and self-sufficient caregiving dynamic. Future research should explore these bidirectional relationships further to develop comprehensive care strategies.

Limitations and future directions

While this study provides important insights, several limitations should be noted. First, the research was conducted in only two centers affiliated with Tehran University of Medical Sciences, which may restrict the generalizability of the findings to broader populations or other healthcare settings. Second, the use of a convenience sampling method may introduce selection bias, as the participants may not fully represent the diverse population of leukemia patients and their caregivers. Third, the study employed a cross-sectional design, which limits the ability to establish causal relationships between caregiver burden and hope in leukemia patients. Finally, the reliance on self-reported measures may have been influenced by social desirability bias, potentially leading participants to provide responses that they perceived as more favorable or acceptable. Future studies should address these limitations by employing longitudinal designs, expanding to multiple centers for a more diverse sample, and utilizing qualitative methods to gain deeper insights into the experiences and perspectives of both caregivers and patients regarding their emotional and psychological challenges.

Conclusion

This study underscores the relationship between caregiver burden and patient hope, highlighting the interdependence between caregivers' well-being and patients' psychological variables. The findings reveal a significant inverse correlation between these variables, emphasizing the need for integrated care approaches. Addressing caregiver burden through targeted interventions, such as counseling, respite care, and financial support, can indirectly enhance patient hope by fostering a more supportive caregiving environment. Similarly, promoting hope in patients through psychological therapies and social support can alleviate caregiver burden and improve the overall caregiving experience. Future research should explore the interactions between caregiver burden and patient hope and investigate the impact of cultural, social, and economic factors on these relationships. By implementing holistic strategies that prioritize the needs of both patients and caregivers, healthcare systems can improve outcomes, ensuring better quality of life for both parties.

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Author contributions
AG and MS conceptualized and designed the study. MS carried out the sampling. MS and MMR contributed to the analysis and writing of the manuscript. All authors read and approved the manuscript.

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Data availability
The data generated and analyzed during the current study is not publicly available to ensure data confidentiality but is available from the corresponding author on reasonable request and with the consent of the research participants.

Declaration

Ethics approval and consent to participate

The Research Ethics Committees of Tehran University of Medical Sciences approved the current study (no. IR.TUMS.IKHC.REC.1402.293). In this study, we adhered to the principles of the Committee on Publication Ethics (COPE) and the ethical declaration of Helsinki. Written informed consent was obtained from all patients and caregivers prior to their participation in the study. Participants were thoroughly informed about the study's objectives and assured that their involvement was entirely voluntary, with the option to withdraw at any time without repercussions. Confidentiality of their responses was strictly maintained, and the research team ensured that no identifying information was disclosed at any stage of the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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