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Research Article

The Burden Encountered by Caregivers of Hemophilia Patients and the Associated Factors in Iraq: A Field Study

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Abstract

Background: Hemophilia demands long-term care, profoundly affecting both patients and their families. ***Objective***: To evaluate the burden and productivity loss encountered by caregivers of hemophilia patients and associated factors in Iraq. ***Methods***: This cross-sectional study was conducted among caregivers of hemophilia A and B patients at the Children Welfare Teaching Hospital, Medical City, Baghdad, Iraq. Caregiver burden was measured using the Arabic version of the Zarit Burden Interview (ZBI-12) via face-to-face survey. Caregivers' productivity loss was assessed by determining annual income loss and missed workdays. Data were collected from November 2024 to February 2025. ***Results***: The study recruited 109 caregivers. The mean caregiver burden score of 29.56 reflects a high level of strain, particularly in emotional distress, stress, health impact, and loss of personal time. Families with more than one hemophiliac had significantly higher burden scores (33.79) compared to families with one patient. Mothers had the highest burden scores compared to fathers and other caregivers, but no significant difference was found among these groups. Caregivers reported an average of 16.2 missed workdays annually due to caregiving responsibilities. ***Conclusions***: The Zarit Burden Interview revealed a high caregiver burden, especially due to emotional strain, the stress of balancing responsibilities, and health challenges. Families with multiple children with hemophilia experience an even greater burden. The study recommends providing financial aid, counseling, and mental health services to help caregivers manage emotional strain and stress.

Keywords: Caregiver burden, Caregiver productivity loss, Hemophilia, Socioeconomic impact, Zarit burden interview.

العبء الذي يواجهه مقدمو الرعاية لمرضى الهيموفيليا والعوامل المرتبطة به في العراق: دراسة ميدانية

الخلاصة

الخلفية: يتطلب مرض الهيموفيليا رعاية طويلة الأمد، مما يؤثر بشكل عميق على كل من المرضى وعائلاتهم. **الهدف**: تقييم العبء وفقدان الإنتاجية الذي يواجهه مقدموا الرعاية لمرضى الهيموفيليا والعوامل المرتبطة به في العراق. **الطرائق**: أجريت هذه الدراسة المقطعية بين مقدمي الرعاية لمرضى الهيموفيليا A و B في مستشفى رعاية الأطفال التعليمي، المدينة الطبية، بغداد، العراق. تم قياس عبء مقدم الرعاية باستخدام النسخة العربية من مقابلة عبء زاريت (ZBI-12) عبر المقابلة وجها لوجه. تم تقييم خسارة إنتاجية مقدمي الرعاية من خلال تحديد خسارة الدخل السنوية وأيام العمل الفائتة. تم جمع البيانات من نوفمبر 2024 إلى فبراير 2025. **النتائج**: جندت الدراسة 109 من مقدمي الرعاية. يعكس متوسط درجة عبء مقدمي الرعاية البالغ 29.56 مستوى عاليا من الإجهاد، لا سيما في الضيق العاطفي والتوتر والتأثير الصحي وفقدان الوقت الشخصي. كان لدى العائلات التي لديها أكثر من مرض هيموفيليا درجات عبء أعلى بكثير (33.79) مقارنة بالعائلات التي لديها مريض واحد. كان لدى الأمهات أعلى درجات العبء مقارنة بالآباء وغيرهم من مقدمي الرعاية، ولكن لم يتم العثور على فرق كبير بين هذه المجموعات. أبلغ مقدموا الرعاية عن 16.2 يوم عمل ضائع في المتوسط سنويا بسبب مسؤوليات تقديم الرعاية. **الاستنتاجات**: كشفت مقابلة زاريت بورد عن عبء كبير على مقدم الرعاية، خاصة بسبب الإجهاد العاطفي، وضغوط الموازنة بين المسؤوليات، والتحديات الصحية. تعاني العائلات التي لديها أطفال متعددون مصابين بالهيموفيليا عبئا أكبر. توصي الدراسة بتقديم المساعدة المالية والاستشارات وخدمات الصحة العقلية لمساعدة مقدمي الرعاية على إدارة الإجهاد العاطفي والتوتر.

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INTRODUCTION

Hemophilia A and B are X-linked hereditary diseases marked by a lack of clotting factors VIII and IX, respectively. They induce spontaneous or post-traumatic hemorrhage, resulting in gradual destruction, particularly in joints, and lead to permanent impairment of joint function [1]. The 2022 annual report of the World Federation of Hemophilia (WFH) indicates that in 125 countries, 257,146 individuals with hemophilia are recognized, comprising 208,957 with hemophilia A (HA) and 42,203 with hemophilia B (HB), with Iraq having 3,306 hemophilia patients, comprising 2,671 with hemophilia A (HA) and 635 with hemophilia B (HB), resulting in a prevalence of around 7.4 per 100,000 population [2]. Replacement of clotting factors is used to manage bleeding in patients with hemophilia either episodically or regularly. Early prophylaxis has been demonstrated to reduce joint bleeding, slow the progression of arthropathy, and improve quality of life [3,4]. Prophylaxis has been recognized as the current accepted standard of care for people with severe hemophilia and is advised to be initiated prior to the onset of recurrent bleeding in young children [5]. Effective treatment alleviates the psychological and economic consequences of this hemorrhagic condition on the patient and their family [6]. Hemophilia care requires intensive, lifelong treatment, irrespective of the treatment approach, because of its frequent diagnosis in early childhood. As hemophilia begins in childhood, this impacts the caregivers' lives. The majority of therapy is presently delivered at home. Consequently, caregivers play a crucial role in managing patients with hemophilia [7]. However, home care requires greater responsibility for caregivers. The child's illness results in the parents' suffering. This individual's suffering is referred to as "burden" [8]. Parental load encompasses noticeable practical challenges, such as the time required for child treatment, visiting the hospital, additional supervision and attention, diminished opportunities for employment and entertainment, and economic consequences. Parental burden includes perceived psychological distress, including disrupted familial connections, despair, anxiety, and the forfeiture of aspirations and expectations [9]. Providing care for someone with a chronic health condition can be challenging, including continuous alertness and significant lifestyle changes [10]. Additionally, caregiving can influence work, finances, social relationships, career progression, and physical well-being [11,12]. Focusing on the ill family member supersedes the interests and desires of other family members [13]. To the best of our knowledge, this is the first study in Iraq to assess the burden faced by hemophilia patients' caregivers. The study aims to evaluate the psychosocial burden and productivity loss encountered by caregivers of hemophilia patients and the associated factors in Iraq.

METHODS

Study design and setting

This cross-sectional study using a face-to-face survey was conducted at the Children Welfare Teaching Hospital/Unit of Inherited Blood Disorder, Medical City, Baghdad, Iraq. The Arabic version of the Zarit Burden Interview (ZBI_12) was used to measure caregivers' burden. Data were collected from November 2024 to February 2025.

Study participants

This study recruited caregivers of patients with hemophilia A and B, who were in different relationships to the patients, including parents, siblings, sisters, wives, and other family members involved in the patients' care.

Inclusion criteria

The study invited caregivers responsible for the daily care of patients with hemophilia A and B, with different age groups and relationships to the patients.

Exclusion criteria

The caregivers of newly diagnosed patients and those who were not responsible for the daily care of the patients were excluded.

Data collection

Data were collected from caregivers of hemophilia patients who visited the hospital after obtaining verbal consent. The collected data includes caregivers' socio-demographic information (age, relationship to the patient, education level, work status, family income, and number of hemophilia patients in the family). Patients' information, such as age, gender, hemophilia type, severity, and the number of annual hospital visits, was extracted from each patient's medical records. Caregiver burden was evaluated using the Arabic version of the 12-item Zarit Burden Interview (ZBI_12), a validated questionnaire for assessing the perceived burden among caregivers of individuals with chronic illnesses. It is used to determine the degree of psychological, physical, emotional, social, and financial problems experienced by caregivers. The instrument comprises 12 items, with responses evaluated on a 5-point Likert scale from 0 (never) to 4 (nearly always), with the total scores ranging between 0 and 48 [14,15]. These 12 items are summed to determine the total burden score; a higher score indicates a greater perceived burden. The short Zarit Burden Interview includes 12 items. The Zarit Burden Interview (ZBI) categorizes caregiver burden into three levels based on the total score. A score of 0-10 indicates no to mild burden, 10-20 reflects mild to moderate burden, and a score greater than 20 signifies high burden. This classification helps healthcare professionals assess the extent of caregiver strain and develop appropriate support strategies. It assesses the physiological stress on caregivers and how caregiving affects their physical health, social relationships, and daily life. This questionnaire was completed independently by caregivers who were literate, able to read and write, and provided adequate time to fill it out. The researcher interviewed caregivers who could not read or write via a face-to-face interview, reading each question aloud and recording the verbal responses. Additionally, caregivers' productivity loss was assessed by determining annual workdays and income loss. Caregivers were asked about their average daily wage, and then the patient's annual hospital visits were obtained from the patient's medical records. The number of annual workdays missed by the caregiver was estimated to be equivalent to the total number of patient visits. The caregiver's annual income loss was then calculated by multiplying the missed workdays by the reported daily wage.

Ethical consideration

The ethical committees at the College of Pharmacy and the participating hospital provided ethical approval for the proposed study. Additionally, verbal consent was obtained before the caregivers' recruitment, and the caregivers' and patients' names were de-identified. No incentives were offered to the participants.

Statistical analysis

Data was analyzed using Statistical Package for the Social Sciences (SPSS) software version 25. Descriptive statistics were conducted for all study items. Continuous variables were expressed as median (for skewed variables) or means ± standard deviation (SD) (for normally distributed variables), whereas categorical variables were expressed as frequencies and percentages. The continuous variable (total burden score) was not normally distributed according to the Shapiro-Wilk test. Thus, the Mann-Whitney test (for variables with two categories) and Kruskal-Wallis test (for variables with more than two categories) were used to measure the factors that may influence the total burden score of the caregivers. A *p*-value of less than 0.05 was considered statistically significant. GraphPad Prism was used to develop the figures.

RESULTS

The study recruited 109 caregivers of patients with hemophilia: 80.7% with hemophilia A and 19.3% with hemophilia B. Among the patients, 108 were male and one was female, with different disease severity ranging from mild to severe. The caregivers represented different relationships with the patients, including parents, siblings, and other family members involved in the patient's care. Thirty-four parents had more than one child with hemophilia. Mother represents 47.7% of the total participants, father represents 43.1%, and other caregivers represent 9.2% (Table 1).

Table 1: Socio-demographic characteristics of patients and caregivers

Characteristics	Subcategories	n (%)
Patient Gender	Male	108(99.08)
	Female	1.0(0.92)
Hemophilia type	A	88(80.7)
	B	21(19.3)
Severity	Mild	2.0(1.8)
	Moderate	7.0(6.4)
	Sever	100(91.7)
Caregiver education level	No formal education	5.0(4.6)
	primary school	50(45.9)
	Secondary school	31(28.4)
	University	23(21.1)
Caregiver job	Governmental Employee	31(28.4)
	Retired	2.0(1.8)
	Private business	22(20.2)
	Unemployed	54(49.5)
Relationship to the patients	Father	47(43.1)
	Mother	52(47.7)
	Other	10(9.2)
Number of hemophilia children/patients in the family	One adult patient	2.0(1.8)
	One child	73(67)
	More than one child	34(31.2)
Family income	Less than 500,000IQD	59(54.1)
	500,000- 1 million	40(36.7)
	1-3 million	10(9.2)

The caregivers had a mean age of 42.65 ± 8.85, and the average Zarit burden interview score was 29.56 ± 10.40, indicating a high caregiver burden (seeTable 2).

Table 2: Descriptive statistics

Parameter	n	Range	Mean±SD
Caregivers Age	109	22-69	42.65±8.848
Total score	109	4-44	29.56±10.409

Based on the Zarit classification, 6.40% of caregivers experienced no to mild a burden, 14.70% had mild to moderate burden, and 78.90% reported a high burden (Figure 1). Caregivers from families with more than one hemophilia patient reported significantly ($p < 0.05$) higher burden scores median = 36) compared to those with only one affected patient (median burden score = 32).

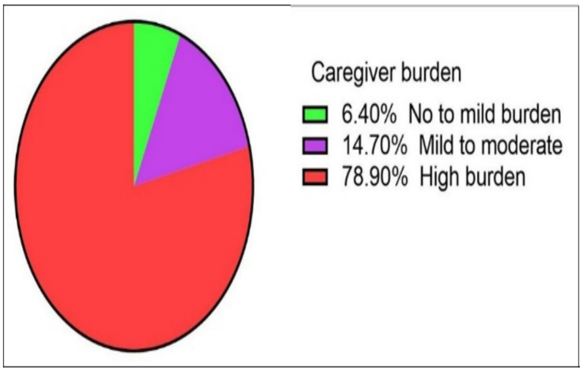

Figure 1: Distribution of caregiver burden levels.

Although there was no significant difference in burden score according to the relation of the caregiver, mothers experienced higher burden compared to fathers and other caregivers (Figure 2).

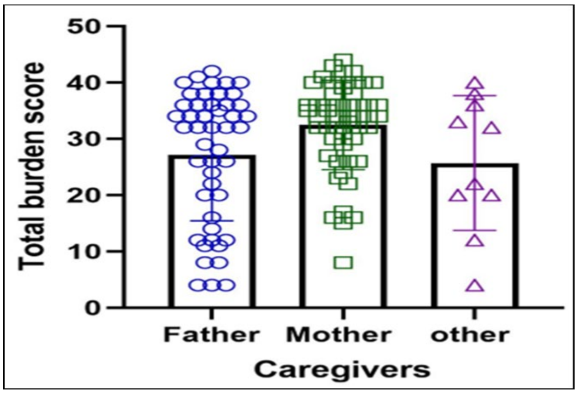

Figure 2: The burden score according to the relationship of caregivers with hemophilia patients. Non-significant differences (*p*>0.05) among the three caregivers.

Further analysis of Zarit items indicated that the greater burden was reported in areas related to stress (3.37±1.35), emotional strain (3.13±1.49), impact on health (3.13±1.52), lack of personal time (3.10±1.47), and feeling they could do a better job in caregiving (3.87±0.54) (Tables 3 and 4**)**. Regarding response frequency, 69.7% of caregivers reported nearly always) a lack of personal time, 79.8% felt nearly always) stressed due to difficult balancing responsibilities, and 71.6% of caregivers reported nearly always) feeling emotional strain, and their health deteriorated due to caregiving responsibility.

Table3: Results in different domains of the Zarit Buden scale (n=109)

Questions	Range	Mean±SD
Lack of personal time	0-4	3.10±1.47
Stress balancing responsibilities.	0-4	3.37±1.35
Feeling angry	0-4	1.28±1.57
Negative impact on relationships	0-4	0.78±1.33
Emotional strain	0-4	3.13±1.49
Impact on health	0-4	3.13±1.52
Loss of privacy	0-4	2.48±1.76
Social life suffering	0-4	2.42±1.82
Loss control on life	0-4	2.88±1.57
Uncertainty about how to care	0-4	0.46±0.91
Feeling of needing to do more	0-4	2.78±1.65
Feeling could do better	0-4	3.87±0.55

Table 4: Zarit Burden interview frequency and percentage

Questions	Never	Rarely	Sometimes	Frequently	Nearly always
Lack of personal time	15(13.8)	2.0(1.8)	16(14.7)	---	76(69.7)
Stress balancing responsibilities	12(11)	2.0(1.8)	7.0(6.4)	1.0(0.9)	87(79.8)
Feeling angry	59(54.1)	4.0(3.7)	23(21.1)	3.0 (2.8)	20(18.3)
Negative impact on relationships	77(70.6)	1.0(0.9)	20(18.3)	---	11(10.1)
Emotional strain	16(14.7)	1.0(0.9)	14(12.8)	---	78(71.6)
Impact on health	17(15.6)	4.0(3.7)	5.0(4.6)	5.0(4.6)	78(71.6)
Loss of privacy	31(28.4)	3.0(2.8)	16(14.7)	1.0(0.9)	58(53.2)
Social life suffering	36(33)	1.0(0.9)	10(9.2)	5.0(4.6)	57(52.3)
Loss control on life	19(17.4)	3.0(2.8)	18(16.5)	1.0(0.9)	68(62.4)
Uncertainty about how to care	84(77.1)	4.0(3.7)	19(17.4)	---	2.0(1.8)
Feeling of needing to do more	24(22)	---	18(16.5)	1.0(0.9)	66(60.6)
Feeling could do better	1.0 (0.9)	---	4(3.7)	2.0(1.8)	102(93.6)

Values were expressed as frequency and percentage. Scoring: Never= 0; Rarely= 1; sometimes= 2, frequently= 3, nearly always= 4.

The greatest proportion of caregivers, 93.6%, reported nearly always) feeling they could do better in their caregiving role. Additionally, Mann-Whitney and Kruskal-Wallis tests showed no significant difference in the burden score according to disease severity, hemophilia type, caregivers' education level, and family income level (Table 5).

Table 5: The differences in the caregiver burden scores according to different characteristics

Characteristics	Subgroups	n	Burden score (Median)	*p*-value
Caregiver Relationship to the patient	Mother	52	34	0.065‡
	Father	47	32	
	Other	10	27	
Severity of patient hemophilia	Mild	2	28.5	0.723‡
	Moderate	7	32	
	Severe	100	34	
Education level	No formal education	50	33.5	0.41‡
	primary school	31	34	
	Secondary school	23	28	
	University	5	34	
Household income (IQD)	Less than 500,000	59	33	0.89‡
	0.5- 1 million	40	33	
	1-2 million	7	32	
	2-3 million	3	35	
Type of hemophilia	A	88	32	0.274‡
	B	21	34	
Number of hemophilia patients in the family	1.0	75	32	0.002*
	>1.0	34	36	

‡ Non-significant according to Kruskal-Wallis test. *Significant according to Mann-Whitney test.

Regarding productivity losses, 50 employed caregivers experienced missed workdays due to hospital visits. The average number of missed workdays per year was calculated for this subgroup, amounting to 16.2 missed workdays per caregiver annually. Among these employed caregivers, only 23 reported income losses resulting from their inability to attend work on these days. The calculation of average annual income loss was based solely on this subset, excluding caregivers who missed workdays without experiencing a corresponding loss of income. On average, working caregivers who reported income loss incurred an annual financial impact of 460,086.9 IQD due to hospital-related absences.

DISCUSSION

This study offers valuable insights into the burden experienced by caregivers of patients with hemophilia, as measured by the Zarit Burden Interview scale (ZBI-12). Findings indicate that 78.90% of caregivers reported a high burden, while 14.70% experienced a mild to moderate burden, and 6.40% reported no to mild burden. Our results revealed that mothers and fathers reported high burdens compared to other caregivers, with no statistically significant difference. This is consistent with previous studies conducted in Nepal and Europe that measured the psychosocial burden among parents of hemophilia patients, demonstrating that both fathers and mothers face an equal psychosocial burden [16,17]. Such findings reinforce the concept that caregiving responsibilities for chronically ill patients, such as those with hemophilia, are shared equally between parents and create similar psychological and physical demands, regardless of gender. Similarly, the type of hemophilia (A or B) was not significantly associated with variations in caregiver burden in our study. Our results align with the findings of a previous study in multiple countries, which found no significant difference in parental stress based on hemophilia type [9]. The common challenges across all hemophilia types, such as the lifelong prophylaxis, risk of spontaneous bleeding, and fear of long-term complications such as the development of inhibitors or hepatitis C, which is highly prevalent among hemophilia patients according to an Iraqi study [18]. This may explain the comparable burden experienced by caregivers. A significant association was found between the number of hemophilia-affected children in the family and caregiver burden. Caregivers of families with multiple children affected by hemophilia reported a heightened burden, indicating that responsibilities, emotional strain, and time demands are significantly intensified in such situations. In contrast, a previous multi-center Swedish study reported no significant difference in caregiver burden based on the number of affected children [9]. On the other hand, our study did not find significant associations between caregiver burden and family income or educational level. Previous studies indicated higher levels of psychosocial burden among caregivers with lower education and insufficient income. These studies reported that caregivers with no formal education experienced significantly higher burdens, including financial challenges, emotional stress, and a lack of social interaction. Furthermore, the psychosocial burden increased threefold in caregivers with insufficient income [16,17,19,20]. These discrepancies may reflect contextual differences. For instance, in Iraq, public health institutions provide many hemophilia-related healthcare services at no charge, potentially easing the financial strain typically associated with the disease [21]. Additionally, cultural norms may instill a strong sense of familial responsibility in parents, particularly fathers and mothers, to care for their children regardless of socioeconomic status. Consequently, the physical and emotional demands remain high even among those with higher education or income, which may explain the lack of statistically significant differences in burden across this study. Regarding the overall ZBI scores, item-level analysis revealed heightened responses (nearly always) in areas related to psychological stress (79.8%), impact on health (71.6%), lack of personal time (69.7%), emotional strain (71.6%), and the greatest proportion (93.6%) feel they are able to do better in caring. These findings underscore that the burden on caregivers is not solely linked to practical responsibilities but is also deeply physical and emotional. Caregivers may experience chronic anxiety due to the fear of bleeding episodes and the unpredictable nature of hemophilia, alongside feelings of lack of personal time and exhaustion. This is consistent with a study conducted in European countries that describes the impact of psychosocial factors on caregivers [19]. Furthermore, the current study indicated significant productivity losses, with caregivers missing an average of 16.2 days each year due to hospital visits and follow-up care. The average annual income loss is 460,086.9 IQD per working caregiver. This figure is notably lower than that reported in a study in Turkey, where caregivers of patients missed an average of 43.7 days each year [20]. This difference may be attributed to variations in accessibility to the healthcare system.

Study limitations

This study presents significant findings related to the burden encountered by caregivers of hemophilia patients; however, it has several limitations. First, the cross-sectional design of this study constrains the capability to determine causality between caregiver burden and its associated factors. Second, the Zarit Burden Scale (ZBI-12) may not capture all the challenges faced by caregivers, such as anxiety related to bleeding episodes, pain due to the patient's suffering, difficulties in administering treatments, or long-term psychosocial effects of caregiving. Additionally, this study was conducted in a single hospital within one province, utilizing a convenience sampling approach, which could constrain the generalizability of the findings. Nevertheless, this hemophilia treatment center is among the largest in the country.

Conclusion

Our study shows that hemophilia patients' caregivers, particularly parents, experienced a higher burden due to the stress of balancing responsibilities, emotional strain, and health challenges. The burden is particularly significant among families with more than one child with hemophilia, reflecting the difficulties compounded by managing chronic care. However, no significant differences were observed based on caregivers' education levels, income, or type and severity of hemophilia. Regarding the productivity loss, the caregivers reported an average of 16.2 missed workdays annually due to their caregiving responsibilities. This study represents the multifaceted nature of caregiver burden in hemophilia, including emotional, physical, social, and economic aspects. Therefore, providing financial assistance, counseling, and mental health services is essential to support caregivers in managing emotional strain and stress effectively.

Conflict of interests

The authors declared no conflict of interest.

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The authors did not receive any source of funds.

Data sharing statement

Supplementary data can be shared with the corresponding author upon reasonable request.

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