Open Journal of Pediatrics, 2026, 16(3), 448-461
https://www.scirp.org/journal/ojped
ISSN Online: 2160-8776
ISSN Print: 2160-8741

Assessment of the Quality of Life of Parents of Children with Hemophilia in Yaounde, Cameroon

Ginette Claude Mireille Kalla[1,2*], Annick Ndoumba Nkengue[3], Emilie Solange Tangmeu Silinou[1], Marcelle Nina Ehouzou Mandeng[2], Nelly Kamgaing Noubi[1,2], Claude Tayou Tagny[3,4]

[1]Department of Pediatrics, Faculty of Medicine and Biomedical Sciences, University of Yaounde I, Yaounde, Cameroon
[2]Department of Pediatrics, Yaounde University Teaching Hospital, Yaounde, Cameroon
[3]Department of Microbiology, Parasitology, Hematology, and Infectious Diseases, Faculty of Medicine and Biomedical Sciences, University of Yaounde I, Yaounde, Cameroon
[4]Department of Hematology, Yaounde University Teaching Hospital, Yaounde, Cameroon
Email: *kallaclaude@yahoo.fr

How to cite this paper: Kalla, G.C.M., Nkengue, A.N., Silinou, E.S.T., Mandeng, M.N.E., Noubi, N.K. and Tagny, C.T. (2026) Assessment of the Quality of Life of Parents of Children with Hemophilia in Yaounde, Cameroon. *Open Journal of Pediatrics*, **16**, 448-461.
https://doi.org/10.4236/ojped.2026.163045

Received: April 9, 2026
Accepted: May 8, 2026
Published: May 11, 2026

Abstract

Introduction: The complexity of hemophilia care and its complications can have a negative impact on children with hemophilia and their families. Our objective was to assess the quality of life of parents of children with hemophilia in Yaounde. **Methods:** We conducted a cross-sectional analytical and prospective study over a period of 5 months. Children with hemophilia aged 1 to 18 years who were followed up at the Yaounde University Teaching Hospital and their parents were included. Sociodemographic, socioeconomic, and clinical variables were collected. The Hemophilia Associated Caregiver Burden Scale (HEMOCAB) questionnaire was used to assess parents' quality of life. Data were analyzed using SPSS version 26.0 software. The significance threshold was set at $p < 0.05$. **Results:** The study involved 53 parents and 65 children with hemophilia. The average age of the children was 10.6 ± 5.3 years. The majority had hemophilia A (86.2%), of whom 67.7% had severe hemophilia. The majority of parents who responded were mothers (83%). The most represented age group was [31-40] years old. Most had at least one child with hemophilia (81.1%). Half worked part-time (50.9%), and for 11 of them, their child's illness was the reason. Twelve parents had to change jobs (22.6%). The median overall quality of life score was 140 ± 31.71 (51-197). Poor quality of life was observed in 66% of parents. The associated factors of poor quality of life were significant personal sacrifices ($p = 0.001$), poor relationships with others ($p = 0.030$), poor interaction of the child with others ($p = 0.011$), poor interaction with the child's school ($p = 0.002$), poor management of the child's disease ($p = 0.04$), and the negative impact of hemophilia on parents ($p = 0.001$). **Conclusion:** Two-thirds of parents of children with hemophilia have a poor quality of life. Consideration should be given to implementing health policies and targeted interventions focused on medical and psychosocial support for these families.

Keywords

Hemophilia, Quality of Life, Parents, Yaounde, Cameroon

1. Introduction

Hemophilia is a rare disease caused by a hereditary deficiency in coagulation factors VIII (hemophilia A) or IX (hemophilia B). The incidence varies depending on the type of hemophilia, with 1 case of hemophilia A per 5000 live male births per year, compared to 1 case of hemophilia B per 30,000 [1]. The complications of hemophilia and the complexity of care surrounding this condition are a challenge for patients and their families worldwide [2]. The daily lives of children with hemophilia are marked by repeated bleeding, which causes pain, vascular-nerve compression, chronic joint disease, anemia, and sometimes death, depending on the site of the bleeding [3]. Financially, although the World Federation of Hemophilia regularly provides clotting factors in the form of donations to countries with limited resources, all other healthcare expenses related to this disease, including the purchase of hemostatic drugs, painkillers, mobility aids, the cost of blood transfusions and physical therapy, multiple hospitalizations, and additional paraclinical tests depending on the site of bleeding, are the responsibility of the parents [4]-[7]. Like any hereditary disease, hemophilia often causes parents to feel guilty, affecting their emotional well-being and causing emotional stress, anxiety, and depression [3] [4] [7]-[11]. Social relationships are also disrupted due to restrictions on physical and recreational activities, as well as multiple hospital visits requiring the constant presence of parents at their children's side [2] [7] [10] [12]. All of this can affect quality of life. Numerous studies have examined quality of life as perceived by children with hemophilia, but very few have focused on the quality of life of parents of children with hemophilia [1] [2] [11] [13] [14]. The overall objective of this study was to assess the quality of life of parents of children with hemophilia and thereby contribute to the development of targeted health policies and interventions focused on medical and psychosocial support for these families.

2. Methods

A cross-sectional and analytical study was conducted from March 1, 2024, to July 31, 2024 (5 months). Children with hemophilia aged 1 to 18 years who were being treated at the Yaounde University Teaching Hospital, and their parents who agreed to participate in the study, were included. The recruitment was non-probabilistic and consecutive. The parents' quality of life (QoL) was assessed using a tool called "Hemophilia Associated Caregiver Burden Scale (HEMOCAB)" [15].

This scale was developed in the United States and linguistically validated in various European languages. In our context, it has been translated into English and French, which are the two official languages of Cameroon. It is a self-assessment questionnaire, comprising 54 questions in 13 areas, nine of which relate to the frequency of the burden (emotional stress, financial burden, personal sacrifices and limitations, employment-related burden, parents' interactions with others, the child's interactions with others, interactions with school, the child's perception, and managing the child's hemophilia) and four relating to the intensity of the burden (medical care, professional situation related to the child's hemophilia, interaction with the child's father, and the impact of the child's hemophilia).

Responses for each domain were reported on a five-point Likert scale. Responses relating to the frequency of the burden ranged from "never" to "always", and those relating to the intensity of the burden ranged from "not at all" to "a lot". High values corresponded to a high burden. For each domain, the total score was calculated by adding up the responses to the questions. The overall quality of life score was calculated by combining the scores for the 13 domains. This overall assessment, which ranged from 51 to 255 points, was converted to a scale of 0 to 100. In our study, we considered an average score below 50% as a good quality of life, while a score of 50% or higher indicated a poor quality of life. The children's sociodemographic and clinical variables (age, sex, school level, place of residence, type of hemophilia, severity of hemophilia, type of current treatment), as well as the parents' sociodemographic and economic data (age, sex, occupation, marital status, level of education, weekly working hours, change of job), were collected.

2.1. Operational Definition of Terms

"Low income" was defined as an income below the guaranteed minimum wage in Cameroon (<$79).

"Important bleeding" referred not only to the volume of blood lost but also to the location of the hemorrhage, which can be life-threatening.

"Poor care" was defined as inadequate treatment that could lead to disabling sequelae or even death.

A HEMOCAB domain was considered "good" when the average score was less than 50%.

A HEMOCAB domain was considered "poor" when the average score was 50% or higher.

2.2. Data Analysis

The data were analyzed using SPSS version 26.0 software. Qualitative variables were expressed as numbers and percentages, while quantitative variables were expressed as means and standard deviations, or medians and interquartile ranges.

Comparisons between the different variables were performed using the Chi-square or Fisher's exact test. The strength of association was estimated using the odds ratio and its 95% confidence interval. Quality of life was reduced to two categories (good or poor). To identify the factors associated with parents' quality of life, a bivariate analysis was conducted with quality of life (good, poor) as the dependent variable, and the psychosocial variables from the HEMOCAB were considered as predictors. A value of $p < 0.05$ was considered statistically significant.

2.3. Ethical Considerations

Approval was obtained from the Institutional Ethics and Research Committee of the FMSB at UY1 (Reference: No. 0667/UYI/FMSB/VDRC/DAARS/CSD dated June 10, 2024). The free and informed consent of parents and the assent of children aged 10 and over were obtained. Anonymity and confidentiality were strictly observed.

3. Results

During the study period, of the 76 eligible parents, 23 who could not be reached by phone were excluded, leaving 53 parents with 65 children with hemophilia selected for the study.

3.1. Sociodemographic and Clinical Characteristics of Children with Hemophilia

More than half of the children were aged 10 years or older (58.5%), with a mean age of 10.6 ± 5.3 years, ranging from 1 to 18 years. Forty nine of them had a secondary education level (49.2%). They were carriers of hemophilia A (86.2%), most of whom had severe hemophilia (67.7%). Nearly half had had at least two bleeds in the past 12 months (49.2%). The majority were on on-demand treatment (73.8%) (Table 1).

Table 1. Distribution of children with hemophilia according to their sociodemographic and clinical characteristics.

Variables	Number (N = 65)	Percentage (%)
Age groups (years)		
[1 - 3]	3	4.6
[3 - 5]	9	13.8
[5 - 10]	15	23.1
≥10	38	58.5
child's grade level		
None	5	7.7
Primary	26	40.0

Continued

Secondary	32	49.2
Tertiary	2	3.1
Type of hemophilia		
Hémophilia A	56	86.2
Hémophilia B	9	13.8
Gravity		
Mild	2	3.1
Moderate	19	29.2
Severe	44	67.7
Total number of important bleeding events during the last 12 months		
≥2	32	49.2
<2	33	50.8
Treatment		
On demand	48	73.8
Prophylactic	12	18.5
No treatment	05	7.7

3.2. Sociodemographic and Economic Characteristics of Parents

The main respondents were mothers (83%). The most represented age group was 31 - 40 years old (43.4%). The type of family is biparental in the majority (64.1%), and the educational level is secondary for 54.7% of parents. Twenty-one had at least three dependent children (39.6%), most of whom had hemophilia (81.1%). Two-thirds (69.8%) had low incomes. Just over half worked part-time (n = 27, 50.9%), and for 11 of them, this was due to their child's illness (40.7%). Twelve parents reported having changed jobs because of their child's illness (22.6%). Parents reported spending a great deal on transportation to the hospital (92.5%), medication (88.7%), and physical therapy sessions and physiotherapy (30.1%) (Table 2).

Table 2. Distribution of the parents according to their sociodemographic and economic characteristics.

Variables	Number (N = 53)	Percentage (%)
Respondents		
Mother	45	85
Father	4	7.5
Others (aunts and uncles)	4	7.5

Continued

Age groups (years)		
[26 - 30]	10	18.9
[31 - 40]	23	43.4
[41 - 50]	15	28.3
≥ 50	5	9.4
Family type		
Biparental	34	64.1
Monoparental	19	35.9
Level of education		
Unschooled	2	3.8
Primary	10	18.9
Secondary	29	54.7
Tertiary	12	22.6
Number of children		
< 3	15	28.3
3 - 4	21	39.6
≥5	17	32.1
Number of children with hemophilia		
1	43	81.1
2	8	15.1
3	2	3.8
Profession		
Senior government officials, private sector executives, import/export traders	4	7.6
Traders and middle-ranking civil servants	12	22.6
Traders with little capital, workers, and laborers	16	30.2
Farmers and casual workers in cities, housewives	21	39.6
Working frequency		
Part-time work	27	50.9
Full-time work	26	49.1

Continued

Part-time work due to child's hemophilia (n = 27)		
Yes	11	40.7
No	16	59.3
Changed profession due to child's hemophilia.		
Yes	41	77.4
No	12	22.6
Healthcare spending		
Transportation	49	92.5
Medical supplies	47	88.7
Physical therapy	12	22.6
Mobility aids	7	13.2
Psychotherapy	5	9.4
Physiotherapy	4	7.5

3.3. Quality of Life of Parents of Children with Hemophilia

Poor quality of life was found in 66% of parents. The average overall quality of life score was 140.04 ± 31.72, with extremes of 51 and 197 (Table 3).

Table 3. Quality of life score according to the different areas of the HEMOCAB scale.

Domain	Number	Means ± DS	Min	Max
Emotional stress	53	69 ± 19	23	100
Financial burden	53	66 ± 26	20	100
Personal sacrifices	53	49 ± 24	20	100
Work-related burden	53	31 ± 27	0	93
Relationships with other people	53	43 ± 19	20	80
Interaction between the child and others	53	43 ± 25	0	90
Relationships with the child's school	53	48 ± 32	0	100
Perception of the child	53	72 ± 16	37	100
Managing the child's hemophilia	53	61 ± 14	30	95
Medical care	53	72 ± 19	20	100
Work situation related to hemophilia	53	32 ± 31	0	100
Interaction with the child's father	53	30 ± 31	0	100

Continued

Impact of the child's hemophilia	53	56 ± 23	20	100
Global quality of life	53	140.04 ± 31.72	51	197

3.4. Factors Associated with Poor Quality of Life among Parents of Children with Hemophilia

Significant personal sacrifices [OR = 32.6 (3.8 - 275.3), p = 0.001], poor relationships with others [OR = 5.3 (1.1 - 26.9), p = 0.030], poor interaction of the child with others [OR = 4.9 (1.4 - 17.3), p = 0.011], poor interaction with the child's school [OR = 9.6 (2.3 - 39.8), p = 0.002], poor management of the child's disease [OR = 6.4 (1.1 - 36.9), p = 0.04], and the negative impact of hemophilia on parents [OR = 9.1 (2.4 - 33.3), p = 0.001] were factors significantly associated with poor quality of life for parents (Table 4).

Table 4. Associated factors of parents' poor quality of life.

Variables	Quality of life of parents		OR (CI 95%)	p value
	Poor	Good		
Personal sacrifices				
Normal	12 (34.3)	17 (94.4)	1	1
Important	23 (65.7)	1 (5.6)	32.6 (3.8 - 275.3)	0.001
Relationships with other people				
Good	21 (60)	16 (88.9)	1	1
Poor	14 (40)	2 (11.1)	5.3 (1.1 - 26.9)	0.030
Interaction between the child and others				
Good	12 (34.3)	13 (72.2)	1	1
Poor	23 (65.7)	5 (27.8)	4.9 (1.4 - 17.3)	0.011
Relationships with the child's school				
Good	12 (34.3)	15 (83.3)	1	1
Poor	23 (65.7)	3 (16.7)	9.6 (2.3 - 39.8)	0.002
Managing the child's hemophilia				
Good	2 (5.7)	5 (27.8)	1	1
Poor	33 (94.3)	13 (72.2)	6.4 (1.1 - 36.9)	0.04
Medical care				
Increased	34 (97.1)	11 (61.1)	1	1
Normal	1 (2.9)	7 (38.9)	0.1 (0.0 - 0.42)	0.001

Continued

Impact of the child's hemophilia				
Positive	8 (22.9)	13 (72.2)	1	1
Negative	27 (77.1)	5 (27.8)	9.1 (2.4 - 33.3)	0.001

4. Discussion

4.1. Study Limits

This study assessed the quality of life of parents of children with hemophilia and identified factors associated with it. However, several limitations were noted, including the single-center setting, the relatively small sample size, the exclusion of parents who could not be reached by phone, and the potential for selection and information bias.

4.2. Sociodemographic and Clinical Characteristics of Children with Hemophilia

The mean age was 10.6 ± 5.3 years, ranging from 1 to 18 years. A similar average age was also found by other authors [4] [12] [13]. However, a review of the literature shows that average ages vary depending on the age groups used in different studies. Forty-nine percent of them were enrolled in secondary school (49.2%).

The majority of children had hemophilia A, and most cases were severe. This was also seen in other studies [3] [8] [11] [13] [14]. However, other authors found more children with a moderate form [12] [16]-[18]. Half reported having had at least two bleeds in the past 12 months (49.2%). Williams *et al.* found in their study that 5% of parents were anxious about their child's risk of bleeding [3]. With regard to treatment, coagulation factors were administered on demand in the majority of children (80%), while only 20% received prophylactic treatment. Similar results have been found by Wiedebusch *et al.* [13]. On the other hand, Buckner *et al.* had only 17% of children with treatment on demand [12]. Some authors found that treatment on demand could alter quality of life, while prophylactic treatment, although considered chronic treatment, could improve quality of life [2].

4.3. Sociodemographic and Socioeconomic Characteristics of Parents

The main respondents were mothers, as confirmed by numerous studies [4] [6] [9] [10] [12] [13] [15]. This can be explained in cultural and social terms, as mothers are the main sources of support and care for their children, especially when the latter have a chronic illness [2] [11] [12] [17]. However, Ersoy *et al.* in 2023 in Türkiye found that fathers were the main respondents, which can be explained by the low literacy rate among mothers in their study environment [5]. The majority of parents were married. This has been found in other studies [9] [13] [15]. While it is well known that a stable family structure can provide essential support for parents who have to manage the complex and sometimes unpredictable care needs associated with their child's illness [2] [14], couples with children with chronic illnesses may also experience relationship tensions due to the burden of care and financial concerns, resulting in a reduced quality of life [13]. The majority of parents had at least a secondary education level. This has also been found in other studies [4] [7] [9] [13] [15] [18]. A high level of education is often correlated with a greater ability to access medical information and make informed decisions about care [12]. Consequently, the parents' level of education could have an impact on the quality of care received by children with hemophilia and, secondarily, on the parents' quality of life.

Half of parents work part-time because of their children's illness (50.9%). This has also been found in numerous studies [2] [5] [6] [12] [15] [18]. Khair *et al.* found that two-thirds of parents in their study worked part-time [2], and Ersoy *et al.* noticed that the percentage of parents of children with chronic illnesses working full-time was low compared to that of parents with healthy children [5]. Parents of children with chronic illnesses are often forced to stop working or reduce and adapt their working hours to meet their children's medical needs [2] [5] [17]. Sometimes they are forced to change jobs, as found in our study and others [5] [15]. Although necessary, working part-time can have significant economic repercussions for families. Parents who reduce their working hours to care for their children run the risk of seeing their total income decrease, which can make it difficult to manage healthcare-related expenses [18]. In fact, in our study, most parents reported spending a lot on transportation to the hospital (92.5%), medication (88.7%), and physical therapy and physiotherapy (30.1%). Other studies have also shown that parents of children with chronic illnesses often invest a significant portion of their income in medical care, transportation, and medication, which causes financial hardship [5] [9]. It is also well known that limited activities can be a source of stress and anxiety [2].

4.4. Quality of Life

A poor quality of life was found in 66% of parents. Von Mackensen *et al.* found results similar to ours (66.2%) [15]. In Nepal, Shakya *et al.* observed moderate and severe levels of impaired quality of life in 60.5% and 9.2% of parents, respectively [18]. Mothers were our main respondents. Studies have shown that mothers of children with chronic diseases report higher levels of stress and impaired quality of life compared to mothers of healthy children [13]. Other studies have shown that the burden on mothers of children with hemophilia is higher than that on fathers due to their involvement in the child's care, but also because of the guilt they feel [12] [13]. Indeed, caring for a child with a chronic disease, and more specifically hemophilia, requires many sacrifices on a physical, financial, socio-professional, and emotional level. In our study, high scores were found for both the frequency and intensity of the burden, namely high emotional stress (69 ± 19). Parents of children with chronic illnesses frequently suffer from increased emotional stress [4] [9]-[11] [13] [17]. The presence of inhibitors in children with hemophilia was a source of psychological stress [2]. According to Williams *et al*., 5% of parents were anxious about the risk of bleeding [3]. Kodra *et al.* found that 54% of parents had anxiety problems [8]. For Von Mackensen, emotional stress was one of the most affected areas among parents (37.4 ± 22.6) [15].

Healthcare and treatment costs can place considerable financial pressure on families. In the study, the financial burden was high (66 ± 26). In fact, 92.5% of parents said they had spent money on transportation and 88.7% on medical supplies. This was also found by other authors [2] [4] [18]. Ersoy *et al.* found that most parents had to travel for care and that many were not affiliated with social security [5]. Von der Lippe *et al.* suggested that home treatment could reduce the financial burden on parents [10]. For Von Mackensen, 26.8% of parents had a high financial burden [15]. Obeidat *et al.* attributed the financial burden to home schooling and the cost of food [17].

The burden associated with the child's perception was high (72 ± 16). In the literature, parents' quality of life is also strongly influenced by their perception of their child. Our results show that 100% of parents with a negative perception of their child report a poor quality of life. This corroborates the work of Dekoven *et al*., who found that a positive perception of the child's abilities could reduce stress and improve parents' quality of life [4]. Von Mackensen found that the perception of the child was one of the areas of quality of life most affected (37.9 ± 24.7) [15]. For Khair, activity limitations were a source of stress and anxiety for parents [2]. According to Williams *et al*., parental perceptions of their children's hemophilia varied depending on the age and severity of the disease [3].

The management of hemophilia in children had a considerable impact on the quality of life of parents of children with hemophilia (61 ± 14). Indeed, parents' quality of life is strongly influenced by how they manage their child's hemophilia. Kish *et al.* reported that the feeling of having to do everything for their children had an impact on parents' quality of life [16]. Other authors also noted that some parents said they did not have enough energy because their child's illness required enormous personal sacrifices on their part to care not only for the child with hemophilia but also for the whole family, and that all of this had a negative impact on their physical health [4] [14] [17].

Medical care was a burden for parents of children with hemophilia (72 ± 19). This has also been found by other authors [4] [15]. Obeidat *et al.* reported that frequent hospital visits to obtain clotting factors and for the management of complications had an impact on the physical health of parents of children with hemophilia [17].

The impact of the child's hemophilia also proved to be a burden for parents in the study (56 ± 23).

The mean overall quality of life score for parents was 140.04 ± 31.72, with extremes of 51 and 197, reflecting the influence of psychosocial factors on quality of life. A high mean overall score was also found by Dekoven *et al.* (80.76 ± 20.14, with extremes of 35 and 144) [4], Manikandasamy *et al.* (63.7 ± 19.5 with extremes of 0 and 100) [14], and Shakya *et al.* (46.8 ± 12 with extremes of 0 and 88) [18].

4.5. Factors Associated with Poor Quality of Life

The significant personal sacrifices [OR = 32.6 (3.8 - 275.3), p = 0.001] observed in the study increased the risk of poor quality of life by 32 times. This result highlights the burden of responsibility that parents must bear. This has also been supported by other authors [4] [16].

Social relationships were also identified as a determining factor in parents' quality of life. We found that poor relationships with others increased parents' risk of having a poor quality of life by 5 times [OR = 5.3 (1.1 - 26.9), p = 0.030], and poor interaction between the child and others by almost five times [OR = 4.9 (1.4 - 17.3), p = 0.011]. Many other studies have shown that chronic diseases are often a source of poor social interactions with friends, but also sometimes with other family members, such as other healthy children or even the father, who feel neglected [2] [7] [12]-[15] [17]. Fear of bleeding, which is responsible for physical restrictions, leads to social isolation for children with hemophilia who cannot engage in the same activities as their peers. Rejection and stigmatization due to disability also cause withdrawal, with negative effects on the quality of life of children and their parents [1] [2]. Von Mackensen *et al.* indicated that positive social relationships play a protective role. They noted that parents with good social support reported less emotional distress and a better quality of life [15].

Poor interaction with the child's school was found to be an associated factor of poor quality of life for parents [OR = 9.6 (2.3 - 39.8), adjusted p = 0.002]. In fact, children with hemophilia very often have disrupted schooling, which has an impact on their parents' quality of life [10] [12] [14] [15]. Collaboration between parents and schools appears to be essential for the child's well-being, but also for the emotional support of parents.

In our study, poor management of the child's disease significantly increased the risk of impaired quality of life in parents by 6.4 times (p = 0.04). It has been shown that parents of children with chronic diseases, including hemophilia, experience increased emotional stress, which often results in a deterioration in their quality of life [15]. This study found that emotional stress was a key predictor of parental satisfaction, which corroborates our findings, where 100% of parents with high emotional stress reported poor quality of life (p < 0.001).

The negative impact of hemophilia on parents was also a factor associated [OR = 9.1 (2.4 - 33.3), p = 0.001]. In fact, the lesser impact of the child's hemophilia on parents was more of a protective factor, reducing the risk of parents having a poor quality of life [OR = 0.07 (0.01 - 0.9), p = 0.041]. Parents of children with hemophilia felt considerable emotional strain, often due to the uncertainty associated with the presence of inhibitors [2] [4], the occurrence of bleeding episodes [4], the constraints of on-demand treatment [2], and disruptions to schooling [10] [15].

On the other hand, we noted a significant protective effect when medical care was not considered to have increased by parents [OR = 0.1 (0.0 - 0.42), p = 0.001]. This corroborates the findings of other authors on the impact of medical management on parents' quality of life [4] [15] [18].

5. Conclusion

More than 60% of parents of children with hemophilia have a poor quality of life, and many factors are associated with this condition. Consideration should be given to implementing health policies and targeted interventions focused on medical and psychosocial support for these families.

Conflicts of Interest

The authors declare no conflicts of interest.

References

[1] Zhang, H., Huang, J., Kong, X., Ma, G. and Fang, Y. (2019) Health-Related Quality of Life in Children with Haemophilia in China: A 4-Year Follow-Up Prospective Cohort Study. *Health and Quality of Life Outcomes*, **17**, Article No. 28. https://doi.org/10.1186/s12955-019-1083-3

[2] Khair, K. and Chaplin, S. (2016) The Impact on Parents of Having a Child with Haemophilia. *The Journal of Haemophilia Practice*, **3**, 4-14. https://doi.org/10.17225/jhp00075

[3] Williams, V.K., Antoniou, G., Jackson, A. and Atkins, A. (2016) Parents' Perception of Quality of Life in Their Sons with Haemophilia. *Journal of Paediatrics and Child Health*, **52**, 1095-1098. https://doi.org/10.1111/jpc.13340

[4] DeKoven, M., Karkare, S., Kelley, L.A., Cooper, D.L., Pham, H., Powers, J., *et al.* (2014) Understanding the Experience of Caring for Children with Haemophilia: Cross-Sectional Study of Caregivers in the United States. *Haemophilia*, **20**, 541-549. https://doi.org/10.1111/hae.12379

[5] Ersoy, G.Z., Ertekin, M. and Dikme, G. (2023) Haemophilia Caregiver Burden in a Low Socio-Economic Region of Türkiye. *Turkish Archives of Pediatrics*, **58**, 618-624.

[6] Fairfax, A., Brehaut, J., Colman, I., Sikora, L., Kazakova, A., Chakraborty, P., *et al.* (2019) A Systematic Review of the Association between Coping Strategies and Quality of Life among Caregivers of Children with Chronic Illness and/or Disability. *BMC Pediatrics*, **19**, Article No. 215. https://doi.org/10.1186/s12887-019-1587-3

[7] Motaharian, E., Mahmood, R., Ziaee, M. and Hojat, Z.N. (2015) Investigating the Relationship between Coping Strategies and Quality of Life among the Principal Caregivers of Children with Hemophilia. *Modern Care Journal*, **12**, 68-73.

[8] Kodra, Y., Cavazza, M., Schieppati, A., De Santis, M., Armeni, P., Arcieri, R., *et al.* (2014) The Social Burden and Quality of Life of Patients with Haemophilia in Italy. *Blood Transfus*, **12**, S567-S575.

[9] Gallegos, C., Aldridge, M.D., Connor, K. and Zuba, L. (2022) Parenting a Child with a Chronic Illness. *Journal of Pediatric Nursing*, **66**, 64-69. https://doi.org/10.1016/j.pedn.2022.05.009

[10] von der Lippe, C., Frich, J.C., Harris, A. and Solbrække, K.N. (2017) Treatment of Hemophilia: A Qualitative Study of Mothers' Perspectives. *Pediatric Blood & Cancer*, **64**, 121-127. https://doi.org/10.1002/pbc.26167

[11] Torres-Ortuño, A., Cuesta‐Barriuso, R. and Nieto-Munuera, J. (2014) Parents of Children with Haemophilia at an Early Age: Assessment of Perceived Stress and Family Functioning. *Haemophilia*, **20**, 756-762. https://doi.org/10.1111/hae.12471

[12] Buckner, T.W., Witkop, M., Guelcher, C., Sidonio, R., Kessler, C.M., Clark, D.B., *et*

al. (2018) Impact of Hemophilia B on Quality of Life in Affected Men, Women, and Caregivers—Assessment of Patient-Reported Outcomes in the B-HERO-S Study. *European Journal of Haematology*, **100**, 592-602. https://doi.org/10.1111/ejh.13055

[13] Wiedebusch, S., Pollmann, H., Siegmund, B. and Muthny, F.A. (2008) Quality of Life, Psychosocial Strains and Coping in Parents of Children with Haemophilia. *Haemophilia*, **14**, 1014-1022. https://doi.org/10.1111/j.1365-2516.2008.01803.x

[14] Manikandasamy, V., Arumugasamy, S. and Mathevan, G. (2017) Impact of Hemophilia on Quality of Life of Affected Children and Their Parents, a Hospital Based Cross Sectional Study. *International Journal of Contemporary Pediatrics*, **4**, 1620-1625. https://doi.org/10.18203/2349-3291.ijcp20173196

[15] Von Mackensen, S., Myrin Westesson, L., Kavakli, K., Klukowska, A., Escuriola, C., Uitslager, N., *et al*. (2019) The Impact of Psychosocial Determinants on Caregivers' Burden of Children with Haemophilia (Results of the BBC Study). *Haemophilia*, **25**, 424-432. https://doi.org/10.1111/hae.13684

[16] Kish, A.M., Newcombe, P.A. and Haslam, D.M. (2018) Working and Caring for a Child with Chronic Illness: A Review of Current Literature. *Child*: *Care*, *Health and Development*, **44**, 343-354. https://doi.org/10.1111/cch.12546

[17] Obeidat, H.M., Habashneh, M.H., Dwairej, D.A., Obeidat, A.H. and Al-Oran, H.M. (2023) The Lived Experience of Mothers of Children with Haemophilia in Jordan: A Phenomenological Study. *Haemophilia*, **29**, 1226-1233. https://doi.org/10.1111/hae.14820

[18] Shakya, M., Banstola, R.S. and Shrestha, R. (2024) Psychosocial Burden of Parents Having Children with Haemophilia in Nepal. *Journal of Chitwan Medical College*, **14**, 67-71. https://doi.org/10.54530/jcmc.1444