

## Original Article

# Determinants of Quality of Life in Children and Adolescents With Hemophilia in Kabul, Afghanistan

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## Abstract

**Background:** Hemophilia is a rare inherited disorder associated with abnormal repeated bleeding and debilitating joint pain due to deficiency in coagulating factors VIII and IX. This study aimed to provide an updated account on the health-related quality of life (HRQoL) in children with hemophilia in Afghanistan.

**Methods:** This cross-sectional study included 65 randomly selected hemophiliacs out of 350 children registered with the Afghanistan Hemophilia Patient Association (AHPA). The patients were 8–16 years old and voluntarily entered the study. Data were collected through a demographic questionnaire and a Persian version of Haemo-QoL Questionnaire (short version) for children aged 8–16 years.

**Results:** The patients' age averaged  $12.9 \pm 3.9$  years with a mean QoL score of  $75.9 \pm 17.4$ . The patients were suffering from hemophilia A, mostly the severe type (80%). They were born to low income families (95 %) with high illiteracy rates (>50%) and hemophilia family history (90%). Spearman test showed a significant correlation between age and QoL scores ( $r = 0.8$ ,  $P = 0.02$ ). One-way ANOVA indicated no significant difference between QoL scores of patients categorized based on hemophilia severity ( $P = 0.2$ ,  $F = 1.3$ ), family incomes ( $P = 0.9$ ,  $F = 0.01$ ) and parents' levels of education ( $P = 0.2-0.4$ ,  $F = 0.82-1.3$ ). The Cronbach alpha for the instrument was 0.82.

**Conclusion:** Regardless of hemophilia severity, Family and Sports were the most impaired domains of QoL. Herein, we have presented the first reliable and updated data on hemophiliacs' demographic characteristics and their quality of life in Kabul.

**Keywords:** Adolescent, Children, Healthcare, Hemophilia, Kabul, Quality of life

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## Introduction

Hemophilia is a rare inherited blood disorder characterized by deficiency in clotting factors VIII and IX, which occurs in 1 of 10 000 births.<sup>1</sup> If not treated, the bleeding in hemophilia patients may last for days and weeks. The most common sites of bleedings are 75 joints including ankles, knees, hips, elbows, wrists and shoulders.<sup>2</sup> Repeated and spontaneous bleeds and pain influence negatively both physical and psychological fitness of hemophiliacs. The high costs of prophylactic treatment and recurrent hospitalizations reduce quality of life in both hemophiliacs and their families.<sup>3</sup> Many studies have evaluated burden of hemophilia in relation to health-related quality of life (HRQoL).<sup>4,5</sup> The disease is also associated with risks of hepatitis, AIDS, anxiety, depression and isolation that worsen quality of life in patients as they get older.<sup>6</sup> The HRQoL is a multi-dimensional concept perceived by individuals in regards to physical, psychological and social health that describes their ability to function.<sup>7</sup>

Nowadays, quality of life (QoL) assessment has become more and more widely accepted as a guide to effective medical treatment and healthcare.<sup>8</sup> Research shows that quality of life in hemophiliacs is lower than that of healthy people.<sup>9</sup> Soucie et al showed that hemophilia patients of all ages experience reduced quality of life due to arthropathy.<sup>1</sup> Hemophilia poses serious challenges to children particularly at adolescence when teenagers struggle to adapt to puberty and associated changes. In fact, it compromises adolescents' ability to take advantage of environmental motivations and impairs their interactions with peers and surroundings. At this stage, dependency on others, for special care requirements, causes frustration, impatience and even depression and anxiety for them.<sup>8</sup> Therefore, hemophilia teenagers need special support from parents, peers and healthcare providers to overcome their challenges. Satisfying such needs comprises a big task for any healthcare system worldwide let alone for those in conflict zones. Afghanistan, as a war stricken country,

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lacks a national data registry base for hemophilia although institutions such as the Central Blood Bank of Kabul and the Afghanistan Hemophilia Association have recorded 87 patients in 2012 and 288 patients in 2016, respectively.<sup>10,11</sup> The statistics on hemophilia will undoubtedly increase as data collection is improved and security prevails in all parts of the country.<sup>12</sup>

Over the past decades, Afghanistan has been ravaged by armed conflict and political instability, which hampered development of a viable healthcare system. Despite recent health gains over implementation of the national Basic Package of Health Service (BPHS) since 2003 and Essential Package of Hospital Services (EPHS) since 2005, Afghanistan still encounters serious health challenges emanating from high rates of population growth, illiteracy, poverty, unemployment, inflation and violence.<sup>13,14</sup> In fact, the national packages have resulted in 66% improvement of accessibility to health services in seven most urgent health priorities excluding rare diseases.<sup>15,16</sup> In other words, there is no hemophilia healthcare plan in Afghanistan, and clotting factors are not always available in public facilities to satisfy the on-demand treatment of patients even against informal fees.<sup>17,18</sup> More often than not, patients and their unprivileged families need to pay for costly drugs and care from private suppliers and caregivers. Besides inadequate access to treatment, insufficient diagnostic facilities remain another major setback in hemophilia care in Afghanistan.<sup>12,17</sup> The war, itself, has inflicted immense traumatic effects on mental health of Afghani children and adolescents particularly young hemophiliacs whose health is already compromised. However, there is paucity of information on the wellbeing of children with hemophilia ( $\leq 18$  years old) who constitute more than 75% of hemophiliacs in Afghanistan. This study aimed to fill the gap by providing updated data on HRQoL in these vulnerable patients. This study may contribute to effective management of hemophilia and its complications both at patient and caregiver levels.

### Materials and Methods

This cross-sectional study was carried out in cooperation with the Afghanistan Hemophilia Patient Association (AHPA), after being approved by the Ethics Committee of Tarbiat Modares University. This diagnostic study included a sample of 65 adolescent hemophiliacs randomly selected from among 350 patients registered with AHPA. The simple random selection was performed using patients' labels in the registration list and a table of random numbers. The patients were then invited by phone call to participate in the study. The inclusion of patients was based on registration record with AHPA, residence in Kabul as well as prior consent. To accomplish the study, we observed the following ethical considerations: (1) self-introduction to patients, (2) provision of details on the study goals and procedures to patients and their parents to

obtain their informed consent, (3) ensuring confidentiality of patients' information and (4) disclosing the information to authorities only upon patient's prior consent. Data were collected through a questionnaire on demographic and socioeconomic information by interviewing patients and their accompanying parents, as well as a questionnaire on the quality of life. The Haemo-QoL Questionnaire (short version) was used for measuring the quality of life of hemophiliacs. Although, the research team provided necessary explanation and assisted illiterates to complete the questionnaires, patients were allowed to freely choose appropriate answers in the presence of their parents. For statistical analysis, the patients were dichotomized into 2 age groups of 8–12 and 13–16 years using median split. The Haemo-QoL Questionnaire (short version) contains 35 index items on 'Physical health', 'Feeling', 'View', 'Family', 'Friends', 'Other', 'School', 'Treatment', 'Future' and 'Relationship'.<sup>2,19,20</sup> The questionnaire was translated into Persian from English version and revised by 12 university professors. The questionnaire had been tested on 10 patients in two intervals (8 days apart) and its reliability calculated to be 81% using Pearson correlation coefficient.<sup>3</sup> For this study, the content and construct validities of the questionnaire were evaluated by judgment of a validation panel of experts of relevant specialties. The questionnaire showed adequate reliability and good internal consistency of 0.82 using Cronbach alpha. The data were analyzed using SPSS software version 20 using Pearson regression and independent *t* tests with a significance level of  $P < 0.05$ .

For the purpose of this study, patients who bleed frequently (sometimes once or twice a week) and their bleeding may occur spontaneously into their muscles and joints were considered to have severe disorder. The income levels of less than \$200, from \$200 to \$400 and more than \$400 were considered low, middle and high. This scale was calculated based on the public feedback on current economic status in Kabul. To help patients measure their health status a scale from 0 to 100 was presented to them in order to be able to correctly complete the questionnaires. The given scores were also used for analysis.

### Results

The study sample included young patients with severe hemophilia A and history of repeated bleedings in knees, elbows and wrists. The mean age of subjects was  $12.9 \pm 3.9$  years and the mean score of QoL was  $75.9 \pm 17.4$ . The majority of patients were suffering from severe disorder (80 %). They also were born to low income (95 %) and illiterate families (>50 %). About 90 % of patients had family history of hemophilia (Table 1). Spearman test showed a significant correlation between age and quality of life scores ( $r = 0.8$  and  $P = 0.02$ ) (Table 1, Figure 1). In addition, one-way-ANOVA showed no significant difference between QoL scores of patients grouped on the

**Table 1.** Demographic Characteristics of Studied Hemophiliacs and Predictors of Quality of Life<sup>a</sup>

Variables		No.	%	QoL Score (Mean ± SD)	Tests	P Value
Age category (y)	8–12	35	53.8	71.4 ± 10.1	F = 0.7 <sup>b</sup> t = 60	0.02 <sup>d</sup>
	13–16	30	46.2	81.4 ± 16.1		
Mothers' education levels	Illiterate	34	52.3	75.7 ± 16.2	F = 0.82 <sup>c</sup>	0.4
	Elementary school	16	24.6	79.3 ± 18.5		
	Secondary school	10	15.4	69.0 ± 10.5		
	High school	5	7.7	80.4 ± 17.5		
Fathers' education levels	Illiterate	28	43.1	76.8 ± 15.3	F=1.3 <sup>c</sup>	0.2
	Elementary s.	13	20	67.8 ± 10.5		
	Secondary s.	12	18.5	74.7 ± 15.9		
	High s.	8	12.3	73.3 ± 10.9		
	University	4	6.2	75.0 ± 13.8		
Fathers; occupations	Jobless	15	23.1	74.2 ± 18.5	F = 0.01 <sup>c</sup>	0.9
	Laborer	34	52.3	74.3 ± 18.9		
	Employee	6	9.2	74.7 ± 13.1		
	Freelancer	10	15.4	74.2 ± 17.3		
Disease severity	Mild	2	3.1	76.5 ± 13.4	F = 1.3 <sup>c</sup>	0.2
	Medium	11	16.9	83.8 ± 9.7		
	Sever	52	80	74.2 ± 17.3		
Family records	yes	58	89.2	75.6 ± 17.8	F = 0.1 <sup>b</sup> t = 0.4	0.5
	no	7	10.8	79.0 ± 15.2		
Income levels	<\$ 200	26	40	75.7 ± 16.4	F = 0.01 <sup>c</sup>	0.9
	\$200-\$400	36	55.4	76.0 ± 20.4		
	>\$400	3	4.6	77.7 ± 15.3		
Residence	Urban	40	61.5	74.7 ± 15.7	F = 0.7 <sup>b</sup> t = 0.69	0.4
	Rural	25	38.5	77.7 ± 13.2		

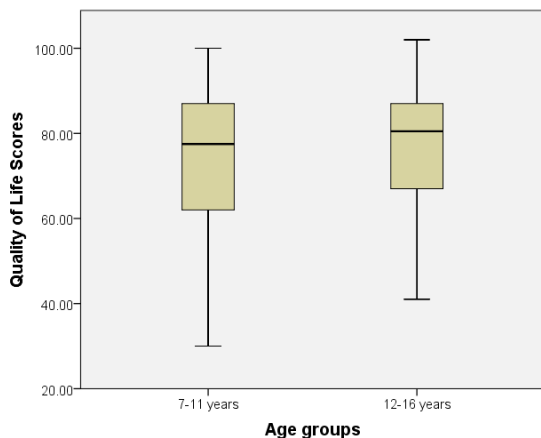
<sup>a</sup> n = 65; results from ANOVA and t test independent regression analyses.

<sup>b</sup> Independent t test; <sup>c</sup> One-way ANOVA test; <sup>d</sup> P value ≤ 0.05.

basis of their disease severity ( $P = 0.2$  and  $F = 1.3$ ). No significant difference was observed between QoL scores of patients based on income categories ( $P = 0.9$  and  $F = 0.01$ ) as well as fathers' occupations, though those from more privileged families scored higher QoL compared to others. On the other hand, parents' level of education had no significant effect on QoL scores ( $P \geq 0.05$ ). Also, QoL scores were independent of residence and family history of hemophilia. In line with cultural context of Afghanistan, patients' mothers were all homemaker and had other occupations. Therefore, mothers' job or income were

irrelevant to this study and overlooked.

Table 2 indicates the mean scores by dimensions. As shown 'Family' and 'Sports' dimensions indicated the poorest QoL with the highest means (10.2 and 10.09 respectively), followed by 'Future', 'View', 'Feeling' and 'Physical health'. The dimension 'Friends', 'School', 'Relationship' and 'Treatment' were the least impaired dimensions among the participants. The overall Cronbach alpha of the instrument was 0.82. Regardless of hemophilia severity, the dimensions 'Family' and 'Sports' were the most impaired. Impairment of dimension such as 'Feeling', 'View' and 'Future' are of special interest given the circumstances of Afghanistan.



**Figure 1.** Comparison Between Quality of Life Scores of Hemophilia Patients in Kabul as Per Age Categories.

**Discussion**

Given the widespread damage to health infrastructures in the war-torn Afghanistan, this study aimed to provide evidence on QoL of Afghani hemophiliacs in a bid to shed light on their current problems and shortcomings in terms of healthcare services and socioeconomic supports. In particular, the study attempted to elucidate, analytically, the experiences of adolescent patients with hemophilia to encourage data-informed development of a disease management plan in Afghanistan.

Despite the existence of many comprehensive tools such as the Haemophilia Experiences, Results and Opportunities (HERO) questionnaire which can provide deeper insight into complex aspects of hemophilia life

Table 2. Mean Scores and Internal Consistency of the Domains Included in Quality of Life Questionnaires for the Studied Hemophiliacs

No of items	Domains	No. of Items	Mean	SD	Cronbach Alpha Coefficient	
					External	Internal
1	Physical Health	3	8.4	3.6	0.75	0.78
2	Feeling	4	9.2	4.2	0.68	0.75
3	View	5	9.9	2.4	0.79	0.80
4	Family	4	10.2	3.5	0.75	0.79
5	Friends	3	4.2	3.4	0.80	0.82
6	Others	2	8.3	4.1	0.74	0.79
7	Sport	4	10.0	2.4	0.77	0.80
8	School	2	3.4	2.1	0.79	0.80
9	Treatment	4	4.7	2.9	0.80	0.82
10	Future	2	8.9	1.5	0.70	0.76
11	Relationship	2	3.4	2.1	0.71	0.79
<b>Total</b>		<b>35</b>	<b>80.6</b>			<b>0.82</b>

requirements, our study was based on the short version of the Haemo-QoL Questionnaire. This was because validity and reliability of other detailed tools may not be easily established at the current intra-conflict setting of Afghanistan.<sup>20-23</sup> Also, for such tools to be efficient, their cross-cultural applicability needs to be ensured.<sup>24</sup> In the case of Haemo-QoL (short version), the questionnaire proved not only to be a handy, useful and cost effective instrument, but also a valid, reliable and applicable tool as shown by studies undertaken in Iran as a country with similar socio-cultural setting.<sup>3,25,26</sup>

Hemophilia incurs direct and indirect heavy costs on patients, healthcare givers and the society.<sup>27,28</sup> Therefore, to cater the needs of hemophiliacs, countries need disease management plans with optimized clinical and economical outcomes based on accurate nationwide data on patient records and healthcare system necessities. This is not yet feasible in Afghanistan.<sup>29</sup> Our data revealed that most patients were born to consanguineously married families with hemophilia history. Two-thirds of marriages in neighboring Pakistan were reported to be consanguineous.<sup>30</sup> In Middle East and African countries, the offspring of consanguineous marriages are greatly exposed to autosomal recessive genetic disorders including hemophilia.<sup>31</sup> Therefore, tackling consanguineous marriage must be an important issue of concern in any hemophilia management plan for Afghanistan via raising awareness, education and genetic counseling.<sup>32</sup>

In this study, patients aged 12-16 years had significantly higher QoL scores than those aged 8-12 years. This was consistent with the findings of Bagheri et al.<sup>33</sup> However, as hemophiliacs attain adulthood, their QoL decline probably due to frequent hemarthrosis, chronic pain and less adherence to treatment regimens. McLaughlin et al reported an inverse relationship between age and QoL scores as they compared teenagers with young adults.<sup>34</sup> They also found no significant correlation between parents' education levels and QoL scores of patients as in our study. We even found no improvement in the QoL scores of patients whose parents had academic qualifications. This

may reflect patients' satisfaction with the basic care and support that they receive from their family. Otherwise, one may infer that educated parents were health illiterate about hemophilia complications and care, and therefore unable to contribute to the wellbeing of their kids. In fact, parents' health literacy plays a crucial role in family reorganization by promoting self-efficacy of parents and assisting children to develop their cognitive adjustment to hemophilia.<sup>35,36</sup> Providing effective education and information to parents besides appropriate treatment improve wellbeing of children with hemophilia.<sup>37</sup>

In this study, the respondents scored statistically similar QoL, as if they were adapted to and satisfied with their health status. This was consistent with the Rosendaal et al report on adolescents with severe hemophilia.<sup>38</sup> They even stated that patients with severe sequelae maintained a better view on their QoL than it would be perceived by others.

The internal consistency of the Persian version of the questionnaire attained a critical Cronbach alpha coefficient of 0.82. As in other similar studies, Sports, Feeling and Physical Health averaged amongst the highly impaired domains in patients, apparently reflecting high prevalence of arthropathy and pain.<sup>39-41</sup> This seems reasonable given that 80% of adolescents were suffering from severe hemophilia (Table 1). Such impairments at early age in Afghani hemophiliacs require due attention to find out whether it resulted from negligence or failure in timely provision of coagulation factors during wartime or both. It is interesting to note that "Friends", "School" and "Relationships" were the least affected aspects of life due apparently to the traditional cultural settings of the Afghani community where solidarity and ties are strong between families and friends.

One of the limitations of this study was its design as a cross-sectional study, which has predictive limitation and may not be useful to establish a true cause and effect relationship between the variables. The second limitation was the method of data collection, which was mainly based on self-reporting although it is a fundamental concept

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rooted in the definition of health-related quality of life by the World Health Organization. The next limitation was the small sample size of patients although the study covered 65% of the total patients registered with AHPA in 2017.

In conclusion, this study was successful in collecting important and reliable data, for the first time, on demographic characteristics, socioeconomic determinants of health, severity of disease, healthcare services and quality of life in children and adolescents with hemophilia in Kabul, the capital of Afghanistan. Despite their adaptive capacity with the disease complications, probably rooted in Afghani culture of resilience and perseverance, the hemophiliacs seriously suffer from reduced quality of life and expectancy.

**Authors' Contribution**

SHM performed the research, collected the data and provided the first reports. MSD designed and supervised the research, interpreted the analysis and wrote the final manuscript. FP analyzed the data and provided tables and figures, and contributed to the draft. MHD contributed to statistical analyses, outline preparation and drafting the manuscript. SAMN contributed to the discussion and critical revision of the manuscript.

**Conflict of Interest Disclosures**

None to be declared.

**Ethical Statement**

The authors state that they have no interests, which might be perceived as posing a conflict or bias. They also, declare that involvement in this research was ethically based on voluntariness and prior informed consent of patients and their parents. Patients' information was kept confidential.

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