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Assessing health-related quality of life and associated factors on hemophilia patients in Kabul City, Afghanistan

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Abstract

Introduction: Haemophilia is a group of inherited, congenital diseases present all through the life. Those disorders are associated with a chronic burden of morbidity punctuated by episodes of acute deterioration in health-related quality-of-life (HR-QL). Identifying the factors affecting on quality of life in people with hemophilia in Afghanistan and comparing it with other countries can lead to improved quality of life.

Aid: Assessing health-related quality of life and associated factors on hemophilia patients in Kabul City among people with hemophilia in Afghanistan.

Methods: This is a cross-sectional study conducted among patients with hemophilia in Kabul, Afghanistan. A total of 288 patients with type A and B hemophilia consist of 19 mildly, 83 moderately and 186 severe forms. Patients in the age range of 3 to 42 years and the mean age (13.84 ± 8.63) from 3 centers of hemophilic patients in Kabul include the Esteqlal Hospital, the Children's Hospital Indra Gandhi and the Afghan Hemophilia Association. HRQoL uses SF-36 through medical records, interviews and self-report collection.

Result: Based on the results Age with all SF-36 subscales except Physical function (P = 0.055) and General health (General health) (P = 0.755), and hemophilia severity with all sub-scales significant relationship was obtained. (p <0.001).

Conclusion: Totally**,** due to low quality of life in patients with hemophilia, the need to plan for improving quality of life in all aspects patients is necessary.

Keywords*: Haemophilia, health-related quality of life, Kabul*

Introduction

Haemophilia A and B are inherited bleeding disorders characterized by the deficiency of blood coagulation factors VIII and IX respectively. This disease is characterized by bleeding into the joints, muscles and other tissues, which can cause severe pain, joint deformity and disability (1).

Approximately 80% of all patients with haemophilia live in developing countries. Although clotting factor recombinant has been used for treating patients with haemophilia, 75% of haemophiliacs in developing countries received inadequate treatment (2). The Severity of haemophilia is dependent amount the measured activity of clotting factor, and is classified as mild (5–30% of normal clotting factor activity), moderate (1–5% of normal) or severe (<1% of normal) (3). Progress in quality and access to treatment most times has reduced the morbidity and mortality caused by haemophilia complications and has increased the life expectancy of patients (4). The recent advances in the treatment of haemophilia with inhibitors have resulted in improvedoutcomes, pain and disability related to the disorder as well as impaired quality of liferemain a challenge (5). The increasing trend towards the use of healthrelated quality of life (HRQOL) measurements as the outcome parameter could help to distinguish differences between groups with haemophilia (6). The term health-related quality of life (HRQoL) was defined based on the WHO definition as a multidimensional construct pertaining to the physical, emotional, mental, social and behavioural components of well-being and function as perceived by patients and observers. Consequently, haemophilia treatment impact patients' health-related quality of life (HRQOL) and daily functioning. In pediatrics, the issue of quality of life is considered an important indicator of the outcome of treatments that refers to patient-perceived well-being and functioning. Also, QoL is very important issue in evaluating the outcome of treatment strategies, such as prophylactic or ondemand treatment (7). Several studies show that patients with bleeding disorders compared with the general population, HR-QoL was lower in the domain. So that patients with severe bleeding disorders than those with moderate or mild type have a lower quality of life (8) Assessing quality of life in patients with hemophilia to prepare database as an important component that has been significant in recent years. According to searches, study about health-related quality of life has not conducted among people with hemophilia in Afghanistan. For the first time, an assessment is being conducted to identify the factors affecting the quality of life associated with health in people with hemophilia in Kabul City, Afghanistan. Therefore, it is expected that due to sociological characteristics, cultural differences and economic and political process of Afghan society and its direct and indirect effects on society and especially on hemophilic patients, this study can identify and introduce the determinants related to

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quality of life. This article presents the first report on health-related quality of life assessment and its determinants in people with hemophilia in Kabul, Afghanistan.

Materials and Methods

This cross-sectional study was conducted between 2015 in Kabul, Afghanistan. Samples were selected randomly selected 288 male samples with hemophilia A, B type in age range of 3-42 years old. Data collection instrunments was a questionnaire including demographic information, clinical characteristics and quality of life. Quality of life questionnaire 36 items consist of 8 sub-scales including physical function (PF), role limitations due to physical health problems (RP), role limitations due to emotional problems (RE), Energy/fatigue (EF), Emotional Well-being (EW), social function (SF), pain (P) and general health (GH). Quality of life questionnaire was completed in children through interviews with children and parents in adolescents through self-report and interviews with parents and adults through self-report. Statistical analysis included the descriptive variables, One-way ANOVA was used to analysis relationship between demographic and clinical variables with health-related quality of life.

Results

The mean age of patients is 14.53 years (SD = 7.81 years). In terms of education level, 38% of respondents are illiterate. More than 76% of patients were single and More 67% of the financial situation were at a poor level. Accordingly, the majority (91%) of patients had type A hemophilia and more than 65% of patients with severe hemophilic form. None of the patients reported having used preventive therapy prophylaxis and all used On-Damand. The mean scores for 8 domains of SF-36 questionnaire from ranged were at least 32.59 to 59.13. Also among the 8 subscales of main questionnaire, the increase highest in mean value relative to median subscale of Physical functioning (Mean ± SD= 59.13±21.41), the least amount associated to emotional role (Mean ± SD= 32.59±34.41). The higher average score is better a person quality of life in that domain and Conversely. According to results the age and hemophilia form associated with domains of health-related quality of life, As age except with Physical function significant relationship with other HRQoL domains. ($p < 0.001$). Also, the hemophilia form has a significant relationship with all HRQoL domains. ($p < 0.001$). (Table 3).This is result indicative this fact that among the influential factors and predictive of quality of life, those who are particularly affected by severe hemophilia, live in low-income families and are older, their quality of life threat is more aspect physically.

Discussion

The purpose of this paper is to present the first report on health-related quality of life in hemophilic patients and its effective factors in Kabul, Afghanistan. The Results SF-36 indicate a low quality of health-related life in people with hemophilia. Accordingly, the scores highest for quality of life are associated to physical function and the least related to emotional role. On the other hand, the reduction of the emotional role of patients may be more likely occur in people with severe type of hemophilia, because these people have a lot of problems with work and daily activities in comparison to others, which can cause emotional problems for them (9). According to the results of various studies, increasing age among haemophiliacs has been reverse associated with lower HRQoL (10). As with increasing age of patients, they have many health problems that reduce the quality of life of patients. In present study performance of the activities of daily life and sports and leisure it disrupts, contributing to the feeling of selfperception that is different from others, and thus, reducing the well-being and HRQoL (11). The results from the analysis also showed that compared to individuals with moderate/ mild haemophilia, individuals with severe haemophilia generally recorded poorer levels of HR-QoL irrespective of age differences (12). In study Miners et al. patients with severe haemophilia experienced lower levels of HR-QoL; particularly in terms of decreased levels of mobility and increased levels of pain (13) Patients with severe haemophilia not only suffer from physical problems and treatment complications but must also face various psychosocial issues while coping with their illness (14) Chronic illnesses such as haemophilia become a part of daily life. Thus, adaptation to a chronic illness is generally influenced by personality traits and coping style, which may also determine QoL(15). Because these patients because the lack of adequate treatment facilities and the poor economic of households to spending costs to treatment, its less treated and therefore, they were less exposed to infect coagulation products (16). On the other hand, there are no health insurance services for patients, therefore, none of the patients had not ability to use prophylaxis and all them used on-demand treatment, which increased the duration to be confined to bed, increased request for help and increased losing working days indicating a high degree of disability in these patients, and Ultimately, these conditions endangered health care and their quality of life. Other factors affecting on health-related quality of life is education level. Low education level is one of the effective factors in reducing HRQoL in different fields. The study varous there is associate between education levels and HRQoL (17). The study is the first report on HRQoL in hemophilia patients in Afghan society, it has not been possible to examine all factors affecting the quality of life of patients with hemophilia. However, The study is the first report on HRQoL in the number of hemophilic patients in Afghan society, it is not possible to examine all factors affecting the quality

of life in hemophilic patients and also the possibility of comparing the quality of life with other individual in the community. Therefore, it is suggested that future studies, in addition to increasing the number of participants with hemophilia, From other individual in the research community be invited to participate in research. while comparing HRQoL in both groups, other factors affecting HQROL are identified and the affect each one is evaluated.

Conclusion

This study provides the Assessing health-related quality of life and associated factors on hemophilia patients in Kabul City, Afghanistan. This study, using the SF-36 questionnaire, identifies and reports some of the factors affecting HRQoL. Overall, in contrast to other studies in different societies, HRQoL is assessed in all its dimensions. The results this study in compared to other studies in different societies was weakly assess HRQoL domains. In this study, the most important factors affecting on quality of life are age, hemophilia and family income. Although in this study, the education level apparently does not an affect on the quality of life, but patients have a lot of problems in this regard and it is expected that according to the results of the research, which illustrates some of the problems and weaknesses of the system Treatment and supportive care for these patients, the need for more attention from the institutionsand various national and international organizations that are responsible for supporting those patients who needy their support seems to be essential.

References

1-Goldstein G, Kenet G. The impact of chronic disease on the family. Hemophilia. 2002;8:461-5.

2-Isarangkura P. Haemophilia care in the developing world: benchmarking for excellence. Haemophilia 2002; 8: 205–10.

3-Report on the Annual Global Survey 2015. Montreal, QC, Canada. World Federation of Hemophilia; 2016.

4-White GC, 2nd, Rosendaal F, Aledort LM, Lusher JM, Rothschild C, Ingerslev J. Definitions in hemophilia. Recommendation of the scientific subcommittee on factor VIII and factor IX of the scientific and standardization committee of the International Society on Thrombosis and Haemostasis. Thromb Haemost. 2001;85:560.

5-Franchini M, Tagliaferri A, Mannucci PM. The management of hemophilia in elderly patients. Clinical interventions in aging. 2007;2:361.

6-Fischer K, van der Bom JG, van den Berg HM. Health-related quality of life as outcome parameter in haemophilia treatment. Haemophilia 2003; 9(Suppl. 1): 75–81.

7-Janz NK, Janevic MR, Dodge JA, Fingerlin TE, Schork MA, Mosca LJ, et al. Factors influencing quality of life in older women with heart disease. Medical Care. 2001;39:588-98.

8-Wang T, Zhang L, Li H, Zhao H, Yang R. Assessing health-related quality-of-life in individuals with hemophilia in China. Hemophilia. 2004;10:370-5.

9-Carvalhosa AM, Henrard S, Lambert C, Hermans C. Physical and mental quality of life in adult patients with hemophilia in Belgium: the impact of financial issues. Hemophilia. 2014;20:479-85.

10-Fischer K, Van der Bom J, Van den Berg H. Health-related quality of life as outcome parameter in hemophilia treatment. Hemophilia. 2003;9:75-82.

11-Varaklioti A, Kontodimopoulos N, Katsarou O, Niakas D. Psychometric properties of the greek Haem-A-QoL for measuring quality of life in Greek hemophilia patients. BioMed research international. 2014;2014.

12-Miners A, Sabin C, Tolley K, Jenkinson C, Kind P, Lee C. Assessing health-related quality-of-life in individuals with hemophilia. Hemophilia: the official journal of the World Federation of Hemophilia. 1999;5:378-85.

13-Remor E. Predictors of treatment difficulties and satisfaction with hemophilia therapy in adult patients. Hemophilia. 2011;17.

14-Jenkinson C, Ziebland S. Interpretation of data from health status measures: What do the numbers mean. Individual quality of life: approaches to conceptualisation and assessment Amsterdam: Harwood Academic Publishers. 1999:75-86.

15-Von Mackensen S. Quality of life and sports activities in patients with hemophilia. Hemophilia. 2007;13:38-43.

16-Posthouwer D, Plug I, van der Bom JG, Fischer K, Rosendaal FR, Mauser-Bunschoten EP. Hepatitis C and health-related quality of life among patients with hemophilia. hematologica. 2005;90:846-50.

17-Barr RD, Saleh M, Furlong W, Horsman J, Sek J, Pai M, et al. Health status and health-related quality of life associated with hemophilia. American journal of hematology. 2002;71:152-60.

Table 1. Characteristics Demographic of the patients with hemophilia.

Variables	N(%) or Mean± SD
Age (Years)	
3-7 (%21)	
8-16 (%53)	14.53±7.81
>17 (%26)	
Education Level (≥7 age)	
Illiterate	113 (%38)
Primary School	89 (%30)
Secondary School	97 (%32)
High School	0
Marital Status	
Single	215 (%76)
Married	71 (%24)
Family Income (USD)	
250 ≤	193 (%67)
251-500 (Low)	57 (%19)
501-750 (Medium)	25 (%9)
750≥ (High)	11 (%5)
Hemophilia Severity(form)	
Severe	
Moderate	186 (%65)
Mild	83 (%29)
	19 (%6)
Haemophilia type	
A	261 (%91)
B	25 (%9)
Treatment	
Prophylaxis	0
On-demand	286 (%100)

Table 2: Subgroup values according to age for the 8 domains of the SF-36.

Domains	Age				
	3-7 Years(N=68)	8-16 years (N=171)	17+ (N=49)	Total	p-Value
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	
Physical functioning	62.15±18.37	58.53±21.24	56.72±24.63	59.13±21.41	0.071
Role physical	38.22±21.34	45.31±42.12	19.46±26.17	34.33±29.87	0.001
pain	46.14±13.25	37.29±28.41	23.34±18.25	35.59±19.97	0.002
General health	48.55±3.14	51.15±6.54	46.12±5.45	48.60±5.04	0.005
Energy/fatigue	43.31±19.24	59.41±33.12	61.27±28.03	54.66±26.79	0.001
Social functioning	37.24±25.06	56.12±17.23	39.11±19.04	44.15±20.44	0.005
Emotional well-being	41.04±16.73	43.31±18.33	68.29±16.35	50.88±17.13	0.001
Role emotional	50.23±22.12	28.38±35.01	19.16±46.11	32.59±34.41	0.001
Physical component score	49.13±5.55	53.72±21.65	36.27±11.04	46.37±12.74	0.001
mental component score	49.26±15.10	37.39±27.01	46.24±18.53	44.29±22.31	0.001

Table 3: Subgroup values according to Severity Hemophilia for the 8 domains of the SF-36.

Domains	Severity Hemophilia				
	Mild(N=1)	Moderate(N=26)	Sever (N=73)	Total	p-Value
Physical functioning	87.00	76.35±21.32	54.12±43.11	72.49±66.43	0.001
Role physical	97.03	59.32±27.12	34.04±31.23	63.46±29.17	0.001
pain	99.00	59.30±12.33	31.02±37.01	45.16±24.67	0.001
General health	51.02	51.24±6.31	46.51±4.35	49.59±5.33	0.021
Energy/fatigue	76.00	51.01±5.13	39.35±9.33	55.45±7.23	0.001
Social functioning	83.00	63.09±11.01	42.13±25.09	62.74±18.05	0.001
Emotional well-being	78.01	70.34±15.39	55.18±12.37	67.84±13.88	0.001
Role emotional	94.00	68.34±28.04	22.05±34.23	61.46±31.13	0.001
Physical component score	82.00	66.22±11.43	33.43±19.01	60.55±15.22	0.001
mental component score	79.03	72.45±14.53	40.11±19.32	63.86±16.92	0.001