SHORT COMMUNICATION

Cost of care in Iranian hemophilic patients

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Abstract

Background: Lifetime treatment of persons with hemophilia entails a heavy financial burden. The main goal of this study was to determine the factors influencing care cost of hemophilia A in southern Iran.

Methods: The present study comprised 88 of 170 hemophilia A patients who had been registered and virtually treated in Fars Hemophilia Treatment Center in southern Iran. The data concerning patients' characteristics and medication schedules were collected from their past medical records and staff interviews. The scale utilized by the Hemophilia Utilization Group Study (HUGS) was used to assess the status of patients' functional health.

Results: The severe, moderate and mild deficiencies of factor VIII were found in 43.2%, 21.6% and 35.2% of 88 patients respectively. The mean age in the study group was 21.8 years (±12.2) and 58 (65.9%) enjoyed high health status. In regard to laboratory records, 25 (28.4%) patients were HCV-positive, 2 (2.3%) HBS-positive and all were HIV negative. The average cost of care for a patient with Hemophilia A was $8,510 (±8,066) and the total annual costs were significantly ($p< 0.05$) associated with: severity of arthropathy, presence of factor VIII inhibitor and its titer, severity of factor VIII deficiency, positive HCV infection and functional health status. Costs unrelated to foregoing factors included only 1% of the total.

Conclusion: The total cost of patient care was correlated with severity of factor deficiency, arthropathy, positive HCV infection and functional health status. Financial resources to meet factor-unrelated costs should increase, in order to provide patients with improved quality of medical care.

Keywords: Cost of care; Hemophilia A; Iran

Introduction

Lifetime treatment of persons with hemophilia entails a heavy financial burden. Studies from other parts of the world have shown that factor infusion involved largest portion of patients' cost of care. For example in United States, the mean annual cost of care was $139,000 of which Factor VIII constituted about 72%.[1] Studies are needed to estimate the annual cost of care for hemophiliacs, and to predict the cost of each factor relative to the average cost for a specific group of patients. Models, which determine the association between patient characteristics and cost of care, have not been introduced in our region. The association between patient conditions and utilization can be used to estimate predicted annual cost of care.[1] Patterns of over-utilization and under-utilization can be identified by comparing predicted annual cost with actual cost. [1] Iran has 7000 patients with bleeding disorders of which 500 live in Fars province, southern Iran. (Ministry of Health, Fars Hemophilia Society) The total cost of care for both hemophiliacs and non-hemophilia patients which provides about 1.5 units of factors/capita in Iran, is paid by the Ministry of Health, Treatment and Education. (Ministry of Health) The purpose of present investigation was to explore the socio-demographic and clinical characteristics

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associated with utilization of medical resource among persons with hemophilia A, in southern of Iran.

Materials and Methods

A retrospective chart review of health services of 88 cases selected from 170 patients with hemophilia A, who virtually received complete hemophilia care in Fars Hemophilia Society, was carried out from 20 March 2005 to 20 March 2006. Using a standardized form, demographic and clinical information were collected by staff members of Fars Hemophilia Society who had long-standing relationship with each person in connection with patient care. This helped in collecting accurate data, while protecting patients' confidentiality. Socio-demographic characteristics including age and gender, were collected from medical records of the patients.

Health status is defined as the ability to engage in daily behavior, encompassing physical, cognitive, and social functioning, in order to maintain everyday life.[2] Health status was assessed by staff members, using a four-item scale, first used by the hemophilia Utilization Study Group.[2] This had a 10-point maximum scale with four categories of status as orthopedic (0–4 points), work/school/usual activities (0–2 points), social interaction (0–2 points) and overall wellbeing (0–2 points). Higher scores signified a better functional status. The response choices for the five-category orthopedic items were derived from the Karnofsky Daily Performance Scale.[3,4] The item of orthopedic status was defined as the ability to ambulate. A score of zero was assigned to bed-ridden patients who were in need of assistance. Similarly, disabled patients in wheelchairs requiring special care and assistance received a score of 1. Patients who were intermittently disabled, requiring assistance or incapable of self-care, received a score of 2. Individuals with a minor limp who required occasional assistance, but able to self-care for most of their needs were given a score of 3, and those with normal physical activity received the highest score of 4. The remaining three items created, were based on patient and provider interview. The work/school/usual activities item was defined as the consistency of attendance at work or school. This variable had three response choices and was meant to measure the level of disability secondary to the patient's illness. These included disability to attend work or school (score ¼ 0), attending work or school but absence from school interfered with performance (score ¼ 1) and attending work or school but absence from them, did not affect the performance (score ¼ 2). The social interaction item was defined as the degree of participation in social interaction which also had three response choices designated as social isolation (score=0), limited social interactions (score=1), and frequent social interactions (score=2). Finally, the item signifying the general health was defined as an overall level of individual's illness from the provider's perspective. The three response choices graded extremely ill (score=0), moderately ill (score=1), and healthy (score= 2).[5]

Clinical characteristics were abstracted from the patient chart by staff members. The severity of hemophilia was categorized by the percentage of factor VIII deficiency defined as severe (<1%), moderate (1–5%), and mild (6–40%). Arthropathy with somewhat limited range of motion and some pain most of the time, was measured on a four-point scale (1=none, 2=recurrent joint involvement, 3=joint involvement 4=severe/disabling) and based on information obtained from the chart and provider interview.

The annual total cost of care included charges for physician's visit, laboratory, radiographic, surgical, dental, physical therapy, medication, hepatitis related treatments, hospitalizations and factor VIII consumption.

Descriptive statistics included socio-demographic, clinical characteristics, health status and cost of care of the patients. Total cost of care was calculated for each patient and t-tests and nonparametric tests (Mann-Whitney U test and Wilcoxon test) were performed to find the meaningful differences between groups of patients with $P<0.05$ considered significant.

Results

The average age of patients was 21.8±12.2 years with 38.6% being under the age of 18. As expected, in accord with hemophilia genetic behavior (X-linked disease), 95.5% of our patients were males whereas only 4.5% were females. In regard to factor VIII deficiency, 31 (35.2%), 19 (21.6%) and 38 (43.2%) patients suffered from mild, moderate and severe forms respectively.

In this study, 38 (43.2%) patients had no arthropathy, and 35 (39.7%) had mild, 13 (14.7%) moderate and 2 (2.3%) of patients suffered from severe arthropathy. As for HIV infection, all patients were negative, but in connection with HBV and HCV, the

respective numbers of positive cases were 2 (2.3%) and 25 (28.4%). High health status indicated by HUGS>7.0 were found in 58 (65.9%) of patients.
The average annual cost of care for a patient with Hemophilia A was estimated $ 8,510±8,066. Indeed, some clinical characteristics were supposedly associated with the total cost of care. In view of various states of VIII deficiency, the estimated mean annual cost for a patient with mild form was $ 4,138 and for that of moderate condition was higher by only 23% ($ 5,092), while in severe cases it showed a surplus of about 233% ($ 13,787). Mild, moderate and severe arthropathy increased the average annual cost of care by 43, 130 and 80 % respectively (*P<0.001*). Those with factor VIII inhibitor had a higher annual cost of care by 72% than patients without such problem. There was also a high correlation between annual cost of care and the titer of factor VIII inhibitor (*P*<0.001, correlation coefficient: 0.616). Functional status showed a strong reverse correlation with total cost of care (*P*<0.001, correlation coefficient:-0.609).

Discussion

This study showed the total cost of care in patients with hemophilia in relation to the patients' socio-demographic and clinical characteristics, needed for risk-adjustment of the annual cost of care. Predictably, the lowest annual cost of care was for the patients with mild factor VIII deficiency, without any history of inhibitors and arthropathy whose average annual cost of care was $ 3,035±4,598. The presence of severe factor VIII deficiency increased the total cost of care by 233% compared to those with corresponding mild condition (*P*<0.001). According to a study conducted in US, such increase amounted to 267%.[1] The HUGS score was not only a fast way for risk-adjustment of total annual cost of care, but in respect of easy measurement, it was as a valuable practical correlation with total cost of care. The present study showed that our patients enjoyed almost acceptable functional health in that 65.9% had high health status measuring HUGS>7.0, compared with 78.3% in US.[1]
In our study the average cost of care for a patient with Hemophilia A was estimated to be $8,510±8,066SD during one year of study, 99% of which accounted for non-factor costs.

The respective values for US were $ 139,000 of which 72% was assigned to the cost of care for factor VIII.[6] Mean annual cost of care for patients receiving on demand infusion in United Kingdom was 1464 Euros with factor VIII including 29% of the total cost of care. As for Italy, such cost was 3185 Euros including 32% for factor VIII.[7] Non-factor costs in our study was only 1% of the total cost of care. This showed that compared with other countries, we have allocated much less fund to non- factor costs. This accounts for lower education of patients, their parents and staff members of hemophilia care centers, insufficient patient examination and management. Subsequently, trauma prevention becomes less efficient along with inappropriate factor consumption which would finally lead to a high incidence of complications including arthropathy. In this context, we need more training for physicians, nurses, patients and their families, holding proper workshops and providing booklets etc. Finally, in addition to our use of 1.5 units of factors/capita in Iran, we need a good patient registry in order to ensure adequate distribution and usage of factors in all hemophilia centers. This is possible if financial assistance is provided to support non-factor costs.

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