

Exploring the Economic Aspects of β -Thalassemia in Jordan in 2019

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ABSTRACT

Thalassemia are inherited hematological disorders considered among the most common genetic disorders worldwide, occurring more frequently in the Mediterranean Region. The WHO estimates that Beta-thalassemia affects 2.9% of the world's population. In Jordan, the carrier prevalence rate of thalassemia is from 2-4%. Patients with thalassemia need a lifelong care, devastating their quality of life and imposing overwhelming psychological and financial burden on patients and their families. The Jordanian Ministry of Health (MOH) is the sole facility responsible for treating these patients from the pre-marital program until required medications regardless of their nationality. This study aimed to estimate the economic burden of thalassemia in Jordan in 2019. All 680 thalassemia patients admitted to thalassemia centers in Jordan and coming to out-patients' clinics from July 1st to Aug 31st, 2019 are included. Data were collected using a pre-developed questionnaire from the electronic medical records. The economic burden was estimated from MOH perspective and societal perspective. The average annual cost was estimated to be 2,674 JOD for a single thalassemia Jordanian insured patient and 4,627 JOD for uninsured, while the non-Jordanian patient's annual cost was estimated 4,751 JOD if insured and 6,651 JOD if uninsured. The total economic burden of thalassemia in Jordan in 2019 was estimated to be 2,148,741 JOD. Of this amount, 1,393,329 JOD was for Jordanians and 755,412 JOD for non-Jordanians. In conclusion, this high burden of thalassemia in Jordan requires adopting new controlling policies; pre-marriage counseling, education and raising awareness should be encouraged.

Keywords: Thalassemia, Jordan, economic burden, 2019.

INTRODUCTION

Jordan is in the western Asia part of the Middle East in an area of political instability. Jordan is an upper middle-income country, with a population of 10.554

million (4.966 million females=47.1% and 5.588 million males=52.9%), Average annual live births is 197,280 (2019). The Gross Domestic Product (GDP) amounted to 31.435 billion JODs (\$ US\$44.4 billion), and Jordan GDP Per Capita reached 2,990 JOD (\$4,222) in 2019. Jordan has a small economy with limited natural resources (1).

The total expenditure on health in Jordan amounted to 2.566 billion JOD (\$ 3.6 billion), and the per capita

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Received: 14/11/2021 Accepted: 24/1/2022.

DOI: <https://doi.org/10.35516/jjps.v15i3.412>

expenditures was 255 JOD (\$ 361) in 2017 accounting for 8.9 percent of the GDP which is considered high for an upper middle-income country. Expenditures on pharmaceuticals was very high and reached 593 million JOD (US \$ 838 million) in 2017 accounted for 2.05 percent of the GDP and 23.13 percent of the total health expenditures. Public expenditures on curative care accounted for 73.7 percent while expenditure on primary care accounted for 19.6 percent in 2017 (2).

The health sector in Jordan is heavily subdivided to multiple health providers including public, private, international and charity sectors. The largest provider of health care is the public sector via the ministry of health MOH, providing insurance to 40% of the population, followed by the Royal Medical Services (RMS), covering 27.5% of the population. In addition, Jordan University Hospital JUH and King Abdullah University Hospital (KAUH) provide health care services for the Universities employees and dependents and also serve as referral centers (3).

Most of the leading hospitals in Jordan are accredited by the Joint Commission International (JCI) and/or the National Health Care Accreditation Council (HCAC) (4).

Many rare diseases cause chronic or progressive physical deterioration, disability, or premature death and start in childhood, creating a huge burden on parents and caregivers. Most rare diseases are thought to be genetic. Although there is increasing demand for therapies for rare diseases, drug companies were not interested in adopting them to develop treatments, and as such became known as orphan diseases. The development of new rare disease therapies has encountered significant obstacles with respect to understanding the incidence and prevalence (epidemiology), patient reported burden of disease, economic cost of the disease and treatment, health technology assessment, and patient access (5).

There is no universal agreed on definition of what constitutes a rare" disease. A recent survey of definitions from more than 1,100 organizations worldwide found

significant variation, ranging from prevalence thresholds of five to 76 cases per 100,000 population (6). Individual rare diseases affect less than 5 to 7 individuals in 10,000 (7).

β -Thalassemia is a single-gene inherited haemoglobinopathy characterized by a decreased production of globin chains, resulting in chronic anemia and skeletal and organ deformities. The World Health Organization (WHO) estimates that β -thalassemia affects 2.9% of the world's population, creating a major public health problem that burdens health care systems and significantly impacts the quality of life of the affected patients 2011 (8). The survival of individuals with β -thalassemia major is reliant on monthly blood transfusions and iron chelation therapy (9). Without blood transfusions, death usually occurs within the first few years of life. The average life expectancy of those with β -thalassemia major is 32 years compared to more than 75 years general life expectancy, and much shorter if untreated (10). Additionally, regular blood transfusions cause iron overload, leading to progressive cardiac damage and death. The annual cost of blood transfusions for β -thalassemia major patients in the Middle East has been estimated at USD 3,200 per patient (2015) (11-15).

The prevalence of β -thalassemia in the Middle East is high, where 1-15% of the population carries the trait (12, 15). A major contributor to the high β -thalassemia prevalence in the Middle East is the high prevalence (25-60%) of consanguineous marriages, particularly among first cousins (16, 17). Due to the high burden β -thalassemia places on patients, families and health care systems in the Middle East, the WHO advocates prevention and reduction of the burden of β -thalassemia through voluntary genetic screening (18). In poor countries, high costs of treatment and the lack of receiving adequate measures of healthcare cause death to many thalassemia children and adolescents (19-21).

Timely blood transfusion appears to prevent early signs and symptoms of the disease, however, transfusion complication such as excess iron is deposited in all body organs leading to heart failure (22, 23), chronic liver diseases, endocrine problems, growth disorders,

osteoporosis (24-26) etc. The latter leads to increased mortality in these patients (27). Thus, health management as well as planning the required services for early diagnosis and patients' treatment is essential (28-30).

Today, the life expectancy of patients with major thalassemia has significantly increased along with therapeutic advances, and this has changed thalassemia from a fatal to a chronic disease (27). As a result, thalassemia patients need lifelong care, but this requires high spending on blood transfusion, iron chelation drugs, laboratory tests, treatment of side effects, periodic visits, and indirect costs such as the costs of lost opportunities as well as lost welfare and decrease in quality of life (31). Since healthcare funders are seeking to control the costs and effectively allocate the resources (32), having knowledge of the invested costs for thalassemia patients is essential for optimal allocation of resources in this sector. The carrier prevalence rate of thalassemia in Jordan is around 2- 4% (17, 33), according to thalassemia department head in MoH, number of registered cases with B-Thalassemia are around 1450 patients, in which almost 1228 Thalassemia patients are treated.

The aims of the study were to estimate the actual economic burden of β -thalassemia in Jordan in 2019 from the perspective of the payer (Ministry of Health-MOH) (Direct costs), and to inform healthcare policy makers toward better decisions help in containing the economic burden of thalassemia in Jordan.

Methodology:

This study is a retrospective descriptive study. In order to achieve the objectives of the study, a research team was formed consisting of: Physicians from the following departments in MOH: Thalassemia and Hemophilia, Prevention of Genetics Disorders, Non-Communicable Diseases, Cancer Control, Cardiovascular Prevention, Primary Healthcare and a health economist with the following main duties: supervising closely data collection from the 4 thalassemia treatment centers (Middle, North, & South) in Jordan, classifying

thalassemia patients in Jordan demographically and clinically, identify, measure and evaluate costs of managing thalassemia in Jordan and estimating them, quantification of the economic burden of thalassemia in Jordan from the perspective of MOH and reporting the results, drawing conclusions and make recommendations.

Data collection was performed by filling a questionnaire specially designed for the study based on a literature review, revised, and approved by the research team experts after a group discussion meeting. Ethical approval was obtained from MOH IRB committee.

Study population is composed of all patients came to the hospitals and thalassemia outpatient's clinics from (July 1, 2020 – Aug 31, 2020); and/or admitted to the 4 thalassemia centers in Jordan (AL Bashir and Zarga hospitals in the middle region, Rahmeh hospital in the north and Al-Ghor hospital in the south). For these patients, registry medical files were studied from (Jan 1, 2019 to Dec 31, 2019 i.e. for 12 months). The total number of patients was 680 representing 55% of all registered thalassemia patients in Jordan.

Twelve Doctors, 2 registered nurses, 3 data entry employees and a facilitator collected the required data. Jordanians, non-Jordanians, all age groups and both sexes were included in this study. Data were obtained from electronic medical records (patients' medical files). Due to lack of electronic data in Al-Ghor, data was obtained manually from the patients' medical files. In addition, interviews with patients /caregivers were made to complete any missed data.

It is worth mentioning that thalassemia treatment protocols in Jordan are according to the Thalassemia International Federation treatment protocol (TIF).

Costs' data were obtained from the accounting department of the MOH in Jordan for all items included, categorized for Jordanian health insured patients and non-Jordanian patients that are supposed to pay fees for the service. The latter include medications, lab tests and imaging tests. All prices were based on MOH tenders

winning prices in 2019.

Collected data were entered and analyzed using XL 2016.

Results and Discussion:

The study includes a total number of 680 patients (demographics were detailed in Table 1): 398 patients from AL Bashir, 151 patients from Irbid, 91 patients from Al Zarqa and 40 patients from Ghor Al Safi treatment center.

Table (1): Demographic description of thalassemia patients in Jordan (2019) (N=680)

| Item | Amman | Irbid | Zarqa | Ghor Safi | Total | % |
|---------------------|-------|-------|-------|-----------|-------|------|
| Total number | 398 | 151 | 91 | 40 | 680 | 100 |
| Jordanians | 275 | 129 | 77 | 40 | 521 | 76.6 |
| Non-Jordanians | 123 | 22 | 14 | 0 | 159 | 23.4 |
| Male | 196 | 87 | 46 | 26 | 355 | 52.2 |
| Female | 202 | 64 | 45 | 14 | 325 | 47.8 |
| Average age (Years) | 20.14 | 18.71 | 18.8 | 16.55 | 18.55 | |
| Lowest age (Years) | 1.5 | 1 | 2 | 1.8 | 1 | |
| Highest age (Years) | 67 | 44 | 57 | 36 | 67 | |

Jordan's geographic location surrounded by unstable countries increases the burden on the healthcare system in Jordan resulting in big need of support from all international donors to provide a good, equal service and treatment to all patients residing in Jordan.

The average age of patients in the study is 18.5 years, this means that the majority is still young either studying

or working who need care and good health in order to participate in the country production.

Table 2 shows different types of thalassemia in Jordan where Thalassemia Major is the dominant (81% of the total number of thalassemia patients), most of the cases were in the capital (Amman).

Table (2): Types of Thalassemia in Jordan

| Item | Amman | Irbid | Zarqa | Ghor Safi | Total | % |
|--------------------------|-------|-------|-------|-----------|-------|------|
| Major Thalassemia | 325 | 137 | 61 | 27 | 550 | 81 |
| Intermediate Thalassemia | 67 | 14 | 18 | 7 | 106 | 15.6 |
| Sickle Thalassemia | 1 | 0 | 11 | 6 | 18 | 2.65 |
| Alpha thalassemia | 5 | 0 | 1 | 0 | 6 | 0.9 |

The average age of diagnosis as shown in Table 3 is considered late (about 22 months), this may be because thalassemia major, which is usually diagnosed before the age of 12 months, has been combined with the diagnosis of thalassemia intermediate.

It was found that first and second-degree relatives' consanguineous marriage rate is 67% (Table 4), which is considered high compared to the Arabic region, published studies showed that Jordan relatives marriage rate ranges

from 30-50% (34-40) from the total general population. As it is one of the recessive diseases that are transmitted from the father and the mother; the marriage of relatives is considered a risk factor for having a child with thalassemia. Therefore, the specialized health authorities in Jordan and all partners working in the (pre-marital screening test program) must focus on trying to convince the local society of the need to decrease inbreeding.

Table (3): Diagnosis age (Months) for thalassemia patients in Jordan

| Item | Amman | Irbid | Zarqa | Ghor Safi | All |
|---------------------------------------|-------|-------|-------|-----------|-------|
| Average diagnosis age (Months) | 30.16 | 7.69 | 17.8 | 31.8 | 21.86 |
| Lowest diagnosis age | 1 | 2 | 1 | 60 | 1 |
| Highest diagnosis age | 564 | 36 | 211 | 108 | 564 |

Table (4): Percentage of degree of relativeness of Thalassemia patients' parents (Consanguineous marriage) in Jordan

| Item | Amman | Irbid | Zarqa | Ghor Safi | Total | % |
|---|-------|-------|-------|-----------|-------|----|
| Parents not relatives (Not consanguineous marriage) | 140 | 41 | 30 | 13 | 224 | 33 |
| Parents are relatives (consanguineous marriage) | 258 | 110 | 61 | 27 | 456 | 67 |

The average blood units (packed RBCs, washed or filtered) consumed per year for each patient is 23.5 units (i.e. almost 2 units/ month), this is considered good and enough (38, 39, 41).

While the average time of giving blood to patients

with thalassemia major is every 21 days, it was found that each thalassemia patient blood transfusion time is increased to be every 31 days (Table 5), the latter may be attributed to the inclusion of thalassemia intermediate and sickle cell thalassemia in this study.

Table (5): Blood transfusion (BT) consumption for all thalassemia patients in Jordan

| Item | Amman | Irbid | Zarqa | Ghor Safi | Total |
|----------------------------|--------|-------|-------|-----------|--------|
| Average BT interval (Days) | 37.666 | 24.41 | 28.3 | 33.5 | 30.96 |
| BT units consumed / year | 10,090 | 3,625 | 1,621 | 586 | 15,922 |

There are some differences in the level of hemoglobin (Hg) for thalassemia patients before giving blood (pre transfusion) among the 4 areas in Jordan, but this level is

not too far from the typical level of Hb according to Thalassemia International Federation (TIF) protocol is (9-10.5) (38, 42) (Table 6).

Table (6): Hemoglobin (Hg) and ferritin levels for thalassemia patients in Jordan

| Item | Amman | Irbid | Zarqa | Ghor Safi | Average |
|---|-------|--------|---------|-----------|---------|
| Pre BT-Hg level (average) (Last reading in g/dL) | 8.75 | 8.313 | 7.65 | 6.3 | 7.75 |
| Lowest Pre BT-Hg (g/dL) | 5 | 6.2 | 6.5 | 5 | 5.68 |
| Highest Pre BT-Hg (g/dL) | 10.5 | 10.6 | 11 | 9 | 10.6 |
| Average Serum ferritin (ng/dL) | 2659 | 2867.5 | 3290 | 1291 | 2526.9 |
| Lowest Serum ferritin (ng/dL) | 40 | 12 | 32 | 75 | 39.75 |
| Highest Serum ferritin (ng/dL) | 12272 | 9480 | 12725.5 | 4300 | 12725.5 |

As thalassemia patients in Jordan are usually given an adequate amount of blood, the average Serum ferritin level (2526 ng/dL) is considered high, it should be decreased to around 1000 ng/dL by giving patients chelating agents. The discrepancy between centers of the same may be attributed to different amounts of blood given to the patients in those centers, and patients' adherence to taking iron chelation agents (42).

Blood in Jordan is neither sold nor bought, rather is

given to patients free but by bringing a donor, the latter is an exception for thalassemia patients (no need to bring a donor). The results showed that the cost of the blood transfusion accounts for almost 16.5% of the total economic burden of thalassemia in Jordan (Table 7). According to the Jordan National Blood Bank workers and experts, the real cost of each unit of blood in Jordan is 150 JODs compared to more than € 439 (equivalent to 369 JODs) in many European countries (42).

Table (7): Annual cost of blood units consumed for thalassemia patients in Jordan

| Thalassemia patients | Units | Unit cost | Total cost (JODs) |
|-----------------------------|--------|-----------|-------------------|
| Able, not insured Jordanian | 12,025 | 15.0 | 180,375 |
| Non-Jordanian | 3,897 | 45.0 | 175,365 |
| Grand total | | | 355,740 |

The total number of patients treated with iron chelation agents in the study were 556, representing 81.7% of all patients (i.e. there are 18.3% not treated). The annual cost of iron chelation drugs according to the preferential prices for the MoH accounts for almost 55% of the total cost of treating thalassemia in Jordan (Table 8). The latter is consistent with international percentages worldwide. It is worth mentioning that the prices of iron chelating drugs

in Jordan were decreased during the last 3 years. Besides, the adoption of the same international protocol of TIF in treating thalassemia in the 4 centers enables the MoH to buy large quantities with lower prices (economies of scale) through a unified annual tender, furthermore the availability of low-price generic substitutes manufactured locally also decrease the cost.

Table (8): Cost of iron chelating agents

| Chelating agents | Units | | Unit Cost ⁴⁰ (JOD) | | Total Cost (JOD) | | Total (JOD) |
|---------------------------|-----------------------------|----------------|-------------------------------|----------------|-----------------------------|----------------|-------------|
| | Able, not insured Jordanian | Non- Jordanian | Able, not insured Jordanian | Non- Jordanian | Able, not insured Jordanian | Non- Jordanian | |
| Deferasirox 500 mg Tablet | 376,810 | 111,375 | 1.6 | 2.4 | 602,896 | 267,300 | 870,196 |
| Deferasirox 250 mg Tablet | 29,003 | 10,175 | 0.9 | 1.4 | 26,102.7 | 14,245 | 40,348 |
| Deferasirox 600 mg Tablet | 608 | 103 | 2.0 | 2.9 | 1,216 | 299 | 1,515 |
| Deferiprone 500 mg Tablet | 69,798 | 17,979 | 1.5 | 2.4 | 104,697 | 43,149 | 147,846 |
| Deferoxamine inj. Vial | 17,530 | 6339 | 4.0 | 6.5 | 70,120 | 41,204 | 111,324 |

| Chelating agents | Units | | Unit Cost ⁴⁰ (JOD) | | Total Cost (JOD) | | Total (JOD) |
|--------------------------|-----------------------------|----------------|-------------------------------|----------------|-----------------------------|----------------|-------------|
| | Able, not insured Jordanian | Non- Jordanian | Able, not insured Jordanian | Non- Jordanian | Able, not insured Jordanian | Non- Jordanian | |
| Distilled water | 14,280 | 4,222 | 0.05 | 0.1 | 714 | 422 | 1,136 |
| Scalp vein | 3,920 | 1,346 | 0.3 | 0.3 | 1,176 | 403.8 | 1,580 |
| Syringe 20 ml | 4,234 | 2,261 | 0.1 | 0.1 | 423.4 | 226.1 | 650 |
| Hydroxyurea 500mg Tablet | 5,648 | 1,740 | 0.2 | 0.3 | 1,129.6 | 522 | 1,652 |
| Other medications | | | | | 14,600 | 37,755 | 52,355 |

Not all thalassemia patients in Jordan accept taking seasonal flu vaccine despite their doctors' advice. As for the hepatitis vaccination, it is originally taken with the National Vaccination Program for all newborn babies in the first months of life but is considered here for those discovered with no antibodies, so additional vaccine doses were re-administered. Prevenar 13 vaccine is given to patients undergoing splenectomy, but the cost of this vaccine is mostly paid by the patient. Because of these, the cost of vaccination is considered negligible and not included.

The cost of medications other than chelating drugs represent only 1.85 % of the total cost. The latter means that chelation drug still very expensive (Table 8).

The three important imaging examinations required for thalassemia patients are Abdominal Ultrasound (Abd US), Echo and DEXA scan costs 14,727 JOD annually accounting for 91% of all imaging costs. It is worth mentioning that although MRIT2 imaging is very important to follow the accumulation of iron in the heart

and liver for thalassemia patients, it is not included as it is not available in MoH.

The three most important annual routine tests for thalassemia patients according to the international protocol of TIF (43) are: cardiac examination, abdominal examination and the most complicated one (osteoporosis) with very high cost. In order to follow thalassemia patients, it is imperative to conduct many different lab tests. Table 9 shows the costs of these lab tests which accounts for 9.2% of the total cost in which kidney- liver electrolytes, CBC, Vit D, thyroid, TSH, Vit B12 and folate are the major costly ones.

The main complications of thalassemia are (Osteoporosis, Hypothyroidism, Diabetes mellitus, Cardiovascular Disease and Hypogonadism); treating these complications increases the cost of treatment and follow-up for thalassemia patients in outpatient clinics as well as admitted to hospitals.

Table (9): Lab tests cost for thalassemia patients in Jordan

| Item | QYT | Unit Cost (JODs) | | Total Cost (JODs) | | Total (JODs) |
|-------------------------------|------|-----------------------------|----------------|-----------------------------|----------------|--------------|
| | | Able, not insured Jordanian | Non- Jordanian | Able, not insured Jordanian | Non- Jordanian | |
| CBC | 9962 | 3.0 | 6.5 | 23156.7 | 14580.2 | 37736.9 |
| KFT, LFT, S. elec | 2005 | 28.0 | 52.8 | 42189.3 | 26282.2 | 68471.4 |
| Screening: Hb electrophoresis | 680 | 5.0 | 7.0 | 2605.4 | 1112.5 | 3717.9 |
| Ferritin | 1901 | 4.0 | 10.0 | 5651.0 | 4882.4 | 10533.4 |

| Item | QYT | Unit Cost (JODs) | | Total Cost (JODs) | | Total (JODs) |
|----------------------|------|-----------------------------|---------------|-----------------------------|---------------|--------------|
| | | Able, not insured Jordanian | Non-Jordanian | Able, not insured Jordanian | Non-Jordanian | |
| Lab tests | | | | | | |
| TFT | 1477 | 15.0 | 33.0 | 16098.7 | 13323.9 | 29422.6 |
| Folic acid, B12 | 916 | 12.0 | 20.0 | 8004.2 | 4979.7 | 12983.9 |
| VIT D | 978 | 25.0 | 30.0 | 17771.5 | 8014.2 | 25785.7 |
| sex Hormone | 134 | 6.0 | 15.0 | 694.4 | 274.0 | 968.4 |
| HbsAg, HbsAb, HCV Ab | 682 | 9.0 | 30.0 | 4941.0 | 3989.9 | 8930.9 |
| Others | | | | | | 3822 |

Osteoporosis accounts for more than 50% of the complications costs which is high when compared to other studies; the latter need further research particularly as TIF advice that all patients more

than 10 years old must undergo bone scanning and be treated by age of 18 (44).

Table (10) shows the length of stay in hospitals costs

including emergency visits, outpatient visits, admission, and any operation related to disease complications if any. The latter represents 8.6 % of the total cost, noting that the approved prices by MoH are very much less than those in other hospitals in the private sector, which is estimated to double or triple these numbers.

.Table (10): Length of stay (LoS) in Hospital and outpatients' costs for thalassemia patients in Jordan (JODs)

| Item | QYT | Unit Cost (JOD) | | Total Cost (JOD) | | Total (JOD) |
|----------------------|------|-----------------------------|---------------|------------------|---------------|-------------|
| | | Able, not insured Jordanian | Non-Jordanian | Jordanian | Non-Jordanian | |
| Outpatient visits/yr | 8135 | 3.3 | 8.0 | 19779.0 | 17130.9 | 36909.9 |
| Inpatient visits/yr | 2952 | 14.7 | 36.0 | 37140.8 | 15004.4 | 52145.3 |
| LoS in Hospital/yr | 252 | 3.0 | 16.0 | 591.3 | 878.6 | 1469.8 |
| LoS in ICU unit/yr | 336 | 3.0 | 79.0 | 699.9 | 8113.3 | 8813.2 |
| Emergency visits/yr | 495 | 0.4 | 8.0 | 184.6 | 267.2 | 451.8 |
| Cholecystmies | 113 | 300.0 | 425.0 | 26940.0 | 9860.0 | 36800.0 |
| Splenectomies | 147 | 300.0 | 425.0 | 32448.0 | 16507.0 | 48955.0 |

As thalassemia patients need continuous care, the absentee from work for the family caregivers as a result of taking care of their thalassemia patients were considered; the latter was calculated based on absent working days and

transportation to the thalassemia center. These costs were estimated and calculated based on the information obtained from family members accounting for 7.4 % of the total cost of treating thalassemia patients (Table 11).

Table (11): Other costs related to thalassemia (indirect costs)

| Item | | Total Cost (JODs) | | Total (JODs) |
|---|----------|-----------------------------|---------------|------------------|
| | | Able, not insured Jordanian | Non-Jordanian | |
| Transportation related cost/ yr | 103043.0 | 78930.9 | 24112.1 | 103043.0 |
| Caregiver lost working days/yr | 4148.0 | | | |
| Average wage/day for caregiver | 13.6 | | | |
| Total cost of caregiver lost working days | 56412.8 | 43212.2 | 13200.6 | 56412.8 |
| Grand total | | | | 159,455.8 |

The average monthly family income for patients who treated in Jordanian Thalassemia centers is approximately 338 JODs (ranging from 53 JODs to 1313 JODs; 53 JOD is for refugee's income).

Average family (caregiver) daily income assuming 25 working days per month = 13.6 JODs (dividing 338 JOD by 25 days). Jordan GDP for 2019 per capita is \$9,731.1 (45) (Table 12).

Table (12): Average family income of thalassemia patients in Jordan (JODs)

| Item | *Amman | *Irbid | Zarqa | Ghor Safi | Total |
|---|--------|--------|-------|-----------|---------|
| Family average monthly income | 427 | 387 | 307.5 | 233 | 338.625 |
| Family lowest monthly income | 45 | 30 | 90 | 50 | 53.75 |
| Family highest monthly income | 3000 | 1005 | 600 | 647 | 1313 |
| Average family (caregiver) daily income (JOD) (25 working days per month) | | | | | 13.6 |

It was found that the average annual cost for one thalassemia Jordanian insured patient is 2,674 JOD while it is 4,627 JOD for uninsured ones. On the other hand, non-Jordanian patient annual costs is 4,751 JODs if they are subsidized (supported by MOH) and 6,651 JODs if not. The total annual cost of thalassemia for 2019 in Jordan is approximately 2,148,741 JODs in which Jordanians cost a

sum of 1,393,329 JODs while the non-Jordanians cost 755,412 JODs paid by the government (Table 13).

As stated by the UNICEF study conducted earlier in 2017 (47), the cost paid out by the MOH was 3,468,035 JODs indicating the high amount of cost paid for the treatment of non-subsidized thalassemia patients in Jordan.

Table (13): Cost of illness of thalassemia in Jordan for 2019 (JOD)

| Economic burden of Thalassemia | Jordanians | Non-Jordanians | Total |
|---|--------------------|--------------------|---------------------|
| Annual estimated cost (subsidized) | 1,393,328.9 | 755,411.81 | 2,148,740.66 |
| percentage | 65% | 35% | 100% |
| Annual estimated cost (not subsidized) as per UNICEF study (47) | 2,410,458.9 | 1,057,576.5 | 3,468,035.45 |
| percentage | 69.5% | 30.5% | 100% |
| Annual average patient cost (subsidized) (43) | 2674.3356 | 4751.0177 | 3159.91274 |
| Annual average patient cost (not subsidized) (43) | 4626.6006 | 6651.4247 | 5100.05214 |

In general, the average annual cost for thalassemia patients, if subsidized, is about 3,160 JD; while if not subsidized the cost is 5,100 JD.

In summary, the subsidized cost for 680 thalassemia patients is 2,148,740 JODs, subdivided as percentages as follows: cost of iron-chelation drugs (54.6%), blood transfusion (16.5%), laboratory tests (9.2%), visits to clinics, admission to hospital, and operations (8.6%), lost working days and transportation costs (7.4%), other medications (1.85%) and imaging examination (0.7%).

Faced with the rising drug bills, health care organizations have focused on methods of cost containment (46). Life expectancy of patients with major thalassemia has significantly increased recently along with advanced new therapeutic treatment protocols. The latter increases the economic burden on healthcare systems as thalassemia patients need lifelong care including: Blood transfusion for life, Iron chelation drugs, Laboratory tests, Treatment of complications and medication side effects, Periodic visits to outpatient clinic and hospitalizations if needed. In addition to opportunities loss and decreased welfare and quality of life.

Longer life expectancy for thalassemia patients who need these healthcare services raises a very important question: How can MOH gives maximum care to patients, contain the cost and try to allocate scarce resources effectively?

Estimating the annual cost for treating thalassemia patients differs from country to country. Some studies in the United Kingdom (34, 48) , Thailand (35) (35), Taiwan(36), Iran (17, 31), USA (43, 44), India (49) (50) estimated the annual costs (2012 through 2015) to treat a thalassemia patient as follows: \$18583 in United Kingdom (34, 48), \$950 in Thailand (35), \$7,464 in Taiwan (36), \$2068 and \$8321 in Iran (17, 31), \$128,062 in USA (43, 44), \$629 in India (50). The latter estimated costs variation was attributed to:

1- Different types of medications used to treat of thalassemia and the use of new expensive drugs

2- Different treatment protocols used in each country

3- Differences in hemoglobin level before the next transfusion (pre transfusion Hb)

4- Differences in the level of ferritin if more or less than 1000 at treatment start

5- Patients' compliance to the medication

6- Availability and access to blood transfusion

7- Treatment of complications and follow up

8- Availability of thalassemia treatment centers

9- Year of the study

Prevention programs for eradication of thalassemia have already been applied successfully in Cyprus, Italy (particularly Sardinia), and Greece (51, 52). Another study from the United Arab Emirates has shown that if the carrier rate remains high, carrier-carrier marriages will continue, and it will be difficult to curtail thalassemia major. While thalassemia can be controlled, it cannot be eradicated.

However, countries in the Mediterranean belt and countries such as India, Pakistan, Iran, Turkey, Bangladesh, Sri Lanka, and many others have no alternative but to implement screening programs to bring down the prevalence of thalassemia carrier status (53).

Global migration is another factor for increase in thalassemia cases in countries outside the thalassemia belt. This is one of the reasons why international agencies should come forward to help control thalassemia in the Mediterranean belt (13) (54).

Conclusion:

The Jordanian government spends great amount of money treating thalassemia patients as MOH is the only healthcare body offering this service to all patients regardless if they are Jordanians or not.

It was concluded in this study that one major reason that is considered a high-risk factor for increasing thalassemia in Jordan is the relative marriage, so remarriage investigations must be highly encouraged in this regard. Thalassemia treatment costs are very high and

most of these costs are related to the drugs received by the patients, and most of them are for iron chelation drugs.

Limitations of the study:

- Time of the study was not good enough for data collection and analysis

- It might be difficult to obtain the actual costs values as the study relies on prices given from the accounting department at MOH.

- Being one of the pioneer studies in this field and the lack of previous and similar studies in this scope, made it a little difficult to compare results and verifications.

- Many other costs were not calculated e.g. the cost of the time spent by nurses and doctors, and the cost of other utilities such as electricity, water and maintenance...etc.

- The prices considered by MOH have been greatly reduced compared to international and other national institutions. The latter may be attributed to: giving preferential prices to MOH by drug companies, competition through tendering purchasing process and local manufacturers supplying generics with much lower prices.

Recommendations:

- Increase community awareness and education about

the disease and the big impact of consanguinity marriage in spreading thalassemia.

- Further research is needed to study all thalassemia patients in Jordan.

- Improve filing system with proper and sufficient data log keeping with easy and secure access to the data legitimately and may be electronically.

- More training and preparedness for those who accomplish these tasks, in a more scientific and appropriate manner.

Funding: This work was supported as an operating grant from UNICEF (United Nations Children's Fund-Jordan)

Conflict of interest statement: The authors have no competing interests.

Acknowledgments:

Authors would like to thank the good efforts performed by the following MDs in collecting data (Maram Alnawaiseh, Aisheh Alesufi, MoHammad Sweiti, Ahmad Azmi, Ahmad Kheiri, Lateefah Maraqa, Tyseer Alsaheb) and data entry clerks (Arab Almasri, Dania Shaher, Amani Alsayed)

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البحث في الجوانب الاقتصادية لمرض ثلاثيميا - بيتا في الأردن لعام 2019

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ملخص

يعد مرض الثلاثيميا من أمراض الدم الوراثية والاختلالات الجينية الأكثر شيوعاً في العالم، ويزداد انتشارها في منطقة حوض البحر الأبيض المتوسط. تقدر منظمة الصحة العالمية عدد سكان العالم الذين يعانون من الثلاثيميا (بيتا) بـ 2.9%. بينما يقدر معدل انتشار الثلاثيميا في الأردن بـ (2-4)%. يحتاج مرضى الثلاثيميا إلى عناية خاصة مدى الحياة حيث يعانون من نوعية حياة سيئة، وأعباء مادية واجتماعية مرهقة على المرضى وذويهم. وتعتبر وزارة الصحة الأردنية الجهة الوحيدة المسؤولة عن علاج هؤلاء المرضى، حيث تتكفل بالإجراءات العلاجية والوقائية بدءاً من فحوصات ما قبل الزواج، وحتى تغطية الأدوية المستخدمة بغض النظر عن جنسية المرضى. هدفت هذه الدراسة لتقدير العبء الاقتصادي لمرض الثلاثيميا لعام 2019 في الأردن. وتضم (680) مريضاً تم إدخالهم لمراكز علاج مرض الثلاثيميا وراجعوا العيادات الخارجية في الفترة ما بين الأول من يوليو وحتى 31 أغسطس عام 2019. تم جمع البيانات باستخدام استبيان مجهز مسبقاً وقام الباحثون بتعيينته من ملفات المرضى الطبية المحوسبة، ثم تقدير العبء الاقتصادي لهذا المرض من منظور وزارة الصحة والمنظور المجتمعي. قدرت الكلفة السنوية المتوسطة لمريض الثلاثيميا الأردني المؤمن بـ 2674 د.أ بينما تصل كلفة المريض غير المؤمن إلى 4627 د.أ. وتقدر كلفة تغطية مريض الثلاثيميا غير الأردني المؤمن بـ 4751 د.أ بينما لغير المؤمن من نفس الفئة 6651 د.أ. أما الكلفة الإجمالية فتقدر بحوالي 2,148,741 د.أ. تم صرف 1,393,329 د.أ على المرضى الأردنيين بينما تم صرف 755,412 د.أ على المرضى غير الأردنيين في السنة. وفي النهاية فإن العبء الاقتصادي المرتفع لمرض الثلاثيميا في الأردن يحتاج إلى تبني سياسات للسيطرة على المرض مثل تشجيع الاستشارة قبل الزواج، والتعليم والتوعية حول هذا المرض.

الكلمات الدالة: ثلاثيميا، الأردن، العبء الاقتصادي، 2019.

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تاريخ استلام البحث 2021/11/14 وتاريخ قبوله للنشر 2022/1/24.