Estimation of Direct Medical Cost associated with Genetic Consultations among Moroccan Children with Rare Diseases: A Monocentric Retrospective Cost Analysis

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OBJECTIVES

The rising cost of rare diseases is of concern worldwide however, there is scarce research on the economic burden of these diseases in Morocco.

The aim of this study was to estimate the direct medical cost for patients with rare diseases at the center of consultations and external explorations of the Children's Hospital at the Ibn Sina University Hospital in Rabat.

METHODS

- This was a **retrospective descriptive monocentric** study using data obtained from the center's database.
- Data were extracted from the medical records of eligible patients with rare diseases who received genetic consultations (October 1st, 2019 - September 10th, 2020).
- Variables related to socioeconomic status were collected, and we estimated direct medical costs (in 2021 Moroccan Dirhams [MAD]), including consultation fees, biology, radiology, and genetic tests.
- Costs, extracted from the hospital's databases, were used to calculate the total cost.

RESULTS

The study included 83 children with rare diseases.

❖Pediatric consultation fees

- The pediatric consultation fee under the Ministry of Public Health has been set by a joint order of the Minister of Health and the Minister of Finance and Privatization at 100 MAD.
- The average number of pediatric consultations for our patients was estimated to be four.
- The total cost of pediatric consultations is: 4×100 MAD×83 patients = **33 200 MAD**

❖Genetic consultation fees

- The fee for a genetic consultation under the Ministry of Public Health has been set by a joint order of the Minister of Health and the Minister of Finance and Privatization at 60 MAD.
- The number of visits to the genetic consultation center to diagnose the disease is estimated to be an average of 3 visits.
- The cost of genetic consultations is calculated as follows 3×60 MAD×83 patients = **14940 MAD.**

❖Cost of biology tests

	Number of patients	Total cost	Mean cost	Maximum	Minimum
BIOLOGY TESTS	36	**43 201**	1200 ± 1310	6230	54

❖Cost of radiology tests

	Number of patients	Total cost	Mean cost	Maximum	Minimum
RADIOLOGY TESTS	68	**139 849,50**	2056,61 ± 1643,16	5550	81

❖Cost of conventional cytogenetics

- The fee for the karyotype under the Ministry of Public Health has been set by a joint order of the Minister of Health and the Minister of Finance and Privatization at 900 MAD.
- The data collected shows that conventional cytogenetics was needed for 41 patients.
- The total cost of conventional cytogenetics is 900 MAD × 41 patients = **36 900 MAD.**

❖Cost of molecular cytogenetics

MOLECULAR CYTOGENETICS	Number of patients	Costs	Total cost	Mean Cost
FISH	2	3600	**45 600**	5700 ± 2407,13
CGH-Array	6	42 000		

❖Cost of molecular biology

MOLECULAR BIOLOGY	Diseases	Number of patients	Costs	Total cost	Mean cost
***HBB* Sanger Sequencing**	Beta Thalassemia	1	1800	**28 200**	4028,57±4462,70
***PTPN11* Sanger Sequencing**	Noonan syndrom	3	5400		
***SNRPN* Methyl PCR**	Prader Willi syndrom Angelman syndrom	2	1800		
Enzymatic PCR-digestion of exon 7 *SMNt*	Spinal Muscular Atrophy	1	900		
***MECP2* Sanger Sequencing**	Rett syndrom	2	3600		
High-Throughput sequencing of *ABCB11*	Byler syndrom	1	13500		
***FMR* Methyl PCR**	X-fragile syndrom	1	1200		

❖Estimation of total direct medical cost of managing patients at the center of genetic consultations

	Total cost	Mean Cost	Maximum	Minimum
DIRECT MEDICAL COST OF GENETIC CONSULTATIONS	**341 890,50**	**4119,5**	**14 816**	**655**

Byler's disease represented the highest cost per patient (14,816 MAD)

❖genetic tests covered by the RAMED and the health insurance companies

GENETIC TESTS	RAMED	Health insurance (CNOPS, CNSS)
Karyotype	Covered	Covered
FISH	Covered	Not covered
CGH-Array	Not covered	Not covered
***HBB* Sanger Sequencing**	Covered	Not covered
***PTPN11* Sanger Sequencing**	Covered	Not covered
***MECP2* Sanger Sequencing**	Covered	Not covered
***SNRPN* Methyl PCR**	Covered	Not covered
***FMR* Methyl PCR**	Covered	Not covered
Enzymatic PCR-digestion of exon 7 *SMNt*	Covered	Not covered
High-Throughput sequencing of *ABCB11*	Not covered	Not covered

❖Laboratories performing genetic tests prescribed to patients

GENETIC TESTS	Laboratories
Karyotype, FISH, *HBB* Sanger Sequencing, *PTPN11* Sanger Sequencing , *SNRPN* Methyl PCR, *MECP2* Sanger Sequencing , Enzymatic PCR-digestion of exon 7 *SMNt*	▪ National Institute of Hygiene of Rabat
CGH-Array, *FMR* Methyl PCR	▪ Private laboratory with subcontracting abroad ▪ Not available in Morocco
High-Throughput sequencing of *ABCB11*	▪ In France

CONCLUSIONS

There is a considerable economic burden associated with rare diseases in Morocco, therefore efforts focused on introducing basic genetic tests and newborn screening should become a priority.

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