Artículo original

Cystic fibrosis in pediatric patients: are families able to pay their children's diagnosis and treatment?

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Resumen

Objetivo: Investigar el costo del diagnóstico, del tratamiento o de ambos de la fibrosis quística (FQ) y la historia socioeconómica de la familia.

Diseño: Retrospectivo, transversal, observacional y descriptivo.

Sitio y fecha: Departamento de Trabajo Social en el Instituto Nacional de Pediatría, una institución de 3er nivel, entre 1970 y 1997.

Material y métodos: Se estudiaron todos los pacientes con FQ diagnosticados en vida a quienes se realizó una historia social completa. En particular, se investigaron: género, edad de inicio del padecimiento y lugar de procedencia. Con respecto a la familia, cantidad de miembros que la integran, lugar que ocupa el paciente, ingreso familiar y estabilidad laboral del jefe de la familia. También se calculó el costo del diagnóstico, del tratamiento o de ambos de la FQ de acuerdo a las tarifas más bajas del Instituto y se expresaron en salarios mínimos mensuales (SMM) (cerca de $20 dólares).

Resultados: El costo del diagnóstico de la FQ fue de 21 SMM; su tratamiento, 39 SMM. Cumplieron con los criterios de selección 57 pacientes; el promedio de edad del principio de la enfermedad fue de 3 años ± (SD: 3 años 3 meses). Vivían en la Ciudad de México 24 pacientes, el resto provenía de diferentes Estados de la República Mexicana. 35 familias estaban compuestas por más de cuatro miembros. Seis jefes de familia eran profesionales y 15 estaban desempleados. El mayor salario lo recibía una familia (60 SMM); 47 familias ganaban 24 SMM o menos.

Conclusiones: Ninguna de las familias estudiadas podía solventar los gastos ocasionados por la FQ.

Palabras clave: Fibrosis quística, enfermedad crónica, México.

Abstract

Purpose: To investigate the cost of the diagnosis and/or treatment of cystic fibrosis (CF), and the socioeconomic history of the family.

Design: Retrospective, cross-sectional, observational, and descriptive.

Setting and date: Social Work Department at the National Institute of Pediatrics in Mexico City, a third level facility, between 1970 and 1997.

Material and methods: We studied every CF patient diagnosed during his/her lifetime to whom a complete social history had been performed, in particular, with respect to gender, age of inception, place of origin, number of family members, place within the family, family income and labor stability of the head of the family. The cost of the diagnosis and/or treatment of CF was calculated according to the Institute's lowest possible charge and expressed in monthly minimum wages (about $20 US Cy).

Results: The cost of CF diagnosis was 21 monthly minimum wages (MMW) and its treatment was 39 MMW. 57 patients fulfilled the selection criteria; their mean age was 3 years ± (SD: 3 years 3 months). Only 24 patients lived in Mexico City, the rest came from different states in the Mexican Republic. 35 families had more than four members. Six family heads were professionals; 15 were unemployed. One family earned the highest wages (60 MMW); 47 families earned 24 MMW or less.

Conclusions: None of the studied families were able to afford the expenses incurred for the diagnosis and treatment of CF.

Key Words: Cystic fibrosis, chronic illness, Mexico.

Introduction

The diagnosis and treatment of a chronic illness in a 3rd level medical facility is generally expensive due to the high cost of specialized studies required.

Cystic fibrosis (CF) is a complex hereditary, chronic metabolic disorder, with frequent exacerbations and relapses, and a fatal prognosis.[1] In 1998, the median survival in the United States of America was 32.3 years;[2] similar survival

rates have been found in the European epidemiologic registry.[3] In the Instituto Nacional de Pediatría, Pérez-Fernández et al,[4] reported a CF life expectancy after diagnosis of 4.7 years in a sample of 39 patients.

The purpose of this study was to investigate the cost of the diagnosis and/or treatment of cystic fibrosis (CF), and the socioeconomic history of the family, in children seen at the Instituto Nacional de Pediatría.

Material and methods

The cost of the diagnostic procedures and the treatment of cystic fibrosis (CF) during one year were investigated. The following items were included in cost of diagnosis: one day hospitalization, 8 consultation, a nebulizer, and laboratory tests. The cost of treatment included various medicines, two day hospitalization, 24 consultations, and maintenance for the nebulizer. The lowest hospitalization rates at the Instituto Nacional de Pediatría were used in the above mentioned estimate.[5]

Due to changing salaries and inflation during the period of the study, all monetary information was translated into monthly minimum wages (MMW), which at the end of the study during 1997, were about $20 US Cy for Mexico City.

A retrospective, cross-sectional, descriptive and observational study[6] was designed to study all CF patients diagnosed during their lifetime in the National Institute of Pediatrics, between January 1970 and December 1997. The following data were obtained from the social history: age of inception, gender, place of origin, number of family members, siblings, place within the family; number of working family members and family income, type of occupation and labor stability of the head of the family. Due to the small sample size, no statistical comparisons were performed.

The protocol was duly submitted and approved by the Research Committee of the Institute.

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Results

The cost of the diagnosis of cystic fibrosis was 21 minimum monthly wages; the cost of treatment was 39 MMW.[5]

There were 57 patients diagnosed during their lifetime. 31 were male; 30 patients were less than 2 years old; 16 patients, 2-5 years; 8, 6-12 years; the rest, were adolescents. Twenty four families lived in Mexico City; the rest came from nearby States of the Mexican Republic.

Families consisted of 3 to 6 members in 54 cases; three families consisted of two, seven and twelve members respectively. In 20 families there were 3 or more children. 19 patients had no siblings; in 11 families, the patient was the first born; in 24, the last one, and the rest had several siblings. In 54 families there was only one working member. Family income and the number of family members is shown in Table 1. A steady job of the head of the family was found only in 13 families.

Table 1. Number of family members and income of 57 cystic fibrosis pediatric patients

Family members	*Minimun monthly salaries*		
	1 or less n = 25	*2* n = 30	*3 or more* n = 15
2	0	1	0
3	11	8	2
4	4	8	2
5	7	7	1
6	2	2	0
7	0	1	0
12	1	0	0

Discussion

It was evident that a minimum wage does not meet the individual's basic necessities: feeding, housing, dress, transport, medical attention and recreation.

Not a single family in this study was able to afford the expenses incurred by this illness, even though some treatments, consultations, nebulizer, and laboratory tests are offered at 40-50% discount rates at the Cystic Fibrosis Mexican Association.

The annual income of 25 families was 12 MMW or less, and 44 heads of family were not steadily employed. The situation was worse in the case of the 33 patients who came from different States in the Mexican Republic, due to the added transportation and lodging expenses of the patient and an adult. This is one of the limitations of this study since these facts could not be taken into consideration in this study. The more numerous families were formed by non-salaried members, mainly children.

Lack of economical resources may contribute to a certain extent to the short life expectancy of CF patients.

REFERENCES

1. Pogue RE. The prognosis for [children] with [cystic fibrosis based] on [reasoned approaches]. Therapy: [past], [present] and [future]. A. Asthma Head 1968;5:277-84.
2. Cystic Fibrosis Foundation. Patient registry annual data report. 1998; Bethesda: Cystic Fibrosis Foundation.
3. Colin AA, Wohl ME. Cystic fibrosis. Pediatr Rev 1994; 15(5): 192-200.
4. Pérez-Fernández L, Flores-Rojas C, López-Corella E, Parra-Cardeño W, Lezana-Fernández JL. Cystic fibrosis in Mexican children. International Pediatrics 1989;4:266-70.
5. Instituto Nacional de Pediatría. Catálogo de cuotas 1997. México, D. F. Instituto Nacional de Pediatría, Secretaría de Salud. 1997.
6. Sosa-de Martínez MC, Pablos-Hach JL, Santos-Atherton D. Guía para elaborar el protocolo de investigación. II. Clasificación del protocolo de investigación. Acta Pediatr Méx 1994;15:139-45.