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Direct and Indirect Costs of Caring for Patients with Chronic Non-Communicable Diseases

Theme: Chronic care.

Contribution to the Discipline: To find out costs related to caring for patients with chronic diseases, which make visible the change of family dynamics, not only in physical, psychological and functional terms but also in financial terms, due to the increase in expenses and the decrease in the income received by patients and their caregivers. These aspects should be considered when defining policies and strategies for qualifying care and maintaining personal and family well-being.

ABSTRACT

Objective: To determine direct and indirect non-medical costs derived from caring for patients with chronic non-communicable diseases (NCDs) in three health institutions located in the metropolitan area of Bucaramanga, Colombia. **Methods:** A descriptive cross-sectional study was conducted with 77 patients with NCDs and their family caregivers, who were selected through systematic sampling between 2018 and 2019. **Results:** Most people with NCDs are women (55 %) at an average age of 70. Four out of five caregivers are women, at an average age of 40, who deliver care for an average of 14 hours a day. The total monthly cost for patient care was on average 324,207 COP. The most significant costs are related to health, food, housing, transport, and communication. 60.5 % of NCDs patients were responsible for household finances before becoming ill. About half of them stopped working and the other half experienced a reduction of 33 % in their monthly income after becoming ill. **Conclusion:** Due to the need for complementary and comprehensive treatment, care, and interventions, costs related to care of NCDs patients increase despite the income of NCDs patients and their caregivers do not.

KEYWORDS (Source: DecS/MeSH)

Cost of illness; health expenditures; noncommunicable diseases; caregivers; cardiovascular diseases.

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Costos directos e indirectos derivados del cuidado familiar del paciente con enfermedad crónica no transmisible

RESUMEN

Objetivo: determinar los costos directos no aplicables a los servicios de salud e indirectos derivados del cuidado familiar del paciente con enfermedad crónica no transmisible (ECNT) de tres instituciones de salud del área metropolitana de Bucaramanga, Colombia. **Metodología:** estudio transversal descriptivo en 77 personas con ECNT y sus cuidadores familiares, seleccionados mediante muestreo sistemático entre 2018 y 2019. **Resultados:** la mayoría de las personas con ECNT son mujeres (55 %), con una edad media de 70 años. Cuatro de cada cinco cuidadores son mujeres, con una edad media de 40 años, y ofrecen cuidados 14 horas por día, en promedio. El costo total mensual atribuido al cuidado familiar del paciente fue de 324.207 pesos colombianos, en promedio. Los costos más representativos son en salud, alimentación, vivienda, transporte y comunicaciones. El 60,5 % de los pacientes con ECNT asumían las finanzas del hogar antes de enfermar y, de estos, aproximadamente la mitad dejó de trabajar y la otra mitad presentó una reducción del 33 % en sus ingresos mensuales después de enfermar. **Conclusión:** los costos relacionados con el cuidado familiar aumentan y los ingresos de los pacientes con ECNT y de sus cuidadores disminuyen, debido a que se requieren tratamientos, cuidados e intervenciones complementarias e integrales, entre otras.

PALABRAS CLAVE (FUENTE: DECS)

Costo de enfermedad; gastos en salud; enfermedades no transmisibles; cuidadores; enfermedades cardiovasculares.

Custos diretos e indiretos derivados do cuidado familiar do paciente com doença crônica não transmissível

RESUMO

Objetivo: determinar os custos diretos não aplicáveis aos serviços de saúde e indiretos derivados do cuidado familiar do paciente com doença crônica não transmissível (DCNT) de três instituições de saúde da área metropolitana de Bucaramanga, Colômbia. **Metodologia:** estudo transversal descritivo com 77 pessoas com DCNT e com seus cuidadores familiares, selecionados mediante amostra sistemática entre 2018 e 2019. **Resultados:** a maioria das pessoas com DCNT são mulheres (55 %), com idade média de 70 anos. Quatro de cada cinco cuidadores são mulheres, com idade média de 40 anos, e oferecem cuidados 14 horas por dia, em média. O custo total mensal destinado ao cuidado familiar do paciente foi de 324.207 pesos colombianos, em média. Os custos mais representativos são em saúde, alimentação, moradia, transporte e comunicações. Dos pacientes com DCNT, 60,5 % assumiam as finanças do lar antes de ficarem doentes e, destes, aproximadamente a metade deixou de trabalhar, e a outra metade apresentou redução de 33 % em seus ingressos mensais depois da doença. **Conclusões:** os custos relacionados com o cuidado familiar aumentam, e o ingresso dos pacientes com DCNT e o de seus cuidadores diminuem, devido a que são exigidos tratamentos, cuidados e intervenções complementares e integrais, entre outros.

PALAVRAS-CHAVE (Fonte: DeCS)

Efeitos psicossociais da doença; gastos em saúde; doenças não transmissíveis; cuidadores; doenças cardiovasculares.

Introduction

According to the Pan American Health Organization (PAHO), costs related to chronic non-communicable diseases (NCDs) have been rising in recent years, both for health systems and for businesses and individuals. Governments, communities and private companies are also affected by the costs of treatment and care for patients with NCDs, as well as by their premature death and disability (1). This poses a significant risk of economic loss to health systems, as well as a decrease in life expectancy and quality of life of individuals (2).

Moreover, the economic burden of the four major chronic NCDs - cardiovascular disease, cancer, diabetes, and chronic respiratory disease- is high. In a PAHO report, the cumulative loss of GDP for the period 2006-2015 due to heart disease, stroke, and diabetes in Mexico, Argentina, Brazil, and Colombia was estimated at US $13.54 billion (1).

In Colombia, NCDs are very costly because of their difficulty in diagnosis and treatment, which are long and complex. This affects, in particular, the economically active population (3). As NCDs are long-term diseases, these bring about a demand for direct and indirect costs. According to the Observatory on Quality of Health Care, direct medical costs include medicines, diagnostic tests, health infrastructure, health personnel, and medical equipment. Direct non-medical costs involve expenditures made outside the health system such as patient transportation, the cost of informal care or other expenses borne by the patient (4).

Indirect costs are derived from the concept of human capital and their calculation includes estimates of the loss in productivity and income due to mortality and disability (3,4).

NCDs directly affect the individual who suffers them and their family due to the economic impact of the decrease in per capita income, which depends on the duration and severity of the disease that entails the incapacity (or the decrease in the temporary or permanent capacity to work), the costs of treatment and transport, among others (5).

In general, research addresses direct costs related to health care and out-of-pocket expenditure or expenses directly borne by patients since neither public nor private insurance covers the full costs of health goods or services. The ability of countries to estimate private spending on long-term care varies widely. Household final consumption expenditure covers all purchases made by households to meet their daily needs such as food, clothing, rental housing or health services (6). Thus, this study provides a complete estimate of NCDs related costs in the family context by aiming to determine the direct and indirect non-medical costs of caring for patients with NCDs.

Materials and Methods

A quantitative descriptive cross-sectional study was conducted. The sample was made up of adults with chronic NCDs and their caregivers from three hospitals located in the metropolitan area of Bucaramanga, Colombia, who were selected through systematic sampling. The sample size was calculated based on a 95 % confidence interval, 5 % error margin and a variance of 500. 10 % was also added due to possible loss or incomplete information. Thus, the total sample size was 77 patient-caregiver dyads.

The selection criteria were adults with NCDs of at least six months of duration, having a family caregiver during that minimum time, who had received inpatient and outpatient care services from two second-level hospitals located in the cities of Bucaramanga and Floridablanca, and a third-level hospital in Bucaramanga, Colombia. The exclusion criteria were people with neurological or cognitive disabilities that could prevent the provision of reliable information. The information was collected between February 2018 and May 2019.

The patients who met the selection criteria were firstly identified, for which the informed consent was filled in and the instrument for information collection was applied later. The latter consisted of two surveys: 1) Characterization of the patient with chronic disease and caregiver dyad, designed by the Care Group for Chronic Patients and their Families from the Nursing School of the Universidad Nacional de Colombia (7); and 2) Financial cost of care for chronic diseases, which explores the actual effective monthly consumption and the family impact of caring for a person with NCDs, developed by Montoya et al (8).

The evaluated variables were grouped into three sections, as follows:

1. **Sociodemographic characteristics of the patient and caregiver**

Sex, age, neighborhood, family group, schooling, occupation, marital status, religion, PULSES functional assessment scale (the scale assesses: P = Physical Condition, U = Upper Extremities, L = Lower Extremities, S = Sensory Function, E = Excretory Function, S = Social and Mental Status) (9), mental state examination using the Pfeiffer's Short Portable Mental Status Questionnaire (SPMSQ) (10), Zarit Caregiver Burden Interview (11), clinical diagnosis, duration of illness, sole caregiver, number of hours of care, level of psychological, family, religious, economic, social and IT support.

2. Direct costs

Actual effective consumption attributable to care for patients with NCDs:

- Food.
- Housing: rent, energy or electricity, gas, water, housekeeping, and visits.
- Health: Health Promoting Entities (EPS, by its meaning in Spanish), prepaid medical plans, medicines included in health benefits plans (HBP), non-HBP medicines, nursing services and similar support services, complementary services, alternative medicine, insurance, personal care products, consumer products, wheelchairs, special beds, among others.
- Transport: public and private transport.
- Communication: landline, cell phone plans, Internet, television, and other media.
- Miscellaneous goods and services: financial expenses, interest, stationery and photocopies, and administrative procedures.

3. Indirect costs

Loss of labor productivity by quantifying the paid time and income of the patient and family caregiver before and after becoming ill.

The data was double-entered and validated in EpiData 3.1 (12), then analyzed in Stata 14.0. (13). First, proportions were calculated for qualitative variables and the distribution of quantitative variables was evaluated using the Shapiro-Wilk test. Measures of central tendency were calculated according to their normal distribution, using mean and standard deviation for the variables of family financial burden attributable to the care of a person with NCDs.

Regarding ethical aspects, the guidelines for biomedical research adopted by the Council for International Organizations of Medical Sciences (CIOMS) (14) and the standards established by the Colombian Ministry of Health in Resolution 8430 of October 4, 1993 were considered (15). Written consent was obtained from patients and caregivers. The research was approved by the ethics committees of the University (Act CBU-006) and the participants' healthcare institutions. The protection of personal data was carried out in accordance with Decree 1377 of 2013 (16), which regulated Law 1581 of 2012 of Colombia.

Results

Sociodemographic characteristics of the patient and family caregiver are described in Table 1. As for the characterization of patients, more than half were women (55 %) at an average age of 70 living in urban areas (94 %), classified as socioeconomic stratum two[7] (52 %), with four people on average in their family group, primary education level attained (84 %), mainly dedicated to household chores (51 %), married (34 %), Catholic (82 %), with a PULSES score between 12 and 24 (51 %) - that is, with high dysfunctionality or dependency - and a score of 3-4 in the SPMSQ test, that is, with mild cognitive impairment (30 %). The predominant diagnostic group of patients was the cardiovascular group (45 %), with an average illness duration of 118 months (9.8 years). In addition, they have low self-perception of family burden (36 %), sole caregiver (56 %) and require an average of 13.8 hours of care per day. Regarding the perceived support, the majority report having no psychological support (32 %), a high level of family (42 %) and religious (35 %) support, a moderate level of economic and social support and a low level of IT support for their care (83 %).

As for the characterization of caregivers, approximately four out of five were women (78 %) at an average age of 42.8 living in urban areas (94 %), classified as socioeconomic stratum two (44 %), with four people on average in their family group, primary education level attained (47 %), mainly dedicated to household chores (44 %), single (35 %), Catholic (78 %), with a PULSES score between 6 and 8 (49 %) - that is, low dependency - and a score of 0-2 in the SPMSQ test (75 %), that is, with normal mental functioning. One out of five caregivers had a chronic illness, having an average duration of 55.9 months (4.6 years).

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[7] Editors note: Just to give context for a better understanding of the paper: In Colombia the social structure of stratification is divided in six stratums: 1, low-low; 2, low; 3, medium-low; 4, medium; 5, medium-high; 6, high. Acording to the Departamento Administrativo Nacional de Estadística (DANE) of Colombia, the clasification in any of these is a socioeconomical jerarchierized difference and 1, 2, and 3 stratums are low income users that benefit from domiciliary public services subsidies. For more information: https://www.dane.gov.co/files/geoestadistica/Preguntas_frecuentes_estratificacion.pdf

Regarding the care of patients with NCDs, they considered care as a high burden for the family (42 %), most had only one caregiver (56 %) and dedicated an average of 13.4 hours of care per day. Regarding the perceived support, the majority report having no psychological support (36 %), a high level of family support (35 %), a moderate level of religious (38 %), economic (40 %) and social (38 %) support and IT support for care (49 %).

Table 1. Characterization of patients with chronic non-communicable diseases and their caregivers

Variable	Patients	Caregivers
	n (%)	n (%)
Gender		
Female	42 (55)	60 (78)
Male	32 (41)	14 (18)
NR	3 (4)	3 (4)
Age		
Average (SD)	70.1 (15.6)	42.8 (13.2)
Area		
Urban	72 (94)	72 (94)
Rural	5 (6)	5 (6)
Socioeconomic Stratum		
1	16 (21)	12 (16)
2	40 (52)	34 (44)
3	11 (14)	20 (26)
4	6 (8)	8 (10)
6	1 (1)	-
NR	3 (4)	3 (4)
Number of Family Members		
Average	4.0 (1.5)	4.0 (1.5)
Highest Level of Schooling Attained		
Illiterate	1 (1)	1 (1)
Primary education	61 (84)	18 (23)
Secondary education	8 (11)	36 (47)
University degree	3 (4)	6 (8)
Technical degree		12 (16)
Postgraduate degree		1 (1)
NR		3 (4)
Occupation		
None	4 (6)	-
Homemaker	35 (51)	34 (44)
Employee	2 (3)	18 (23)
Self-employed	6 (9)	13 (17)
Student	-	4 (5)
Other	21 (31)	5 (6)
NR	-	3 (4)
Marital Status		
Single	14 (18)	27 (35)
Married	26 (34)	22 (29)
Separated	8 (10)	4 (5)
Widowed	20 (26)	3 (4)
Civil partnership	6 (8)	18 (23)
NR	3 (4)	3 (4)
Religion		
Catholic	63 (82)	60 (78)
Protestant	11 (14)	12 (16)
Other	-	2 (3)
NR	3 (4)	3 (4)
PULSES (functionality)		
Low dependency 6-8	21 (27)	38 (49)
Moderate dependency 9-11	14 (18)	5 (6)
High dependency 12-24	39 (51)	30 (39)
NR	3 (4)	4 (5)
SPMSQ Test		
Normal mental functioning (0- 2)	17 (22)	58 (75)
Mild cognitive impairment (3- 4)	23 (30)	
Moderate cognitive impairment (5- 7)	17 (22)	1 (1)
Severe cognitive impairment (8- 10)	17 (22)	13 (17)
NR	3 (4)	5 (6)

Variable	Patients	Caregivers
	n (%)	n (%)
Perceived Family Burden		
Low burden	28 (36)	30 (39)
Moderate burden	18 (23)	11 (14)
High burden	19 (25)	32 (42)
Very high burden	6 (8)	-
NR	6 (8)	4 (5)
Diagnosis		
None	-	61 (79)
Cardiac diagnostic	35 (45)	-
Cerebrovascular diagnostic	5 (6)	-
Metabolic diagnostic	6 (8)	1 (1)
Respiratory diagnostic	8 (10)	1 (1)
Neurological diagnostic	6 (8)	-
Other	14 (18)	8 (10)
NR	3 (4)	6 (8)
Duration of Illness/Care		
Average	117.8 (111.4)	55.9 (64.1)
Sole Caregiver		
No	31 (40)	31 (40)
Yes	43 (56)	43 (56)
NR	3 (4)	3 (4)
Number of Hours of Care per Day		
Average (SD)	13.8 (7.8)	13.4 (8.1)
Psychological Support		
0	25 (32)	28 (36)
1	2 (3)	8 (10)
2	18 (23)	2 (3)
3	8 (10)	24 (31)
4	21 (27)	12 (16)
NR	3 (4)	3 (4)

Variable	Patients	Caregivers
	n (%)	n (%)
Family Support		
1	2 (3)	9 (12)
2	14 (18)	12 (16)
3	26 (34)	26 (34)
4	32 (42)	27 (35)
NR	3 (4)	3 (4)
Religious Support		
0	8 (10)	9 (12)
1	4 (5)	12 (16)
2	12 (16)	5 (6)
3	23 (30)	29 (38)
4	27 (35)	19 (25)
NR	3 (4)	3 (4)
Economic Support		
0	4 (5)	6 (8)
1	4 (5)	7 (9)
2	26 (34)	9 (12)
3	19 (25)	31 (40)
4	21 (27)	21 (27)
NR	3 (4)	3 (4)
Social Support		
0	20 (26)	13 (17)
1	4 (5)	9 (12)
2	20 (26)	5 (6)
3	13 (17)	29 (38)
4	17 (22)	18 (23)
NR	3 (4)	3 (4)
TI Support for Care		
No	60 (85)	40 (56)
Yes	11 (15)	32 (44)

Variable	Patients	Caregivers
	n (%)	n (%)
Perceived IT Support		
None	2 (3)	-
Low	59 (83)	35 (49)
Medium	8 (11)	24 (33)
High	2 (3)	13 (18)
Gender		
Female	42 (55)	60 (78)
Male	32 (41)	14 (18)
NR	3 (4)	3 (4)
Age		
Average (SD)	70.1 (15.6)	42.8 (13.2)
Area		
Urban	72 (94)	72 (94)
Rural	5 (6)	5 (6)
Socioeconomic Stratum		
1	16 (21)	12 (16)
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3	11 (14)	20 (26)
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6	1 (1)	-
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Number of Family Members		
Average (SD)	4.0 (1.5)	4.0 (1.5)
Highest Level of Schooling Attained		
Illiterate	1 (1)	1 (1)
Primary education	61 (84)	18 (23)
Secondary education	8 (11)	36 (47)
University degree	3 (4)	6 (8)
Technical degree		12 (16)
Postgraduate degree		1 (1)
NR		3 (4)

Variable	Patients	Caregivers
	n (%)	n (%)
Occupation		
None	4 (6)	-
Homemaker	35 (51)	34 (44)
Employee	2 (3)	18 (23)
Self-employed	6 (9)	13 (17)
Student	-	4 (5)
Other	21 (31)	5 (6)
NR	-	3 (4)
Marital Status		
Single	14 (18)	27 (35)
Married	26 (34)	22 (29)
Separated	8 (10)	4 (5)
Widowed	20 (26)	3 (4)
Civil partnership	6 (8)	18 (23)
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Religion		
Catholic	63 (82)	60 (78)
Protestant	11 (14)	12 (16)
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NR	3 (4)	3 (4)
PULSES (functionality)		
Low dependency 6-8	21 (27)	38 (49)
Moderate dependency 9-11	14 (18)	5 (6)
High dependency 12-24	39 (51)	30 (39)
NR	3 (4)	4 (5)
SPMSQ Test		
Normal mental functioning (0- 2)	17 (22)	58 (75)
Mild cognitive impairment (3- 4)	23 (30)	
Moderate cognitive impairment (5- 7)	17 (22)	1 (1)
Severe cognitive impairment (8- 10)	17 (22)	13 (17)
NR	3 (4)	5 (6)

Variable	Patients	Caregivers
	n (%)	n (%)
Perceived Family Burden		
Low ability	28 (36)	30 (39)
Moderate burden	18 (23)	11 (14)
High ability	19 (25)	32 (42)
Very high burden	6 (8)	-
NR	6 (8)	4 (5)
Diagnosis		
None	-	61 (79)
Cardiac diagnostic	35 (45)	-
Cerebrovascular diagnostic	5 (6)	-
Metabolic diagnostic	6 (8)	1 (1)
Respiratory diagnostic	8 (10)	1 (1)
Neurological diagnostic	6 (8)	-
Other	14 (18)	8 (10)
NR	3 (4)	6 (8)
Duration of Illness/Care		
Average (SD)	117.8 (111.4)	55.9 (64.1)
Sole Caregiver		
No	31 (40)	31 (40)
Yes	43 (56)	43 (56)
NR	3 (4)	3 (4)
Number of Hours of Care per Day		
Average (SD)	13.8 (7.8)	13.4 (8.1)
Psychological Support		
0	25 (32)	28 (36)
1	2 (3)	8 (10)
2	18 (23)	2 (3)
3	8 (10)	24 (31)
4	21 (27)	12 (16)
NR	3 (4)	3 (4)

Variable	Patients	Caregivers
	n (%)	n (%)
Family Support		
1	2 (3)	9 (12)
2	14 (18)	12 (16)
3	26 (34)	26 (34)
4	32 (42)	27 (35)
NR	3 (4)	3 (4)
Religious Support		
0	8 (10)	9 (12)
1	4 (5)	12 (16)
2	12 (16)	5 (6)
3	23 (30)	29 (38)
4	27 (35)	19 (25)
NR	3 (4)	3 (4)
Economic Support		
0	4 (5)	6 (8)
1	4 (5)	7 (9)
2	26 (34)	9 (12)
3	19 (25)	31 (40)
4	21 (27)	21 (27)
NR	3 (4)	3 (4)
Social Support		
0	20 (26)	13 (17)
1	4 (5)	9 (12)
2	20 (26)	5 (6)
3	13 (17)	29 (38)
4	17 (22)	18 (23)
NR	3 (4)	3 (4)

Variable	Patients	Caregivers
	n (%)	n (%)
TI Support for Care		
No	60 (85)	40 (56)
Yes	11 (15)	32 (44)
Perceived IT Support		
None	2 (3)	-
Low	59 (83)	35 (49)
Medium	8 (11)	24 (33)
High	2 (3)	13 (18)

Source: Own elaboration

Regarding direct non-medical costs or actual costs attributable to the care of patients with chronic diseases, Table 2 shows the breakdown of costs in COP by expenditure type related to housing, health, transportation, communication, goods and services, and debts, both the total cost for the family and per patient. The biggest household expenditure is food (461,623 pesos), utilities and services (167,418), personal care products (147,610) and transport (106,546). 40 % of families pay an average of 445,645 pesos in rent. The most significant expenses are food in 64 % of families amounting to 169,796 pesos; public transport in 68 % of families amounting to 39,942 pesos; personal care and hygiene products in 42 % of families amounting to 35,531 pesos; administrative procedures in 86 % of families amounting to 24,318 pesos; and patient visits in 67 % of families amounting to 20,313 pesos.

With regard to monthly health-related expenses borne by the family or out-of-pocket expenses, 17 % of families pay contributions for patient healthcare affiliation (97,254 pesos); 30 % spend on HBP medicines (28,600); 16 % on non-HBP medicines (42,408); 10 % on nursing services (157,375); 19 % on complementary services (66,200); 4 % on alternative medicine (96,667); and 6 % on therapeutic devices (103,000). In addition, 22 % of families pay EPS contributions to caregivers amounting to 95,647 pesos. In addition, 31 % of the families incurred an average of 2,166,667 pesos in debt due to the patient's illness and pay 90,417 pesos in monthly interest.

Table 3 shows the average costs for families and patients grouped by expenditure type. From the total value of food, housing, transport, and communication for the family, 23, 10, 29 and 9 %, respectively, are attributable to patient care. The total monthly cost for patient care was on average 324,207 COP per family. Additionally, when converting this variable into quartiles, the distribution of ranges was between 10,000 and 150,000; 150,001 and 225,000; 225,001 and 382,900; and 382,901 and 2,030,002.

In addition, 44 % of the families have concerns about the financial burden of caring for a chronically ill patient and 19 % report that there have been conflicts over the finances of caring for the ill person. The main reason is insufficient money in 67 % of cases. The sick person used to take over the finances in 43 % of households. 6 % reported that they had to sell goods or properties (jewelry, motorbikes, houses) to cover the cost of care. In half of the cases, their children assume the costs of family care.

In addition, indirect costs were evaluated in 38 dyads (collected in 2019), as shown in Table 4. 15 patients (38.5 %) did not engage in any paid economic activity and the remaining 23 patients (60.5 %) worked an average of 8 hours per day, earning 747,826 pesos per month (slightly less than the current legal minimum wage [SMLV]) before becoming ill. Among the latter group, after becoming ill, 12 (52 %) patients stopped working, and the 11 (48 %) patients who continued to work, their working hours and income were reduced to 4 hours (50 %) and 500,000 pesos (33 %), respectively.

As for caregivers, 29 were engaged in any remunerated economic activity. They used to work an average of 10 hours a day and earned 1,007,924 pesos per month. When they undertook the care of their family member, these working hours decreased to 8 and their income to 950,690 pesos (6 %).

Discussion

Direct Non-medical Costs

NCDs are a public health problem as they influence social, cultural, political and economic changes, altering the living conditions of the vast majority of the population (17,18).

Table 2. Breakdown of direct costs of caring for patients with chronic non-communicable diseases and their families by expenditure type

Variable	Family			Differential Cost	Patients	
Housing	**n (%)**	**Average**	**SD**	**n (%)**	**Average**	**SD**
Food	77 (100)	461,623	250,965	49 (64)	169,796	109,573
Rent	31 (40)	445,645	151,552	-	-	-
Electricity	77 (100)	74,545	65,242	14 (18)	45,071	37,674
Gas	77 (100)	29,379	31,421	23 (30)	10,739	5,910
Water supply	77 (100)	63,494	43,846	18 (23)	25,333	21,698
Household services	4 (5)	280,000	116,619	3 (75)	266,667	152,753
Patient visits	48 (62)	24,833	23,153	32 (67)	20,313	11,939
Healthcare Services						
EPS	17 (22)*	95,647*	52,461	13	97,254	38,044
Prepaid medical plans	-	-	-	-	-	-
HBP Medicine	7 (9)*	96,428*	17,796	23	28,600	65,492
Non-HBP Medicine	1 (1)*	50,000*	-	12	42,408	36,825
Nursing and Similar Support Services	-	-	-	8	157,375	110,703
Complementary Services	-	-	-	15	66,200	48,144
Alternative Medicine	-	-	-	3	96,667	25,166
Insurance	-	-	-	-	-	-
Personal Care	77 (100)	147,610	133,055	32 (42)	35,531	19,566
Therapeutic Devices	-	-	-	5	103,000	58,694
Transport						
Public	77 (100)	106,546	161,472	52 (68)	39,942	36,984
Private	24 (31)	71,250	63,198	13 (54)	59,615	38,862
Communication						
Landline	50 (65)	40,940	37,781	6 (12)	13,333	6,055
Cell phone plans	72 (94)	52,222	74,623	24 (33)	29,583	38,608
Internet	18 (23)	42,556	21,064	-	-	-
Television	63 (82)	38,476	32,032	1 (2)	10,000	-
Goods and Services						
Stationery				73 (95)	17,438	10,815
Administrative Procedures				66 (86)	24,318	16,122
Debt						
Debt amount				24 (31)	2,166,667	3,832,517
Interest amount				24 (31)	90,417	119,445

*Caregivers SD: Standard Deviation

Source: Own elaboration

Table 3. Direct Costs of Caring for Patients with Chronic Non-Communicable Disease

Variable	Family		Patients	
	Average	SD	Average	SD
Food	461,623	250,965	108,052	119,759
Housing	367,769	268,164	36,156	62,933
Transport	128,753	179,962	37,039	48,578
Communication	116,844	96,562	10,390	25,942
Healthcare Services	22,643	48,298	64,779	122,602
Goods	-	-	37,376	24,324
Total	-	-	324,207	313,440

SD: Standard Deviation

Source: Own elaboration

Table 4. Indirect Costs of Caring for Patients with Chronic Non-Communicable Disease

Variable	Patients			Caregivers		
	n	Average	95 % CI	n	Average	95 % CI
Number of Hours						
Before	23	8	6 to 9	29	10	9 to 12
After	11	4	2 to 6	29	8	7 to 10
Income						
Before	23	747,826	638,258 to 857,394	29	1,007,924	811,655 to 1,204,192
After	11	500,000	324,814 to 675,186	29	950,690	733,169 to 1,168,210

Source: Own elaboration

These findings indicate that more than half of the people with NCDs are women at an average age of 70, classified as socioeconomic stratum two, with primary education level attained, housemakers, and with a high level of dysfunction or dependency. Four out of every five caregivers are women, approximately half of them have secondary education, dedicated to household work, and concerned about the financial cost of caring for a family member with NCDs. As for direct no-medical costs, about 9 to 29 % of costs are attributable to patient care, for which the most representative expenses are health, food, housing, transport, and communication, respectively. The average total cost of patient care was 324,207 pesos per month.

Regarding the perspective of cost and care, in the cost study from the care of patients with chronic NCDs conducted by Campos et al., one of the main factors that increase costs is the decrease in self-care of the hospitalized person, besides the shift between hospital admission and discharge. Costs during recovery increase due to the need for having a caregiver and additional therapies, in addition to the time it takes for patients to return to their daily life (5).

In a similar study conducted by Sanchez et al. with 92 families in the Andean Region of Colombia, a high financial burden was found in terms of additional money to be spent, namely, on health services, transportation, housing, food, and communication, among others (19). These findings are coherent with those reported in 30 dyads in Guatemala City, as well as those in this study since the biggest cost was health. Other costs were significant but differed slightly in their order (20). In addition, families in the Andean Region spend a monthly average of 349,617 pesos on food, of which 28 % is spent on patient care. These values are lower than those presented in this study, which are 461,623 pesos and 37 %, respectively. Sánchez concludes that it is necessary to rely on public health policies and establish strategies that allow families and patients to reorganize their lifestyles (19).

Out-of-Pocket Health Care Costs

Financial protection, through public or private health insurance, reduces the amount people pay directly for health care. However, in some countries, the burden of out-of-pocket expenses can still create barriers to access and use of health care. Direct non-medical costs include expenses incurred for treatment outside the patient's healthcare system such as out-of-pocket expenses and charges borne by the patient when their health insurer - neither public nor private - covers the full cost of the services. Households facing difficulties in paying medical bills may delay or even forego necessary care. In the Organization for Economic Co-operation and Development (OECD) countries, an average of 19 % of health expenditure is paid for directly by patients (6).

Out-of-pocket expenses depend on people's capacity to pay. As health care financing becomes more dependent on out-of-pocket expenditures, the burden will be shifted to those who use services most and possibly to low-income households, where health care needs are greater. Many countries have adopted policies to protect specific population groups from overpayment, such as partial or total exemptions from social assistance, benefits for the elderly or people with chronic diseases or disabilities (6).

These expenditures in OECD countries in 2013 ranged from less than 1.5 % of total household consumption in Turkey, the Netherlands, France, the United States, and the United Kingdom to more than 4 % in Korea, Switzerland, and Greece. In these countries, 2.8 % of average household expenses were on healthcare goods and services (6).

A directly proportional relationship between the use of health services and out-of-pocket expenditures in households of patients with NCDs can be found. Out-of-pocket health care costs are about 40 % of total health expenditures in Latin America, for which the highest expenses are focused on NCDs. In Colombia, out-of-pocket expenditures in households with a patient with NCDs are twice as high as in a household without this condition (21). In this study, health costs constitute 16 % to 20 % of the total cost of patient care and 8 % of total household consumption expenditure. However, the Government has been implementing different strategies to reduce this situation in recent years, such as expanding health coverage, leveling out health plans, providing benefits between contributory and subsidized regimes, and exempting patients with NCDs (21).

The findings of this study are coherent with those reported by Gallardo et al.: out-of-pocket health care expenditures mainly include transportation, co-payments, medications, and photocopies (3). As for out-of-pocket expenses in patients with respiratory pathologies, more than 90 % of them were affected by co-payments for care and transfers. In addition, 56 % of the users indicated that utilities are the highest payment due to the use of oxygen (22).

Indirect costs

Families and health systems incur high costs for NCDs care, which mainly affects the poor and vulnerable population. Cardiovascular diseases are probably the greatest threat to long-term economic development, given their frequency, direct effects, health care and indirect costs (21).

A study that evaluated indirect costs in Colombian patients with respiratory diseases, such as asthma, concluded that indirect costs constitute a significant burden for patients and their families. The number of emergency department consultations in the last year, the duration of hospitalization, the days of sick leave and the days of limited work are similar to those reported in studies conducted in other countries (22).

Regarding indirect costs in this study, 61 % of the patients used to work before becoming ill and earned, on average, a minimum wage. After becoming ill, this percentage decreased to 29 % and among those who continued to work, there was a 50 % reduction in daily working hours and a reduction of income in 33 %. For caregivers, 76 % were engaged in any remunerated economic activity. However, upon becoming caregivers, the number of working hours per day was reduced from 10 to 8 and their earnings were reduced by 6 %. Furthermore, regardless of whether the caregiver is engaged in paid economic activities or not, caregiver burden is considered to be an additional effort made to meet the needs of the sick person, which is most often unknown and unquantified (23).

In addition to the reduction in working hours and, thus, in the income of both patients and caregivers (who are usually their children), most families from low socioeconomic stratum earning a minimum wage income are mainly affected in their capacity and potential for human development in vulnerable groups. These findings are in line with the PAHO analysis of human development and economic growth related to NCDs, in which, with the reduction in working hours and human capital skills, income decreases as well as technology change, which is fundamental for a country's economic growth, may be slowed down. In addition, working time and disposable income should be devoted to the care of people with NCDs, which decrease savings. This leads to the delay in human development and the persistence of poverty in an intergenerational economic growth context (21).

Furthermore, a study of diabetes in Colombia revealed that the total annual cost of controlled diabetes care is US $1,015 million (US $435 million in direct costs and US $580 million in indirect costs). In addition, the annual direct costs for patients with heart disease represent 24 % and 55 % for indirect costs. Indirect costs of diabetic retinopathy (5 %) double direct costs (2 %) (24).

Health burdens of NCDs represent high economic and social costs that can affect the quality of life and finances of patients and their families. Furthermore, it can increase inequality gaps between those with less income and those with more income, perpetuating patterns of poverty and vulnerability (18). In addition, women generally take on the role of caregivers for chronically ill, disabled, and elderly family members without any remuneration or affiliation to the social security system. Despite the great social value of the caregiving role, women's insertion and permanence in the formal economy is hampered. Therefore, when they get old and sick, they have to confront a deficit in economic resources, social services and health (1).

Therefore, one of the targets of the third sustainable development goal is to reduce by one third NCDs mortality by 2030 (25) through the formulation, financing and development of evidence-based, comprehensive multisectoral policies (18). To this end, the World Health Organization (WHO), through different partnerships, has been working since 2011 on cost-effective and evidence-based interventions (26). Afterward, WHO developed the Global Plan of Action for the Prevention and Control of NCDs 2013-2020, highlighting fifteen interventions as the most cost-effective and feasible interventions (27).

Meanwhile, the Chilean social protection system of the Ministry of Social Development has gradually developed and implemented the National Support and Care System (SNAC) to accompany, promote and support dependent individuals and their support network through actions at home and in the community (28). Similarly, an Uruguayan Law on Care (Law 19,353) was passed in 2015 to structure the National Care System, which aims to improve the lives of children, the elderly, people with disabilities and dependent people through different actions such as the provision of comprehensive care, training actions for caregivers, both paid and unpaid. This was made possible thanks to the coordination of the Ministries of Social Development, Education and Culture, Labor and Social Security, Public Health, and Economy and Finance (29).

Conclusions

Costs related to the care of chronically ill patients were estimated at 324,207 Colombian pesos per family in this article. The most significant costs were health, food, housing, and transportation, affecting family dynamics as they face not only an increase in costs but also a decrease in income. This is because, in half of the cases, the person being cared for was responsible for household finances: 60 % used to work before they became ill and half of them stopped working after they became ill. The other half had a reduction by 33 % in their income. In the case of caregivers, this reduction was by 6 %, which perpetuates the patterns of intergenerational poverty and health inequity.

Therefore, the need to continue to generate evidence at regional and national levels on the effect of NCDs on social and economic development, as well as to assess the costs and benefits of applying prevention and control measures in specific contexts according to the country and the frequency of NCDs on socio-economic inequalities is important (18). In particular, it is essential to analyze information that is difficult to obtain such as the costs of accessing healthcare services provided by informal caregivers and the potential income of both patients and unpaid caregivers (26).

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