Journal of Cancer Policy 28 (2021) 100272

Contents lists available at ScienceDirect

Journal of Cancer Policy

journal homepage: www.elsevier.com/locate/jcpo

The financial impact of a terminal cancer on patient's families in Colombia – A survey study

Esther de Vries [a,*], Oscar Elías Vergara-García [b], Sofía Karduss-Preciado [b], Valentina Baquero Castro [b], Sara Prieto Rodríguez [b], Martín Sánchez Forero [b], Valentina Beatriz Manjarres Tromp [b], Jose A. Calvache [c,d]

[a] *Department of Clinical Epidemiology and Biostatistics, Faculty of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia*
[b] *Faculty of Medicine, Pontificia Universidad Javeriana, Bogota, Colombia*
[c] *Department of Anesthesiology, Universidad del Cauca, Colombia*
[d] *Department of Anesthesiology, Erasmus University MC Rotterdam, the Netherlands*

ARTICLE INFO

Keywords:
Financial toxicity
Cancer
Colombia
Low-and middle income countries
Caregivers

ABSTRACT

Aim of the study: The socio-economic impact of caring for a cancer patient in the family is unknown in Colombia. This survey aimed to evaluate the existence of financial burden caused by cancer on the caregiving families of terminally ill patients.

Methods: We used the Covinsky Family Impact Scale in a telephone survey with families of patients who died from cancer between May 2019 and June 2020 in three Colombian hospitals.

Results: We obtained answers of 176 caregivers, of whom 74.4 % indicated to have experienced at least one hardship of the Covinsky items. The most commonly reported financial hardship involved the use of all or most of the family savings for the care provided to the patient (45.6 %); 27.6 % indicated that a major source of family income was lost. A quarter (25 %) postponed educational or other important plans of family members and 10–11 % indicated to have moved to another home or postponed medical treatments.

Conclusion: In Colombia, a country with universal health coverage, substantial financial impacts of terminal cancer care exist not only for patients, but also for family members and other caregivers. The system is failing to avoid financial toxicity of cancer among this group.

Policy summary statement: Informal caregivers are of vital importance for cancer patients but also to the healthcare system, particularly in LMICs. It is very important for policy makers to consider the hardships, not only emotionally but also financially, that the care for a (terminally ill) cancer patient implies on caregivers.

1. Introduction

Financial toxicity is defined as "the adverse impact of a cancer diagnosis on a patient's financial well-being resulting from direct or indirect costs [1]. However, cancer is a disease which affects not only patients but also their families in many aspects: physically, emotionally and often also economically. The socioeconomic impact of having to take care of a terminal cancer patient on a family is even less studied than the impact on the patients themselves. The underlying causes of such impacts may be related to the costs of treatment but also to indirect costs such as absence from work of patient and caregiver, transportation and in some cases translocation to the city where the treatment facilities are located. All of the above (increased spending and declining income) can create significant economic hardship in the family nucleus of cancer patients or other caregivers. Whereas financial toxicity has potentially greater effect in low- and middle-income countries (LMICs), research on this topic is mainly limited to high-income countries [2].

Colombia has implemented a large healthcare reform in the 1990s, resulting in a coverage of health insurance of now almost 100 % of the population. The healthcare system in Colombia covers treatment of all types of cancer, but the standard coverage does not imply authorization or provision of the most modern or efficient treatments – many of those are not in the "standard package" and in order to get the costs covered, physicians and patients must enter additional and wasteful

---

* Corresponding author at: Programa Doctorado en Epidemiología Clínica, Departamento de Epidemiología Clínica y Bioestadística, Facultad de Medicina, Cra. 7 No 40-62 Edificio Hospital San Ignacio, Piso 2, Bogotá, Colombia.
E-mail address: estherdevries@javeriana.edu.co (E. de Vries).

https://doi.org/10.1016/j.jcpo.2021.100272
Received 5 January 2021; Received in revised form 10 January 2021; Accepted 31 January 2021
Available online 10 February 2021
2213-5383/© 2021 Elsevier Ltd. All rights reserved.

administrative processes. Frequently, the patient must go to the judicial system to obtain financing through a "*tutela*" (legal route to ask for patient's rights) or pay for the treatments out of pocket [3,4]. Patients and caregivers also must bear indirect costs such as transporting the sick and accompanying person to hospitals, often in different cities, which imply additional costs for lodging and food. Many have to pay out-of-pocket for nurses to perform home-care [5].

The socio-economic impact of caring for a cancer patient is unknown in Colombia. This is, to our knowledge, the first relatively large survey to measure the financial burden caused by cancer on the caregiving families of terminally ill patients.

2. Materials and methods

Since there is no uniform tool to assess financial toxicity among caregivers specific for LMICs, we decided in this first survey on the topic in Colombia to use the Covinsky Familiy Impact Survey (CFIS). The CFIS was first described by Covinsky et al. in 1994 [6]. It consists of questions on experienced hardships resulting from illness of either the patient himself or caregivers, such as: Has the patient's illness meant having to use all or most of the family's savings? In our study, the questions were asked from the caregivers' perspective – domains included were illness or stress among family members, loss of income, loss of family savings, ability to pay for medical care or education of family members, moving to less expensive housing. We performed a telephone survey with families of patients who died from cancer between May 2019 and June 2020 in three hospitals, two in the capital city (Instituto Nacional de Cancerología and the Hospital Universitario San Ignacio in Bogota) and one in the smaller city Popayán (Hospital Universitario San José in Popayán). These patients were identified by research staff when they were in terminal phases of their disease and at least two months after their death their caregivers were contacted by telephone, asking them to participate in a study regarding the end of life of the patient, the questionnaire of which included the questions of the CFIS [6]. Data were summarized as frequency measures.

This project was approved by the Medical Ethics and Research Committees of the Pontificia Universidad Javeriana/Hospital Universitario San Ignacio and the Instituto Nacional de Cancerología – Hospital Universitario San José adhered to the medical ethics process performed by the former. All family members provided a verbal consent to participate.

3. Results

For 238 of the total of 348 identified deceased patients there were correct contact data of caregivers available, of whom 176 were interviewed – the remainder did not want to participate (N = 33) or did not answer the phone at the scheduled moment of interview nor replied to later phone calls (N = 29). All caregivers were family members of the cancer patients – whose characteristics are provided in Table 1. The patients were mostly living in urban areas, most had an educational level of maximum high school and affiliation to the contributive health insurance scheme, implying they or their partners had a formally paid income.

We obtained answers to the questions of the CFIS from the vast majority of caregivers, but, depending on the answers, there was always a small group that did not answer (maximum 10 (5.6 %) of the total sample without answer) (Table 2). Of all caregivers, 74.4 % indicated to have experienced at least one of the items of the CFIS; 45.6 % indicated that they or others in the family became ill or unable to function normally because of the stress of the illness.

The most commonly reported financial hardship (45.6 %) involved the use of all or most of the family savings for the care provided to the patient and 27.6 % indicated that a major source of family income was lost. Smaller but still important proportions of 25 % postponed educational or other important plans of family members and 10–11 % indicated to have moved to another home or postponed medical treatments.

Table 1

General characteristics of included patients' (n = 176).

Variable	n	%
Mean age in years (SD)		
Sex		
Male	82	46.6
Female	94	53.4
Educational level		
Primary and High school	115	65.3
Superior education	57	32.3
Unknown	4	2.3
Health care insurance		
Subsidized	72	40.9
Contributive	104	59.1
Cancer type		
Solid tumour	149	84.6
Haematological disease	16	9.1
Unknown	11	6.3
Area of residence		
Urban	132	75.0
Rural	42	23.9
Other	2	1.1

Table 2

Responses to Family impact survey.

	% Yes (No/Total with answer)	Missing answers
Others in the family became ill or unable to function normally because of the stress of the illness	45.6 % (78/171)	5
Most of the family savings was lost/used to take care of the patient	45.2 % (75/166)	10
A major source of family income was lost	27.6 % (47/170)	6
A major change in family plans was made because of the costs related to the illness		
Moved to a less expensive home	10.8 % (18/167)	9
Delayed medical care for another family member	11.6 % (20/172)	4
Altered educational plans for another family member	25.6 % (44/172)	4
Suffered any of the above adverse impacts	74.4 % (131/176)	0

The sample size was too small to study between-group differences with sufficient power to draw firm conclusions, but the supplementary Table 1 shows relatively uniform results with exception of the proportion of families for whom the major source of income was lost, this seemed to be a bit more common when the patient was male and had an educational level of high school or less.

4. Discussion

It was no surprise that in Colombia, as elsewhere, financial impacts of terminal cancer care exist not only for patients, but also for family members and other caregivers. However, in a country with a universal health coverage and with a large proportion of the patients being from Bogotá (implying no need to move to another city to receive care) we were surprised of the proportion of caregivers indicating the use of most or all of their savings, and smaller but important proportions of having to postpone medical treatment or education for themselves or other members of the family.

Literature consistently shows financial toxicity for cancer patients in both the active care phase and end-of-life phases; interestingly, from the USA there are reports that costs in the end-of-life phase are often substantial, partially related to high costs of hospitalizations and the use of additional anticancer treatments in these advanced stages of cancer [7]. Patients who received hospice care had much lower expenditures. Small-scale initial studies show that in Colombia, a very high proportion of patients received potentially unnecessary treatments at the end of life of cancer patient [8,10] and very high proportions of patients dying in hospital [9], indicating that potentially a better weighing of patients′ needs in this last phases of life and working on the provision of palliative care, preferentially home-based, throughout the country could improve quality of death and dying as well as reduce financial costs to patients and caregivers as well as the healthcare system.

Limitations of this study include the limited level of detail on the financial impacts, we do not know the exact costs, nor what were the exact causes of the financial hardships (such as travel costs, absence from work costs, medication co-payments, etc.). Yet, this first approximation to this topic shows the scale of the problem and justifies future, more detailed studies. Preliminary results from a qualitative study among terminally ill cancer patients in the same institutions show that financial hardship of the patient arose because of high costs of certain medication, which is not covered by the Universal Healthcare System, the loss of work of the patient himself (Colombia has no real unemployment benefits) or of caregivers because of incompatibility between caregivers′ tasks and work obligations (supplementary Table 2). Another limitation is the limited generalizability of the study: with three participating institutions in two cities. However, the Colombian population largely lives in (very) large cities, others in a more rural area – the two cities involved in our study represent that, with Popayan serving mostly rural and indigenous populations.

Informal caregivers are of vital importance for cancer patients but also to the healthcare system, particularly in LMICs. It is very important for policy makers to take into account the hardships, not only emotionally, physically but also financially, that the care for a (terminally ill) cancer patient implies on caregivers. We believe that results such as ours can help identify and prioritise interventions on short-term and long-term policies. Wider, nationally representative studies are needed to better understand this problem, with tailor-made instruments being developed and obtaining details on the sources of the costs for the care of the cancer patient in order to understand and therefore address this important topic better.

Financing institution

Supported by Minciencias, in the framework of the "777-2017 Convocatoria para proyectos de ciencia, tecnología e innovación en Salud 2017", project CT-826-2018 - Decisiones médicas al final de la vida en pacientes oncológicos en Colombia".

Role of the funding source

The funding source had no influence in the design, data analysis, interpretation nor the writing of the manuscript. None of the authors were paid to write this article. All authors had full access to the full data in the study and accept responsibility to submit for publication.

Author contributions

- Conception and design of study: EdV, JAC.
- Analyses and interpretation of data: all authors.
- Drafting the paper: EV, JAC.
- Comments and adjustments to draft: OEVG, SKP, VBC, SPR, MSF, VBMT.
- Final approval of manuscript: all authors.

Declaration of Competing Interest

The authors report no declarations of interest.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.jcpo.2021.100272.

References

[1] R. Lentz, A. Benson, S. Kircher, Financial toxicity in cancer care: prevalence, causes, consequences, and reduction strategies, J. Surg. Oncol. 120 (1) (2019) 85–92, https://doi.org/10.1002/jso.25374.

[2] B.S. Poudyal, S. Giri, S. Tuladhar, et al., A survey in Nepalese patients with acute leukaemia: a starting point for defining financial toxicity of cancer care in low-income and middle-income countries, Lancet Haematol. 7 (9) (2020) e638–e639, https://doi.org/10.1016/S2352-3026(20)30258-1.

[3] R. Guerrero, A.I. Gallego, V. Becerril-Montekio, et al., The health system of Colombia, Salud Publica Mex. 53 (Suppl. 2) (2011) s144–55.

[4] E. de Vries, G. Buitrago, H. Quitian, et al., Access to cancer care in Colombia, a middle-income country with universal health coverage, J. Cancer Policy 15 (Part B) (2018) 104–112, https://doi.org/10.1016/j.jcpo.2018.01.003.

[5] A.N. Páez Esteban, C.C. Torres Contreras, M.S. Campos de Aldana, et al., Direct and indirect costs of caring for patients with chronic non-communicable diseases, Aquichan 20 (2) (2020) e2022, https://doi.org/10.5294/aqui.2020.20.2.2.

[6] K.E. Covinsky, L. Goldman, E.F. Cook, et al., The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, JAMA 272 (23) (1994) 1839–1844, https://doi.org/10.1001/jama.272.23.1839.

[7] B. Hanratty, P. Holland, A. Jacoby, et al., Financial stress and strain associated with terminal cancer–a review of the evidence, Palliat. Med. 21 (7) (2007) 595–607, https://doi.org/10.1177/0269216307082476.

[8] D.N. Cuadrado Franco, L. Torregrosa Almonacid, F. Gempeler, Tratamientos no proporcionados al final de la vida en pacientes fallecidos en un hospital universitario de 4 nivel, 2019. Available from: http://hdl.handle.net/10554/41059. (Accessed 20 Dec 2020).

[9] Y.J. Valdivieso Prada, E. de Vries, Factores asociados al lugar de muerte de personas con cáncer a partir de análisis de datos administrativos, 2014-2017, Colombia, 2020. Available from: http://hdl.handle.net/10554/49892. (Accessed 20 Dec 2020).

[10] P. García Padilla, C. Ordóñez Reyes, P. Medina, G. Fernández Deaza, O. Lucía Morales, R. Murillo, (Intervenciones médicas no proporcionales al final de la vida en un hospital de alta complejidad en Colombia) Non-Proportional Medical Interventions at the End of Life in a High Complexity Hospital in Colombia, Colombia Medic (2021), https://doi.org/10.11144/Javeriana.umed62-1.pppu.