

Care for All: Palliative Care Strategy to Provide Intensive Acute Symptom Control Management for Patients with Previously Undiagnosed Terminal Cancer

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Abstract

Introduction: Despite the fact that important reforms in the Mexican health system have allowed it to offer coverage to 95% of Mexicans, important differences continue to exist in health service quality. The Fund for Protection Against Catastrophic Expenditures allows people with some types of cancer to receive expensive treatments, however, the timely diagnosis of some neoplasms in primary and secondary stages continues to be inefficient and delayed diagnosis is not rare. The present work describes a strategy model implemented by the Palliative Care Service of the Instituto Nacional de Cancerología (INCan) in Mexico City to provide acute symptomatic management to individuals with advanced cancer without antineoplastic treatment options.

Patients and Methods: Patients considered on preconsultation as patients on a terminal stage of the disease were sent to the Palliative Care team on the very same day. In a process that lasted 3 hours on average, patients and their families received medical, psychological, and nutritional care.

Results: From January to December 2010, a total of 564 patients with advanced, terminal-stage cancer without prior antineoplastic management were treated at the palliative care unit. More than half of them were considerably underprivileged, with little to no schooling, and suffering from five or more symptoms at the time of their diagnosis. The majority of them presented fatigue and severe pain, and none had received treatment with strong opioids.

Average survival was 36.6 days.

Conclusion: Timely diagnosis of cancer continues to be an important challenge for the Mexican health system, a pattern that is, understandably, most notable amongst the patients living in poverty. The model implemented at the Institution avoids costly, unnecessary treatments, affording patients and their families' specialized, humanitarian, and ethical care.

Keywords: Advanced cancer; Acute palliative care; Acute symptomatic management; Terminal phase; Quality of death; Popular insurance; Bioethical aspects

Introduction

The increment of life expectancy at birth in the last decades has been key in documenting the improvement of health conditions in the Mexican population. The country finds itself in an advanced phase of demographic and epidemiological transition in which chronic diseases have become the main cause of death [1,2]. Ninety five percent of the Mexican population has basic health insurance coverage through social security programs for people with formal employment, and a voluntary scheme called Seguro Popular for people who are unemployed; the country's most vulnerable population. Seguro Popular finances medical care for primary- and secondary- care-level interventions. [3-7] Similarly, by means of the Fund for Protection Against Catastrophic Expenditure, care is provided to those with diseases that are significantly more expensive due to their degree of complexity or specialty; this care includes all of the pediatric cancers and some of the more frequently found neoplasms in adults. [3-8] However, with over one half of Mexicans living in poverty and high

marginalization in 52.7% of the country's localities, there are important differences in access to and quality of medical services, particularly for the most vulnerable parts of population. [8-13] As is the case with other middle-income countries, there is an emphasis in the prevention and treatment of diseases which leaves care for terminally ill far from being a priority. [8,14-16] Among the chronic diseases with a rapidly increasing incidence, cancer in Mexico has become a serious public health issue that should be approached with multidisciplinary ambitions; through programs ranging from education toward prevention and early detection of some neoplasms, to the possibility of providing palliative care to those in the terminal stages [12,13,16,17]. Unfortunately, the larger part of diagnosed neoplasms in Mexico are caught an advanced stage, which means a smaller chance of remission and high costs for their diagnosis and treatment, in addition to the suffering patients and their families must endure [17-20].

Being diagnosed with cancer is understandably flanked by great anxiety and the frequent desire to receive treatment regardless of whether or not they will benefit from it. [21-23] Recently, the need for ensuring the best treatment while avoiding unnecessary costs for patients and their families has been made evident to both medical

oncology societies and governments. However, it is not easy for physicians to determine the best option for patients with advanced cancer with low functional status, especially if this implies not offering antineoplastic treatment. Doing nothing has 100% morbidity and 0% efficiency. It is in this scenario that expensive therapies that rarely benefit the patients are instituted [24-28]. The Instituto Nacional de Cancerología (INCan) is an autonomous entity of the Mexican Ministry of Health (SS); a research and high technology center that offers specialized care to cancer patients over the age of 18 from all over the country. To be admitted to the hospital, patients must have a cancer diagnosis, an initial appointment is scheduled at the preconsultation where the patients are evaluated by an oncologist with the purpose of channeling patients to specific hospital services according to tumor type, clinical stage, etc. Those patients considered to have advanced terminal stage cancer, with important comorbidities, low functional status (Karnofsky scale <50%; Eastern Cooperative Oncology Group [ECOG], 3 or less) and with histology with poor response to neoplastic treatments [29,30] (a stage at which antineoplastic therapy does not afford any benefit due to disease progression or poor activity level), were not admitted to receive full care at the institution. This study describes a palliative care strategy used by the Palliative care service at INCan in which patients in the most advanced stages of their disease are provided intensive acute management to alleviate their symptoms before they are referred to the secondary or primary health care services.

Patients and Methods

After the initial evaluation at the preconsultation, those patients considered to have end stage disease were informed on the day of their arrival at the INCan of the diagnosis, the prognosis of the disease and of the reasons for which no antineoplastic therapy was feasible. Because of the large number of patients seen at the institution, poor prognosis and limited resources, these patients were not admitted to receive full care at the hospital. Aware of the important ethical questions and medical implication of this decision the INCan authorities instructed the Palliative Care Service to develop an intensive acute symptomatic relief strategy as an option to receive treatment at the institution. The Program of Care and Symptomatic Attention for patients with terminal stage cancer (PACO) were developed with the aims to provide an integral palliative symptomatic treatment to the patients and their families in a one-day-visit to the hospital.

Patients who decided to enter the PACO program were evaluated by the medical team of Palliativists, who employed the Edmonton Symptom Assessment Scale (ESAS) for symptom evaluation, [31] the Palliative Prognostic Performance Scale, [32] and the Palliative Prognostic Index (PPI). [33] With this information in addition with the oncologist evaluation, the Palliative team, gave detailed information to the patients and their relatives about the objectives and philosophy of palliative care, emphasizing the palliative, symptomatic, non-antitumoral character of the care, before they were asked to sign the Informed Consent forms. All patients, in accordance with Palliative Service management protocols, were seen by the medical team (medicine, nursing, nutrition) and the psychosocial care teams (psychiatry, psychology, and social work); the patients' families received an introductory talk on the disease, its management and symptoms, and the most relevant aspects of palliative home care. All patients received acute and intensive symptom management, weekly follow-up and tele-follow-up through our virtual care center

Telemedicine, as well as continued contact with their primary-care physician and the possibility of requesting home visits.

Results

From January to December 2010, 7,359 patients were evaluated at the INCan preconsultation, out of which 76% (5,595 patients) met the requisites for admission to the institution (diagnosis or suspicion of cancer, sick people without social security or another federal medical service). 90% of the patients admitted to the INCan during 2010 were candidates for antineoplastic treatment (surgical, radiotherapy, chemotherapy), however, the 564 patients with advanced, terminal-stage cancer, poor activity level, and poor prognosis, were not considered candidates for any disease-modifying treatment and were offered the option of receiving acute palliative symptomatic treatment. A provisional chart number was given (PRZ), allowing them to have access to medical procedures and fill their prescriptions at the hospital pharmacy (particularly opioids).

Demography

Demographic variable		Value
Number of patients		564 patients
Age (years)	Median	65 years old
	Range	19–95 years
Gender (%)	Masculine	39
	Feminine	61
Monthly income (received in Mexican pesos)	Median	\$192.00 USD*
	Range	\$61.5–538.00 USD
Schooling (years)	Median	3 years
Place of residence (%)	Federal District (D.F.) and suburban areas	62
	Morelos State, Hidalgo State, State of Mexico	38

Table 1: Socio demographic characteristics of the patients (\$13.00 Mexican pesos/\$1.00 U.S. dollar (USD)).

In Table 1, the socio demographic characteristics of the patients are described. The patients' average age was 65 years old (in a range from 1 to 95 years old), and more than half of them were women (61%). Similar to the majority of the patients seen at this institution, monthly incomes per-family are low (median income, \$2,500.00 Mexican pesos) and they are people with poor or little schooling (median, 3 years). In fact, 34% of the patients are illiterate (Table 1). The majority of the patients treated were residents of the Mexico City Federal District (D.F.) and suburban areas, however, one fourth of the patients came from neighboring states (Morelos, Hidalgo, and the State of Mexico), investing an average of 4–6 hours of travel to the INCan.

Medical characteristics

None of the patients had received antineoplastic treatment, 48% of the patients were cared for exclusively at the primary-care level at Health Centers (6%) or private general physicians (42%) for variable time periods (6-12 months) prior to establishing a diagnosis of cancer and their being referred to the INCan. Among the studies requested by

the patients' physicians, we found Computed tomographies (CT), x-rays, endoscopies, Ultrasound (US) studies, various laboratory studies and, on occasion, Magnetic resonance (MR) and Positron emission tomography (PET). The established treatment included surgery (incomplete surgical interventions or laparotomies), analgesics (non-opioids), anti-inflammatory drugs, Proton pump inhibitors (PPI), prokinetics, antacids, and antibiotics. It is noteworthy that an important percentage of sick people were transported to the Institution from general (40%) or high specialty hospitals (12%). In general, this group of patients was found to have greater physical deterioration. Despite multiple symptoms, including severe pain, the patients were not approached adequately and strong opioids were not prescribed. The most frequent tumor sites in these patients were bile ducts, pancreas, and liver (30%), followed by digestive tract (18%) and unknown primary (17%); this all in contrast with the patients seen with the most frequently seen tumors at the institute and in the country, which include breast (3%), uterine cervix (3%), and prostate (2%) [18] (Table 2).

Tumor site	%
Bile ducts., pancreas, liver	30
Stomach and digestive tract, colon, and rectum	18
Unknown Primary site	17
Kidney	7
Ovary	6
Lung	5
Sarcomas	3
Cancer of the uterine cervix	3
Breast	3
Prostate	2
Hematological neoplasm	2
Other sites	4

Table 2: Cancer sites

Activity level (Karnofsky Performance Scale and Palliative Activity Scale) in 87% of patients was less than 50. 72% of the patients had five or more symptoms, among which severe pain and fatigue were the most frequent (Figure 1), while more than half of these subjects were found to be cachexic (61%) and/or delirious.

Average stay at the institute of this group of patients was 36.6 days (median, 11 days; range, 1–270 days). Nearly half of the patients died during the first week. Only 3% of patients had a survival of more than 6 months, 85% passed away at their own homes, 5% in clinics or private hospitals. On average, three calls were made for follow up purposes with patients/relatives.

The INCan Palliative Care Service established a strategy of acute symptomatic management for these patients referred for pre consultation. On the same day as their arrival at the institute, they were evaluated by the Palliative Care Service and informed of their diagnosis, treatment options, prognosis, and the objectives of palliative care, while the family information and the training necessary for the patient's care, means for comfort, and administration of medical

treatment. Referral strategies were established for primary-level care, as well as the orientation necessary for establishing telecontact with the Service and management of the administrative paperwork that must be taken care of in case of the patient's death at home. On average, this process lasted 3 hours. No patient was hospitalized.

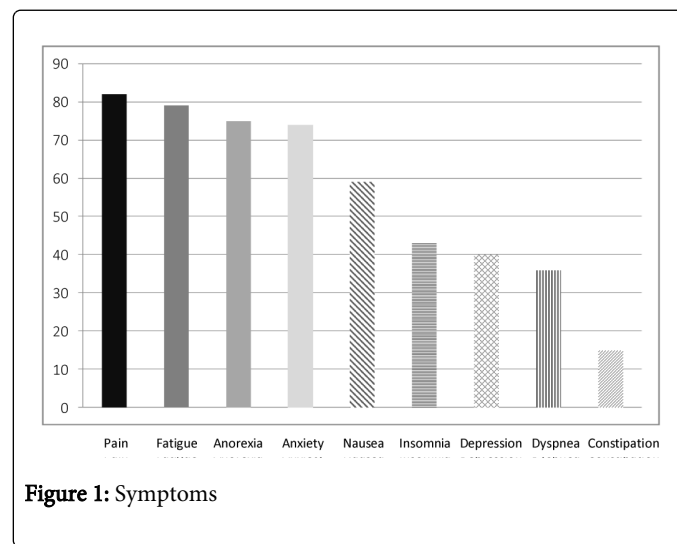


Figure 1: Symptoms

Discussion

In Mexico, the right to health forms part of the individual's social rights, that is, the State is obliged to guarantee and protect the individual, offering a series of benefits and the means necessary for satisfying the needs related to it. [12,32] According to official data, 95% of the population has basic health insurance coverage through a complex and fragmented health system. [31,33] However, affiliation with health services is not a sufficient indicator for measuring access to and use of health services, nor of the quality of these.

According to National Evaluation Council of Social Development Policy (CONEVAL), although lack of access to health services has lessened, indicators of timely access to health care and effective access to health services has not undergone a similar variation, [12] and in this work, this evaluation has been confirmed.

In many communities, especially in rural ones, the out-of-pocket expenditure for healthcare is high because it implies the transportation costs to health care units. These people reside in communities with a single health care center, where only mobile phone is available, where there are only primary care health services, or where there are no hospitals. This situation becomes more serious when the patient's health problems are more complicated, or when issues such as those described in this paper arise.

This work sheds light on the important inequalities that exist in regards to availability, accessibility, implementation and quality of health services in a population with important economic and academic limitations.

In a country in which the median monthly income is approximately \$190 USD, it is interesting to note that nearly half of these patients were cared for by general physicians in the private sector; they were submitted to multiple diagnostic studies and received treatments that implied high out-of-pocket expenses. It is important to mention that the greater part of the patients had tumors for which there are no early detection strategies. However, the symptomatology of these patients is

important, particularly severe pain, treated only with Non-steroidal anti-inflammatory drugs (NSAIDs), antispasmodic drugs, myorelaxants, and some patients referred from secondary and tertiary level hospitals with weak opioids.

The objective of this study was not to evaluate the economic impact of the strategy; however, the choice to keep patients with such advanced neoplasms out of the hospital and without treatment options, provides the opportunity to use the finite care and medical resources on patients in whom treatment could either improve chances of survival or quality of life.

Management of these complex cases in which patients and their families feel – understandably – deflated, are not an easy task and it ideally requires a multidisciplinary team that can handle informing patients and their families of the prognosis, disease, psychological distress and multi-symptomatic medical management. The process itself is not a quick one since, on average; three hours are devoted to each patient and his/her family.

Cancer is a complex problem, and its adequate treatment requires a significant infrastructure with important expenses for the health system [23-27]. The increase in life expectancy and chronic diseases such as cancer make strengthening health services urgent, especially for the most vulnerable patients requiring integral and timely care.

It is important to mention that the low incidence of patients in terminal stage admitted to PACO with the most frequent types of cancer (breast, uterine cervix and prostate). The availability of the Popular Insurance scheme for the treatment of these types of cancer, allows to provide anti tumor treatments for the patients with this types of cancer.

Conclusion

The decision not to implement anticancer treatment to end stage cancer patients raises important ethical and medical questions. The present study shows the need for acute palliative provided to oncological patients who are too late for an anticancer treatment.

This represents a highly vulnerable population with a great bioethical impact due to the complexity of its characteristics: low economic resources; low academic level, and few opportunities for receiving care in the health system.

The strategy implemented by the institute to offer exclusively symptomatic treatment avoids costly and unnecessary treatments, providing specialized, humanist, and ethical care for the patients and their families.

References

1. Populations Projections 2010-2050. Department of Interior (Proyecciones de la Población 2010-2050. Secretaría de Gobernación) CONAPO.
2. Frenk J, Bobadilla JL, Sepúlveda J, López-Cervantes M. (1989) Health transition in middle-income countries: new challenges for health care. *Health Policy Plann*; 4: 29–39.
3. Frenk J (2006) Bridging the divide: global lessons from evidence-based health policy in Mexico. *Lancet* 368: 954-961.
4. Dirección General de Información en Salud, Secretaría de Salud, México (2005) [Mexico's mortality statistics. Deaths registered in 2003]. *Salud Publica Mex* 47: 171-187.
5. Popular insurance medical coverage (Cobertura Médica del Seguro Popular).
6. Universal Health Care Services catalog (Catálogo Universal de Servicios de Salud) (CAUSES) (2012).
7. (2012) Fund to prevent Catastrophic Health Expenditure (Fondo de Protección Contra Gastos Catastróficos), Apéndice A.
8. (2010) OECD Perspectives: Mexico Key Policies for Sustainable Development.
9. Alternatives for rural people living in poverty to generate sustainable income: Diagnosis (Diagnóstico: alternativas de la población rural en pobreza para generar ingresos sostenibles) Mayo de 2010 Secretaría de Desarrollo Social.
10. (2012) Poverty in Mexico. Results of poverty in Mexico 2012 at the national level and by States. (Pobreza en México. Resultados de pobreza en México 2012 a nivel nacional y por entidades federativas). Consejo Nacional de Evaluación de la Política de Desarrollo Social (CONEVAL).
11. (2006) Policy Note: Poverty Alleviation by Directorate for Employment, Labour and Social Affairs September. OCDE.
12. Access and use of the health services of people affiliated to The Popular insurance Plan: Indicators. National Council of Evaluation of Social Development Policy (Indicadores de acceso y uso efectivo de los servicios de salud de afiliados al Seguro Popular Consejo Nacional de Evaluación de la Política de Desarrollo Social) (CONEVAL).
13. Gutiérrez-Delgado C, Guajardo-Barrón V. (2009) The double burden of disease in developing countries: The Mexican experience, in Chernichovsky D, Hanson K (Editors). *Innovations in Health System Finance in Developing and Transitional Economies (Advances in Health Economics and Health Services Research. Vol. 21. Emerald Group Publishing Limited; 3–22.*
14. Neal RD, Allgar VL (2005) Sociodemographic factors and delays in the diagnosis of six cancers: analysis of data from the "National Survey of NHS Patients: Cancer". *Br J Cancer* 92: 1971-1975.
15. Grant L, Brown J, Leng M, Bettiga N, Murray SA (2011) Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *BMC Palliat Care* 10: 8.
16. Cancer Care: Assuring quality to improve survival. FOCUS ON HEALTH November 2013. Directorate for Employment, Labour and Social Affairs.
17. Epidemiological profile of malignancies in Mexico. Ministry of Health Undersecretary of Prevention and Health Promotion General Direction of Epidemiology. SINAIS/SINAVE/DGE/SALUD/ (Perfil epidemiológico de los tumores malignos en México. Secretaría de Salud Subsecretaría de Prevención y Promoción de la Salud Dirección General de Epidemiología). SINAIS/SINAVE/DGE/SALUD 2011.
18. (2012) Estimated Cancer Incidence, Mortality and Prevalence Worldwide. Mexico: World Health Organization.
19. Knaul FM, Nigenda G, Lozano R, Arreola-Ornelas H, Langer A, et al. (2008) Breast cancer in Mexico: a pressing priority. *Reprod Health Matters* 16: 113-123.
20. Mohar A, Bargalló E, Ramírez MT, Lara F, Beltrán-Ortega A. (2009) Available Resources for breast cancer treatment in Mexico (Recursos disponibles para el tratamiento del cáncer de mama en México). *Salud Publica Mex*: 51; S263–S269.
21. Schofield PE, Butow PN, Thompson JF, Tattersall MH, Beeney LJ, et al. (2003) Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol*; 14: 48–56.
22. Butow PN, Thompson JF, Tattersall MH, Beeney LJ, Dunn SM (2003) Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol*; 14: 48–56.
23. Fojo T, Noonan A, Grady C (2011) How much is life worth: the multibillion dollar question in contemporary oncology. *J Clin Oncol*; XXX. 79–81.
24. Lippert TH, Ruoff HJ, Volm M (2014) Could a revision of the current guidelines for cancer drug use improve the quality of cancer treatment? *Ther Clin Risk Manag* 10: 69-72.
25. Schnipper LE, Smith TJ, Raghavan D, Blayney DW, Ganz PA, et al. (2012) American Society of Clinical Oncology identifies five key

-
- opportunities to improve care and reduce costs: the top five list for oncology. *J Clin Oncol* 30: 1715-1724.
26. Peppercorn JM, Smith TJ, Helft PR, Debono DJ, Berry SR, et al. (2011) American society of clinical oncology statement: toward individualized care for patients with advanced cancer. *J Clin Oncol* 29: 755-760.
27. Smith TJ, Hillner BE (2011) Bending the cost curve in cancer care. *N Engl J Med* 364: 2060-2065.
28. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K (1991) The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 7: 6-9.
29. Anderson F, Downing GM, Hill J, Casorso L, Lerch N (1996) Palliative performance scale (PPS): a new tool. *J Palliat Care* 12: 5-11.
30. Morita T, Tsunoda J, Inoue S, Chihara S (1999) The Palliative Prognostic Index: a scoring system for survival prediction of terminally ill cancer patients. *Support Care Cancer* 7: 128-133.
31. Gómez Dantés O, Sesma S, Becerril VM, Knaul FM, Arreola H, et al. (2011) [The health system of Mexico]. *Salud Publica Mex* 53 Suppl 2: s220-232.
32. World Health Organization. The right to Health Consulte don line lud.
33. Frenk J, Gómez-Dantés O (2008) To inderstand Mexican Health System. México, D.F. Nostra Ediciones: 60.