

Symptoms and End-of-Life Experiences of Mexican Health and Aging Study Participants Who Died of Cancer

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Abstract -

Introduction: The aim of this study was to describe the symptoms and end-of-life experiences of older Mexicans who had participated in the baseline Mexican Health and Aging Study (MHAS) and died of cancer within 2 years.

Methods: We conducted a retrospective study by reviewing the participants' demographics, diseases and symptoms, and access to health care during the last year of life, as provided by their widows/widowers or other family members and used statistical analyses to determine the frequency of symptoms and identify associations between the symptoms and access to health care.

Results: A total of 91 participants were included in our analysis, and 59% died at home. Older age was associated with not being affiliated with a health care source ($p = .04$). Poor appetite was reported for significantly more patients who died at home than for those who died in a hospital (52% vs 48%; $p = .04$). Respondents reported severe pain in 55% of the participants. Younger participant age was significantly associated with reports of severe pain; the mean ages at death of participants with and without reports of severe pain were 69.5 and 75.1 years, respectively ($p = .02$).

Conclusions: Palliative care programs in Mexico must provide home care

services, offer coverage to patients lacking affiliation for health care and improve the access to pain management services.

Keywords: Cancer, Terminal Care, End-of-life, Mexico

I. INTRODUCTION

Cancer is among the leading causes of death in the world, and 70% of all cancer-related deaths worldwide occur in low- or middle-income developing countries¹. In Mexico, patients tend to be diagnosed with cancer in advanced stages², and for many of them, pain control and palliative care are the recommended options for care.³ Despite the large proportion of patients diagnosed with advanced cancer, palliative care services are not fully integrated into the Mexican health care system. The physicians who specialized in palliative care tend to practice in tertiary care hospitals located mostly in the metropolitan areas. In Mexico, more than half of cancer-related deaths occur at home³; however, evaluations of these patients' symptoms and their access to care at the end of life have not been reported. Caring for patients dying of cancer at home may be particularly challenging because these patients tend

to be older and live in less urbanized and less affluent areas.

Collecting information about the end-of-life experiences could help physicians and health planners to understand the barriers to accessing care, identify preferences for end-of-life care, and define the unmet needs of these patients and their families in order to develop better services.

As home care services tend to comprise only medical visits and prescription deliveries, family members become the main caregivers for patients with cancer. Caregivers of loved ones dying at home must provide help with activities such as bathing, eating, walking, scheduling medical appointments, refilling prescriptions, administering medications, and housekeeping. Including their perspectives about the diseases and symptoms suffered by their loved ones at the end of life, is an initial step in understanding the needs of those who die at home.

In this study, we aimed to identify the end-of-life experiences of patients ≥ 50 years old who died of cancer in Mexico to determine their access to care, learn about their illnesses and symptoms, and identify the presence of pain during their last year of life.

II. METHODS

To accomplish this retrospective study, we retrieved data from participants of the Mexican Health and Aging Study (MHAS). The MHAS baseline survey was conducted in 2001 and targeted Mexicans 50 years and older. A follow-up survey attempting to contact the initial participants was completed in 2003. We selected participants of the

2001 survey who had died of cancer at the time of the follow-up survey, which was consequently completed by each deceased participant's surviving spouse or another family member. The details of the survey content and data collection methods have been reported previously⁴⁻⁶.

The MHAS survey data are publicly available, and personal identifiers were removed prior to their release. Our study was approved and declared exempt from the requirement to obtain informed consent by The University of Texas M. D. Anderson Cancer Center Institutional Review Board.

We collected data on the relationship of the respondent to the deceased (widow/widower or other family member), the place of death of the deceased (in a hospital or at home), and the access to health care during the last year of the life of the deceased (affiliated to receive care with an institution or a private provider; number of visits to a physician; and days spent in a hospital). We also collected data about the demographic characteristics of the deceased, including their age at death, sex, marital status (married vs. non-married), years of education, and the size of the town of their usual residency before death (<100,000 residents vs. $\geq 100,000$ residents; rural vs. urban, respectively). We also recorded whether the death had occurred in the same town of their usual residency and whether someone had temporarily moved during the last year of life of the deceased to help with his/her care. Additionally, we obtained information about the participants' illnesses and symptoms during the last year of life. We reported the mean number of illnesses and symptoms of participants and identified

the illnesses and symptoms reported for >50% of the deceased.

Informants were asked if the deceased experienced pain most of the time during the last year of life, and if the respondents answered yes, they were prompted to categorize the pain as mild, moderate, or severe. Based on this information, we dichotomized pain as not present or not severe (including mild or moderate), and severe. The rationale for this classification was to provide data on the patients more likely to need specialized pain control. We also determined whether at the moment of death participants lost ≥ 5 kg of body weight as compared to the weight they had 12 months before death and whether they needed help to perform the activities of daily life during the last 3 months of life; we classified these variables as dichotomous (yes/no). The survey was used to calculate up to 25 diseases and symptoms recalled by the respondent during the last year of the participant's life. The questions were typically worded as follows: "During the last year of life of X, did the doctor say X had pneumonia?" These responses were also categorized as dichotomous (yes/no) variables.

III. STATISTICAL ANALYSIS

All statistical analyses were conducted using SPSS Predictive Analytics Software version 17. We examined frequencies and measures of central tendency and reported numbers (with percentages) for categorical variables and means (sd) or medians for continuous variables. We used univariate analysis to determine whether age, sex, health care affiliation or place of death

was associated with symptoms reported for >50% of the deceased.

We evaluated pain separately and used univariate analysis to determine whether age, sex, affiliation source for health care, or place of death was associated with pain. Additionally, we evaluated whether the respondent's relationship to the deceased (widow/widower or other family member) and the size of the town of usual residency (urban/rural) were associated with severe pain. For the univariate analyses, we used two-tailed *t*-tests or chi-square tests, as appropriate. When we found associations between independent and dependent variables, we used logistic regression to adjust for potential confounders such as age, affiliation for source of health care, or sex. For all analyses, $p < 0.05$ was considered statistically significant.

IV. RESULTS

When the MHAS follow-up survey was conducted in 2003, a total of 529 participants had died. Among them 92 [17%] died of cancer. After exclusion of one case with unknown place of death a total of 91 cases remained for study.

The mean and median time elapsed from the baseline survey until death was 11.8 and 11 months. The widow/widower was the respondent in 41% of the follow-up interviews. The responses showed that 16% of the participants had required someone to move temporarily to their homes in the last year of life to help with their care; in 73% of these instances, the person who moved to the participant's home was a close relative, such as a daughter, son, or grandchild.

The participants' mean age at death was 72 years and 48 [52%] of them were women. The demographic characteristics of the participants are shown in Table 1. Responses to the follow-up survey showed that 73 [88%] of the participants had a source of health care by affiliation to an institution or private company, and 79 [86%] had access to some type of cancer treatment. Their access to health care was also reflected in the number of days they spent in hospitals and the number of times they visited physicians during the last year of life. Nevertheless, we found that older age was significantly associated with not having affiliation to a source for health care ($p = .04$), and compared to those who died in a hospital, more participants who died at home were not affiliated to receive healthcare (7% vs. 17%; not significant). The majority of the deceased (78%) needed help for activities of daily life during the last 3 months of life but the number of visits to a physician or days in hospital were not associated with needing help for the activities.

The median number of diseases and symptoms reported was 9.1 (range 0–18). No associations were found between age, sex, place of death, or affiliation to a source for health care with the total number of symptoms reported. The most frequent symptoms and diseases reported were weight loss of ≥ 5 kg 76 [84%] participants, poor appetite [71%], depression [63%], severe fatigue [63%], severe pain [55%], pain in the legs when walking [55%], and cough [51%]. Table 2 shows a detailed list of the symptoms and diseases included in the survey. A higher proportion of participants who died at home had lost weight than those who died in a hospital (63% vs. 37%; $p =$

.06), indicating that the place of death was marginally associated with weight loss. The place of death was significantly associated with reports of poor appetite, as respondents suggested that a higher proportion of participants who died at home had poor appetites than those who died in a hospital (52% vs. 48%; $p = .04$). We did not find associations between age, sex, place of death, or affiliation to a source for health care and reports of depression, severe fatigue, pain in the legs when walking, or a persistent cough.

Only 28 respondents [31%] reported no pain during the participant's last year of life; 50 [55%] reported severe pain and 13 [14%] reported mild or moderate pain. When we dichotomized the reports of pain in severe vs. not severe or not pain as reported by respondents, we found the mean age of the participants without reports of severe pain was 75.1 (sd 11.8) years and the age of participants with reports of severe pain was only 69.5 (sd 10.8) years ($p = .02$). This association remained significant after we adjusted for the source of information (widow/widower vs. other family member) and the place of usual residency (urban vs. rural).

V. DISCUSSION

According to their families, the MHAS participants who died of cancer suffered a large variety of symptoms during their last year of life. The majority of the participants died at home, and at the time of their death, more than two-thirds of the of the participants had lost at least 5 kg and needed help to perform the activities of daily life. Prior to their death, more than

half of the participants had poor appetites, a persistent cough, had depression, severe fatigue, and pain in their legs when walking. Overall, the mean number of symptoms experienced by the participants was nine (Table 2), and more than half had severe pain. Poor appetite and weight loss were reported for more participants who died at home than for those who died at hospitals; older participants were significantly less likely to be affiliated to a source of healthcare; and younger ones more likely to report severe pain.

These findings may help to define the clinical characteristics of patients dying of cancer in Mexico as well as to identify groups of patients lacking access to appropriate palliative care. Palliative care programs should include home care services and train personnel to provide management for pain and mood disorders, maintain nutrition, and administer physical therapy, in addition to other palliative interventions and therapies already indicated for patients with advanced stages of cancer.

From the health policy perspective, the finding that old age was associated with not being affiliated to a source of healthcare is an important observation and indicates that older patients with cancer lacked of access to a regular source of care at the end-of-life. Because of the probability of suffering of more comorbidities than younger patients with cancer, older patients may need more complex palliative care that could be better coordinated if having a regular source of health care.

Other researchers have reported on the pain and other symptoms of patients with cancer in Mexico. Allende et al.⁷ evaluated a group of 100 patients admitted to hospitals and found that 89%

had pain and 29% had severe pain. The difference between the numbers of reports of severe pain in the studies may be due to the tools for measuring pain severity, study design, or recall bias. Allende et al. used a scale from 0 to 10 to assess pain severity, with 0 representing no pain at all and 10 representing the worst pain a person could imagine. The MHAS survey had only 3 categories to measure the severity of pain (mild, moderate, severe). In their study, Allende et al. asked patients directly about their pain; however, the MHAS survey relied on the memories and opinions of the widows/widowers and family members to assess the participants' pain, thus potentially introducing recall bias about the information elicited. The family members may have been more prone to report the presence of a disease or symptom when the interviewer listed or mentioned it, perhaps contributing to an overestimation of some diseases and symptoms reported.

One limitation of this study is the small sample size, which could led to the observation of the marginal association between the place of death and the reported loss of weight; nevertheless, this finding could be useful in directing future research toward the needs of older Mexicans with terminal chronic diseases.

The strength of this study is the inclusion of participants who died at home. By reviewing family members' responses about the participants' diseases and symptoms, this study provides valuable information about the experiences of those dying at home. This information could help to select topics to be explored in future assessments of the needs, barriers, and outcomes of older Mexicans with chronic diseases

particularly those with advanced cancer. The results of the assessments should guide interventions to improve the coverage of, access to, and quality of palliative care in Mexico.

In summary, our study demonstrated that according to their families, those who died of cancer in Mexico suffered an average of nine symptoms during the last year of life, including a high proportion of reports of severe pain. We also observed the majority died at home and the older group of participants lacked of affiliation to a source of health care. These findings suggest palliative care programs in Mexico must provide home care services, target older patients lacking affiliation to a regular source for health care and improve the access to pain management services.

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1 *Table 1. Demographic characteristics of the participants and their access to health care.*

Characteristic	N (%)
Total	91 (100)
Married	54 (59)
Education, years (median)	3.5 (3)
Lived in a town with 100,000 or more residents	58 (63)
Died in the town of usual residency	72 (79)
Died at home	54 (59)
Affiliated for source of health care ^a	73 (88)

Received treatment for cancer ^b during the last year of life	79 (86)
Needed help with activities of daily living during the last 3 months of life	71 (78)
Stayed overnight in a hospital during the last year of life	79 (86)
Mean number of days spent in a hospital during the last year of life, days	20
Visited a physician during the last year of life	77 (84)
Mean number of visits to a physician	17

a. Affiliation to one or more institutions including Instituto Mexicano del Seguro Social, Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado, Secretaria de Salud, Secretaria de la Defensa Nacional, Secretaria de Marina, Petroleos Mexicanos, a private clinic/hospital, or Red Cross/Green Cross

b. Includes chemotherapy, surgery, radiotherapy, or pain or symptom control

Table 2. Diseases and symptoms suffered during the last year of life.

Disease/Symptom	N (%)
Mean number of diseases and symptoms reported, sd	9.1, ± 4.6
Weight had decreased by ≥5 kg	76 (84)
Poor appetite	65 (71)
Depression	57 (63)
Severe fatigue	57 (63)
Severe pain	50 (55)
Pain in the legs when walking	50 (55)
Cough	46 (51)
Swelling in feet or knees	45 (49)
Stomach pain or diarrhea	39 (43)
Dyspnea when lying down	36 (40)
Frequent vomit	35 (38)
Dizziness or vertigo	34 (37)
Sweating while sleeping	30 (33)
Falling during the last year of life	30 (33)
Intense thirst	28 (31)
Temper out of control	25 (27)
Frequent confusion	24 (26)
Involuntary bladder movements	21 (23)
Pain or burning while urinating	21 (23)
Kidney or liver infection	13 (14)
Bleeding while going to the bathroom	12 (13)
Bleeding while coughing ^a	11 (12)
Illness related to memory	6 (7)
Pneumonia	2 (2)
Tuberculosis	0

^asite of bleeding unspecified