Review

Research on Palliative Care in Mexico. Scoping review

Investigación sobre Cuidados Paliativos en México. Revisión Sistemática Exploratoria

Abstract

The normative process initiated with the reforms to the General Health Law in 2009 has paralleled the institutionalization of Palliative Care and the development of academic and research work in our country. With the objective of describing the scientific activity developed in the area of palliative care in Mexico in the last 25 years, a scoping review was carried out to describe the characteristics of research papers published in scientific journals. Descriptive statistics were calculated, and content analyzed. We found 608 articles, selected 81. The first report was publisher 1992; the year with the most publications was 2013 with 19.

The national journal that most covered the subject was Gaceta Medica Oncologica, at the international level was Psicooncologia. The most recurrent themes are professional attitudes/decisions, end-of-life care and activities of hospice teams. The most studied disease is cancer. Those who maintain the leadership in the publications are doctors with clinical and epidemiological perspectives, in journals of low impact and national distribution.

Keywords

Palliative Care, scientific activity, scoping review, Mexico, end of life care.
Resumen

La institucionalización de los Cuidados Paliativos y el desarrollo del trabajo académico y de investigación en nuestro país ha sido paralelo con el proceso normativo iniciado con las reformas a la Ley General de Salud en 2009. Con el objetivo de describir la actividad científica desarrollada en el área de Cuidados Paliativos en México en los últimos 25 años, se realizó una revisión sistemática exploratoria para describir las características de los trabajos de investigación publicados en revistas científicas. Se calcularon las estadísticas descriptivas y se analizó el contenido. Encontramos 608 artículos, seleccionamos 81. El primer artículo data de 1992, el año con más publicaciones fue 2013 con 19.

La revista nacional que más abordó el tema fue Gaceta Médica Oncológica, a nivel internacional fue Psicooncologia. Las temáticas más recurrentes son: actitudes/decisions de los profesionales, cuidados prestados al final de la vida y actividades de los equipos de cuidados paliativos. La enfermedad más estudiada es el cáncer. Quienes mantienen el liderazgo en las publicaciones son médicos con una mirada clínica y epidemiológica, en revistas de bajo impacto y distribución nacional.

Palabras clave
Cuidados paliativos, actividad científica, revisión sistemática exploratoria, México, cuidado al final de la vida.

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Introduction

The World Health Organization (WHO) defines Palliative Care as "the active total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount." Palliative care includes the family and is attended by a multidisciplinary team. In 2002, the WHO specified that every person who has a progressive and advanced disease has the right to receive palliative care. The current epidemiological context characterized by the aging of the population and the increase of chronic degenerative diseases—whose progression in most cases is towards advanced and terminal stages—makes the need to know and to apply palliative care a pressing matter.

The background of the current concept of palliative care is found in the first efforts to control pain, mainly regarding cancer. However, the source nearer to the current definition is derived from the work of Dr. Cicely Saunders at St. Christopher’s Hospice in London. In 1967, after ascertaining that patients with pain and in terminal stages did not receive adequate treatment, she suggested rethinking the procedure in these cases. She coined the term "total pain" to emphasize that pain is not limited to a physical expression but is a total experience for the patients that include anxiety, depression, and fear, the worry about the grief that will afflict the family, and often the need to find meaning in the situation, a deeper reality in which to trust. This rethinking is so important that, from this moment, hospices with this approach were developed in England to meet the demand at the National Health Service for the care of patients with cancer and terminal illnesses. It laid the foundations to deploy a comprehensive international approach for the care of these patients, considering not only their needs but also the needs of their families and people close to them, with interdisciplinary work, and social support.

In Mexico, palliative care emerges as a movement to control pain in cancer patients, stemming from the increase of this disease and epidemiological reports. In 1996, the Mexican Association for the Study and Treatment of Pain convened a group of experts, the Cocoyoc Group, to analyze, propose, and modify the regulation and control of opioids. At this moment, work began to establish the Official Mexican Standard (NOM in Spanish) for the practice of pain medicine and palliative care. A consensus was reached in the management of cancer pain in 2006. Pain clinics were developed in the various institutions in the country, which encouraged many algologists to train as palliative doctors. Discussions began in the legislature about legal changes in the management of pain with opiates and palliative care. In December 2009, the decree establishing reforms to the General Health Law (LGS in Spanish) was published in the Official Journal of the Federation (DOF in Spanish). The modified articles were: 166 Bis (palliative care for terminally ill patients); 3rd frac. II and XXVII bis (medical care and comprehensive treatment of pain); and 33 frac. IV (palliative medical care activities by a multidisciplinary professional team). On December 31, 2010, the National Palliative Care Program (PALIAR in Spanish) was initiated.

On November 5, 2013, the decree amending and adding various provisions to the LGS regulation regarding the provision of healthcare services was published in the DOF. On December 9, 2014, NOM-011-SSA3-2104 was published, establishing the criteria for the care of terminally ill patients through palliative care. On December 26 of the same year, the General Health Council’s agreement was published in the DOF making obligatory the integral management schemes in palliative care. Added to this normative process was the institutionalization of palliative care service in the different health systems.

There also was academic and research work devoted to this area to identify the development of palliative care and the needs and evaluations of specific therapeutic actions through reviews, reports, and research with cross-sectional studies. In 1996, the Ethics and Humanities Subcommittee of the American Academy of Neurology stated: "Many patients with neurologic disease die after
Objective

To describe the scientific activity developed in the area of palliative care in Mexico in the last 25 years. We are interested in knowing who writes, where, and what they write.

Methods

A scoping (systematic exploratory) review\textsuperscript{10,11} was carried out to offer a general description of the characteristics and current knowledge of the research work in palliative care in Mexico, published in scientific journals during the period from 1990 to 2015. We reviewed the following databases: PubMed, SciELO, CONRiCyT, Scopus, and Web of Science. The search criteria were: ("palliative care" [MeSH Terms] OR ("palliative" [All Fields] AND "care" [All Fields]) OR "palliative care" [All Fields]) OR (end [All Fields] ] AND ("life" [MeSH Terms] OR "life" [All Fields])) OR ("terminal care" [MeSH Terms] OR ("terminal" [All Fields] AND "care" [All Fields]) OR " terminal care "[All Fields]) AND ("mexico" [MeSH Terms] OR "mexico" [All Fields]). The selection criteria used were: articles published during the period from January 1990 to December 2015, in peer-reviewed scientific journals, whose main topic was palliative care, and whose content made reference to works or research with samples of patients, caregivers, and health professionals in Mexico. The exclusion criteria were: works that had not been done in Mexico and which were not scientific publications (e.g. letters to the editor, news, indicators, bibliographic reviews, conference proceedings, posters, guides, and triptychs). The search was conducted by four researchers who subsequently selected the articles through the title, abstract, and full reading of the article. We found 608 articles of which we selected 116. Thirty-five of these were discarded in the peer review because they were: not focused on palliative care (23), international multicentre studies (4), standardization studies of scales not centered on palliative care (3), editorial works (3), unpublished work (1), a congress report (1). In total, 81 articles were included in an Excel database. (Figure 1)

Synthesis and Analysis of Data

The following data were obtained: author, title, journal, year of publication, study design, participants, context, theme, and indexation. The data were entered into an Excel database and analyzed together. The descriptive statistics were then calculated and the content of the studies analyzed.

Results

The first publication was made in 1992, and from then to 2005 the articles were sporadic. By 2006 publications increased, and from then to 2011 there was an average of 4.1 articles per year. From 2012 to 2015 there was a significant increase, and 2013 was the year with the most publications (19 articles). The journal that most published works on palliative care was the Mexican Oncology Gazette.

We found that the publications writing about palliative care were 72.8% national (59) and 27.2% international (22). The Mexican Oncology

Consequently, the question that motivates this investigation is: What are the characteristics of palliative care research work in Mexico published in scientific journals during the period from 1990 to 2015?

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Gazette had the most articles on palliative care—17 in total—with cancer the main theme. In the International field, Psycho-Oncology is the journal where Mexican researchers published the most.

In order to know the academic impact of the journals, we used the evaluation parameters of the Regulation for the Admission, Promotion, and Permanence to the Institutional System of Researchers in Medical Sciences of the current Ministry of Health. According to this regulation, articles can be classified from group I to VII ascending in the qualitative classification of periodic scientific journals and the impact factor allocated by the publication of the 2014 Journal Citation Report. Of the works reviewed, 60 belong to group I (74.1%), 10 to group II (12.3%), and 11 to group III (13.6%).

Sixty-eight articles were written in Spanish (84%) and 13 (16%) in English. The journals publishing the most were focused on neoplasms. There are six international journals whose main topic is palliative care, and only one of them publishes in Spanish. In Mexico, there is no publication dedicated to palliative care. The most studied condition with a palliative approach is cancer (33.3%) and those who write on this subject are mostly multidisciplinary teams headed by doctors. One of the working groups that have published the most on the subject belongs to the Palliative Care Service of the National Cancer Institute.

Regarding the topics reviewed, we found that the most recurrent were attitudes and decisions of professionals regarding palliative care and care provided at the end of life. (Table 1)

The diversity of issues did not allow for an integrated review; however, it allowed us to describe the most representative topics. The articles categorized as professional attitudes/decisions were written during the period from 1996 to 2015, and 2013 was the year with the highest productivity at six articles (26%). With regard to attitudes, they explore social representations,
meaning, and beliefs (fear, experiences, etc.) about palliative care. Regarding decisions, they evaluate knowledge, skills, problems in pain management, informed consent management, and physicians’ positions regarding palliative care.

The works on care provided at the end of life were carried out in the period from 2006 to 2015, and 2014 was the year with the highest productivity at seven articles (44%). In general, these were proposals, recommendations, and measures to improve the care of patients in the terminal stage and the benefits that this provides for a dignified death.

In order to classify the articles by type, we reviewed the description indicated in the text of the work (classification granted sometimes by the journal itself) and found: 38 original articles, 6 clinical cases, 13 trials, and 24 reviews. However, a more detailed reading of the content was made, classifying the works according to the type of study and we found: review of the topic (33), descriptive studies (32), retrospective review (5), clinical cases (5), qualitative approach (2), intervention studies (2), exploratory studies (1), and instrument validation (1).

### Table 1. Thematic categorization of the review of palliative care studies (n=81).

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
<th>%</th>
</tr>
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<tr>
<td>Attitudes/decisions of professionals</td>
<td>23</td>
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</tr>
<tr>
<td>Care provided at the end of life</td>
<td>16</td>
<td>19.8</td>
</tr>
<tr>
<td>Activity of the palliative care teams</td>
<td>9</td>
<td>11.1</td>
</tr>
<tr>
<td>Review on the subject</td>
<td>9</td>
<td>11.1</td>
</tr>
<tr>
<td>Management of pain, agitation, sedation of patients</td>
<td>6</td>
<td>7.4</td>
</tr>
<tr>
<td>Transmission of bad news</td>
<td>4</td>
<td>4.9</td>
</tr>
<tr>
<td>Needs of informal caregivers</td>
<td>4</td>
<td>4.9</td>
</tr>
<tr>
<td>Legal and juridical aspects</td>
<td>4</td>
<td>4.9</td>
</tr>
<tr>
<td>Validation of measuring instruments</td>
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<td>Ethical dilemmas</td>
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</tr>
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<td>Spirituality</td>
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<td>1.2</td>
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Table created for this study by its authors.

### Discussion

In the present review, it is clear that the research was initially focused on attitudes and knowledge of physicians and health personnel, which were certainly necessary given the little knowledge on the subject in our country. Progressively, the range of research topics was broadened to include matters such as the type of palliative care provided, team development, and some revisions. Maintaining the leadership in publications on palliative care are physicians with a clinical and epidemiological perspective in journals that, according to the classification and the criteria used, are of low impact and limited distribution.

Another element we found is that, since it’s a discipline in development, the research in Mexico uses models and instruments developed in other populations that do not necessarily consider the cultural, social, structural, economic and political conditions, or even the morphological characteristics of our population and context.

The fact that the topics most addressed in Mexico are the attitudes and beliefs of the health personnel and the conceptual review of the subject reveals at least two dimensions to reflect on: 1. The uncertainty in which many doctors work on
the conceptualization and application of palliative care—an example of this is the lack of consensus in key terms such as terminal illness, terminality, and palliative sedation, among others. Adding a lack of clear criteria on the application and interpretation of regulations and administration, it generates defensive attitudes from doctors as well as from patients and family members. 2. Another issue of great relevance that deserves analysis is that the concept and application of palliative care transforms some fundamentals and practices on which modern medicine is based—specifically the paradigm of healing and the paternalistic model in the doctor-patient relationship. This could be related to the institutional structuring of palliative care services and the reluctance of some physicians to apply these measures in a timely and appropriate manner.

As noted in the results of the review, in our country (as well as internationally), there is still a tendency to focus strictly on cancer as the only object of palliative care application in contrast to the recommendations by the WHO and the British Health System, both of which emphasize the need to extend research and palliative application in other chronic and advanced diseases such as amyotrophic lateral sclerosis, chronic renal insufficiency, refractory heart failure, or advanced HIV/AIDS, dementia, and frailty in the elderly, among others. 2

Aspects such as pain, and especially the use of opiates, have been poorly reported. Just a few data on their use in pain control: high-income countries consume 92% of the morphine produced for therapeutic purposes against only 8% of low-income countries (83% of the world population).13 One reason for this omission in Mexico is the limited approach to the topic in medical schools because opioid management is touched tangentially and left to specialties such as anesthesiology in the curriculum. This school deficiency has resulted in general practitioners and many specialists not using them, even when indicated. Another problem shared by many doctors and some of the general population is the myth about the dangers implied in their therapeutic use and their relationship with addictions, specifically regarding morphine. A structural limitation was the difficulty to obtain a prescription for narcotics, which was resolved in early 2016 through a resolution by the Federal Commission for the Protection against Sanitary Risks facilitating electronic prescriptions.

It is interesting to mention our observation that palliative care publications and their qualitative content are related to the political and legislative work on the subject. Stemming from the 2009 changes in the General Health Law, its regulation, and NOM-011, there has been an increase in the number of publications as well as diversification in themes regarding this research. However, issues such as living wills, capacity and autonomy in patients with advanced and terminal illnesses, and the right to die are still under discussion in the legal, clinical and institutional areas.
Conclusion

What we can conclude is that the application of palliative care is extremely complex, both in its conceptualization and in its implementation. There are many topics to review such as the bioethical dilemmas, the psychological and subjective implications, the social structures that underlie the decision making, the cultural construction of death, and the administrative needs in the field of public health, which is to say, a broader approach and more inclusive of other disciplines such as sociology, anthropology, psychology, and law. We propose there should be a more direct junction between palliative care programs and scientific and academic work.

Conflict of Interest
The authors declare they have no conflict of interest.

Funding
No funding was received for the realization of this work.
References

Review

Palliative Care in Mexico


