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Palliative care research in Latin America

Latin America (LA) is a developing region and although palliative care (PC) has been upscaled over the past 20 years, there has been very limited research activity.

Most treatment protocols, assessment tools and educational PC material come from developed countries. But there are significant differences between these countries and LA (for example, socioeconomic and cultural issues, different causes of morbidity and mortality). Consequently, the information generated in developed countries often has limited applicability in LA. To meet the needs of patients in the region with the available resources, palliative care workers need to carry out research.

Current status

A search on MEDLINE of publications on PC in indexed journals showed that only 81 out of a total of 54,521 were from Latin American authors.[1] According to these figures, research activity is almost non-existent (<1%).

There is also an indeterminate number of regional papers that are published in general media, medical and PC journals, that are presented in regional and national PC meetings; for example, 95 papers were accepted for presentation at the 7th Latin American Congress of PC in Montevideo (Uruguay) and 84 at the 8th Latin American Congress of PC in Isla Margarita (Venezuela).

This rough evaluation of research activity based on the publications and submissions on PC from Latin American authors shows that there is an unknown, small amount of unshared heterogeneous research.

The preliminary results of an online survey conducted to obtain current information about the status of PC research in Latin American countries[2] showed that slightly more than half of the people surveyed had carried out some kind of research activity in the last five years. It also showed that those who have training in research or receive specific technical assistance carried out more research than those who do not.

The resulting situation is that limited information is available on how and where people die, on interventions for symptom control and on clinical, organisational and economic issues related to the provision of PC. It is assumed, rather than known, what patients and families need and receive at the end of life. The value of PC is anticipated rather than demonstrated.

There are several reasons for this but the most important barrier is that in 80% of Latin American countries PC is not recognised as a discipline. This has a negative impact on research activity: resources are limited, the availability of trained researchers and training opportunities are scarce and, consequently, knowledge and expertise in research are minimal.

Challenges

Research is a pending task of the development of PC in LA. In LA there are resources to carry out research, and people who are committed to do research in palliative care.

The Asociación Latinoamericana de Cuidados Paliativos (ALCP) has a unique role in identifying and solving the challenges of research activity. We hope to obtain information about the regional PC status and to assist individuals and programmes to start or optimise research activity with two current initiatives.

1. The development of a regional database (with the assistance of the National Hospice and Palliative Care Organization [NHPCO], the Sociedad Española de Cuidados Paliativos [SECPAL] and the Worldwide Palliative Care Alliance [WWPCA]) posted on the ALCP website to map the nature and extent of PC across LA. The data collection process will start in 2007. The database will develop in three stages over several years:
    - Stage one – identification of regional providers; contact information, 2007
    - Stage two – providers' demographics. Patients' demographics; services provided, 2007
    - Stage three – outcomes, measurement and evaluation, 2008.
2. The development of a regional research task force with the following objectives:
    - To increase communication about research activity and, if possible, to develop a network
    - To formulate a research agenda according to regional needs
    - To develop protocols for multicentre studies, according to the research agenda and the available resources
    - To support those who conduct research (technical information, data analysis, software, grants and so on)
    - To monitor both offers of, and requests for, technical assistance and fulfilling them to ensure accomplishment of the project's goals and objectives.

LA needs support from developed countries to carry out these research activities. The developed countries have collaborated actively in the dissemination of PC and supporting research is a way to improve this. There have been various concrete efforts to collaborate, but in many cases the timing and the personnel were not adequate.

We are confident that we can enter a new, organised and productive era of collaborative and progressive research activity. It will allow us to answer questions about the suffering of dying patients and their families, PC providers, epidemiological issues, the quality and magnitude of the use of existing knowledge, and organisational and economic factors. This information may result in the regional increase of excellent PC ■

1. De Lima L, Harding R, Higginson I. Pallliative care research in the developing world: how can we move forward? 9th EAPC Congress, Aachen, 2005.
2. Wenk R, de Lima L, Eisenchias J. Palliative care research in Latin America. Current status and challenges. 4th EAPC Research Forum, Venice, 2006.

Roberto Wenk and Liliana de Lima, ALCP, Argentina

Morphine booklet in Latvian

One thousand copies of a booklet about morphine will be soon published in Latvian. The target audience is family doctors and those involved in primary care where PC patients receive the basic care and treatment. The booklet may also be of interest to doctors from other specialties, patients, relatives and other interested persons. It will be distributed free of charge to family doctors, medical nurses, students, residents and specialists at lectures and seminars.

Morphine is still the firstline opioid, the cheapest and the most studied drug in the strong opioid class. The booklet will consist of two parts: the first part will contain general knowledge about morphine, mechanisms of action, management of side-effects and combinations of drugs. The second part is constructed in ‘question and answer’ form. This includes the most frequent questions from patients to doctors about morphine and strong opioids in general, both short-acting and prolonged substances. Answers will explain different myths about morphine in society, correct usage, managing chronic pain, which should be considered as a disease itself, both cancer-related and in non-malignant conditions. There is still a strong belief that morphine can be used only in cancer and that its use indicates a well-advanced disease or a terminal condition. Many patients with incurable diseases suffering from pain are still concerned about the problem of addiction. There is still a lack of knowledge about dependence; pseudo-dependence syndrome, when the patient is undertreated and the dosage of opioids is not sufficient; and the problem of tolerance.

The above-mentioned problems are well known to PC specialists but still poorly recognised by family doctors, patients and their relatives. Public education should be extended.

At the beginning of 2006 the booklet, *Tramadol in clinical and outpatient practice* was published in Latvian, where similar problems were discussed. This booklet became popular in Latvia, especially with family doctors. Clinical information was extended and explained in regional conferences, where free discussion with specialists was available.

Education on different levels is the most important factor in disseminating PC. This concerns not only Latvia but other countries as well. Better understanding of PC by patients and their relatives, doctors and policy makers will lead to the development of palliative care as an integral part of fundamental medicine and care. By being a well-organised system, rather than separate units with scattered specialists and a lack of knowledge, PC can survive and develop dynamically, showing good management of different problems on biopsychosocial, spiritual or existential levels ■

Vilnis Sosars and Spartaks Ratiani, Latvian Oncological Centre, Latvia

The interdisciplinary preventive intervention

The Laguna Care Centre is an innovative project in human health and social care for the elderly and patients who need palliative and psychogeriatric care. One of our main objectives is to provide relief from suffering and provide support for the needs of the patient and their families or carers.

Since January 2003, two home care units have begun provisional work in the Latina district. The building will be inaugurated soon and will have two day centres and a unit with 40 beds. It is the first integral social health centre in the Spanish capital. It has, at the moment, an interdisciplinary team of professionals and 30 volunteers who collaborate in assisting the patients and their families at home.

Since the start of the project, the common objective has been the care of palliative patients and their relatives. Each new demand of attention gives rise to an evaluation of the patient and their family, which includes an analysis of their social and health situation. Since the first visit, a joint evaluation of the patient and their family is carried out by the doctor, the nurse and the social worker, giving rise to an individual care plan. The initial diagnosis, which is the basis for the social and health intervention with the patient and their family, requires the combination of knowledge from the different disciplines. As these disciplines are complementary, they provide a global vision of the problems and the common work objectives. We aim to prevent complications, which would not otherwise be detected until a more advanced stage was reached. The scientific evaluation of this methodology will confirm whether the quality of life of these patients and their families is improved.

Over the past three years, we have consolidated the teamwork, improving ourselves with the different and complementary contributions of each of the professionals who care for the patients and their families.

We have also developed practical theoretical courses for carers and courses of training for the volunteers who have been evaluated as very positive by the participants. Our next objective is to set in motion the day centres and the hospitalisation unit. For more information please visit: www.laguna-cc.org ■

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