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Symptom Control and Palliative Care in Chile

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Abstract.

Chile demographic profile is comparable to that of developed countries. The leading chronic conditions affecting the Chilean population are cardiovascular disorders, cancer, cirrhosis, diabetes, chronic obstructive pulmonary diseases and external injuries. Adequate coverage of cancer remains low, and there are no academic programs to adequately form specialists in palliative medicine and comprehensive palliative care in allied medical professionals including nurses, psychologists and specialists in pastoral care. Major efforts have been made to incorporate palliative care as an important health care issue in the last decade and also, in the development of an effective police for opiate availability. Chile is accomplishing 84% of the 17 criteria outlined by the World Health Organization and the International Narcotics Control Board for opioides availability. Post degree medical education in symptom control, use of opioides and end of life issues is relatively poor as judged by the results of a questionnaire administered to 158 residents of the Pontificia Universidad Católica de Chile. Improvements in symptom control and palliative care development in Chile depend on the possibility to put into practice evaluation instruments to assess the effectiveness of symptom control programs and to improve the teaching programs of health professionals on clinical pharmacology, symptom control, clinical ethics and end of life issues.

Key words. Chile – symptom control – opiates availability – palliative care.

Introduction.

In Chile, social and economic transformations of the last several decades have contributed to the emergence of a new set of health priorities. While the prevalence of infectious diseases has diminished sharply, there has been an increase in the relative importance of chronic incurable diseases and injuries. This scenario is mainly the consequence to the aging of the population due to the decline in fertility and increase in life expectancy, as well as rapid urbanization and industrialization, changes in life styles, and improved access to health care. This improvement has not been paralleled by appropriate control of chronic pain and other chronic symptoms, and palliative care.

The National Health Service System (NHSS), which is coordinated by the Ministry of Health (MOH), approximately covers 70 percent of the population, delivering care in 26 geographically defined Health Service Areas which operate the public hospitals within their boundaries. Insured workers contributing to the National Health Fund (FONASA) and their dependents have the option of private providers under the Preferred Provider System, which is regularly used by 15 percent of the population; under this system users pay varying levels of co-payments for generalist and specialist care. No more than 20% of Chileans have private insurance through the ISAPRE (*Instituciones de Salud Previsional*) private system.

Palliative care and symptom control for chronic ailments, particularly pain in the oncology setting, are not explicitly covered by any of the insurance system. The NHSS theoretically should provide opioids and other drugs for symptom control on demand; however this accomplishment is irregular because of economical and cultural constraints. This last aspect related to the “risk of addiction” is true not only in the public, but also among health professionals, including internists and specialists. This situation contrasts with the fact that opioides availability through the NHSS have markedly increased in the last decade. The roots of this inconsistency depends on the philosophy of the Chilean medical school system, very much influenced by the United States medical culture, and the absence of the application of appropriate evaluation instruments of quality of life in the patients with chronic incurable diseases. Common problems faced by incurable patients with chronic symptoms and the

health professional team in Chile, are similar to those found in the developed world, including the ethical issues of assisted death, futile therapies and insufficient care of patient's family.

Chronic diseases profile and cause of death among Chileans.

The leading non-communicable conditions affecting the Chilean population are cardiovascular disorders, cancer, cirrhosis of the liver, diabetes, chronic obstructive pulmonary diseases, and external injuries, which together account for approximately 70 % of all deaths (1,2), a profile very much similar to that of developed countries. The particular cancer death profile among Chileans is shown in Figure 1 to emphasize the epidemic characteristics of 2 incurable cancers, gallbladder and gastric cancer in women and men, respectively (2).

The public health system's infrastructure for secondary and tertiary prevention is also limited. Public hospitals, particularly outside of Santiago, lack basic diagnostic and treatment equipment and suffer from shortages of specialized personnel, resulting in common delays in treatment, especially for radiation therapy, chemotherapy and supporting laboratory services. The growing aged population will only exacerbate this problem by increasing the demand for diagnostic and treatment services. This situation is particularly demanding in the area of cancer treatment.

Palliative care and symptom control.

It is apparent that appropriate symptom control and palliative care of incurable patients is not explicitly acknowledged as an important issue in the public and private health providers in Chile. The quality of care for patients with AIDS and disseminated cancer is very variable among Chilean health institutions and strongly depends on the capacity and interest of individual physicians and nurses in charge. Implementation of adult-health related programs, specifically those oriented to symptom control and palliative care has been usually hampered by lack of operational funds and trained personnel. As result, activities related to palliative

care have not been continuous and systematic, and have not been developed consistently throughout the country as a national policy.

Despite some improvements since 1991, the current structure of activities related to adult health care including palliative care in Chile is fragmented and lacks of appropriate evaluation. Similarly, there is a marked contrast between the appropriate diagnosis of the situation of pain control made by some policy makers of the NHSS and private organizations, and the capacity of the medical culture to understand the importance of palliative care. This incongruence affects the public perception of the quality of care they are receiving from the system. These characteristics are hampering the dissemination of guidelines and standards, including the organization of comprehensive palliative care programs in both the public and private system. Adequate coverage of cancer remains low, and there are no academic programs to adequately form specialists in palliative medicine and comprehensive palliative care in allied medical professionals including nurses, psychologists and specialists in pastoral care. A significant step forward has been made in the last decade by trying to incorporate palliative care in the NHSS, including a strong police for opiate availability, which unfortunately has not been enforced by the medical community.

Another important factor responsible for the slow incorporation of palliative care in the Chilean Health system is probably the result of cancer treatment policies, provided according to the traditional western model. This model has prevailed in Chile during the last 4 decades (4), with poor dedication to symptom control and comprehensive palliative care. However, during the last decade a number of private organizations and specific symptom control programs have been organized along the Country, but more extensively and intensively now in some provinces and in the more populated capital, Santiago, where live one third of the Chilean population. Particularly relevant has been the specific effort of the Cancer Program of the MOH, trying to develop models of multidisciplinary palliative care and pain control programs for outpatient clinics and major hospitals run by the public system. The major problem has been the physician commitment and the permanence of these programs in time, since they do not have a strong and permanent support of the different medical departments and administrators of clinics and hospitals. Usually the palliative care team at the hospital has a nurse and a part time physician, who try to maintain programs in

spite of scarce integration and participation of internists and primary care physicians. Care is basically oriented to pain control rather than to a comprehensive multidisciplinary palliative care approach in the majority of clinics and hospitals, including those that belong to universities. This aspect has important negative implications, because medical and nurse students, interns and residents are exposed to the traditional disease – oriented medical approach rather than to the modern holistic approach of comprehensive palliative care and appropriate symptom control.

The cultural problems related to the inappropriate use of opioids still are present in Chilean society. A modern approach to adequate pain control is found scattered now in some hospitals and private institutions dedicated to palliative care. In addition, some important progress has occurred in the last decade with respect to opioids availability through the NHSS. De Lima et al (5) recently communicated that opioids were not always available in many developing countries, including the majority in Latin America. These authors found that, according to the principles set by the World Health Organization (WHO) and the International Narcotics Control Board (INCB), the compliance of the six main principles and 17 criteria outlined by WHO and INCB for opioids availability (6) was very variable among 5 Latin American countries. The compliance for Mexico was 24% and 53% for Colombia and Costa Rica. In the case of Chile, 14 of the 17 (82%) WHO and INBC criteria are fulfilled at the present time, compared to approximately 50% compliance a decade ago, according to the staff members of the Chilean Health Ministry. This accomplishment compares well to the 94% accomplishment in the State of Texas.

A positive result of the above efforts is reflected in the progressive increase of opioids consumption *per capita* during the last decade, as shown in Figure 2. This important, but still insufficient achievement has been the result of specific involvement and understanding of the MOH Cancer Program authorities, which are actively lobbying and supporting to involve health professionals in local multidisciplinary palliative care programs. However the great majority of the population does not have access to oral morphine preparations. A major drawback is the cultural attitude against opioids due to an exaggerated perception of potential danger of addiction and the poor education of physicians in the area of symptom control and palliative care. A strong support for a modern model of symptom control and comprehensive

palliative care has originated from some institutions in the last decade, including *Clinica Familia for Palliative Care*, *Instituto Nacional del Cáncer* and *Hogar de Cristo*, among others.

Clínica Familia for Palliative Care born in 1989, has been able to build a nest of excellent support for some of the poorest and abandoned cancer and AIDS patients, based on a very well trained group of nurses and a nest of approximately 100 permanent well trained voluntaries. The *Clínica* receives patients from all of the country, but mainly serves the community of south Santiago with a population of one million people. The 2 principal hospitals of the area are now sending all terminal AIDS patients and incurable cancer patients who do not have adequate family and economical support. During 2001, *Clínica Familia* took care of 142 in-patients that died in the *Clínica* and approximately 400 incurable patients who died in their homes and were supported by the permanent well – trained voluntaries of the *Clínica Familia* who developed their activities mainly inserted in the community. Approximately one third of the individuals were cancer patients, 50% were AIDS patients and the rest, were patients with other chronic incurable ailments. All spending has been covered with private donations, including food and all drugs needed particularly oral morphine and other opioids (7). In 1997, *Clínica Familia* and the Pontificia Universidad Católica de Chile signed an Agreement of mutual support to develop all the disciplines related to palliative care. One of the more important scopes has been to improve the quality of communications with the Community and the NHSS to collaborate and extend the expertise acquired along these past years to other Institutions. A major difficulty has been to convince academic chairs of the different departments about the importance of palliative medicine and also the directors of the medical schools to appropriately change the curricula of medical and nurse schools.

Another important good example of modern palliative care in Chile is represented by the *Programa Nacional Alivio del Dolor y Cuidados Paliativos* that covers the northern quarters of Santiago with a population of approximately 650,000 inhabitants (8, 9). This pilot program includes a number of specialized nurses, social workers and physicians full time dedicated to cover palliate care as a modern multidisciplinary team. One of their important tasks is the process of sensibilization of the public health care system including state universities.

Physician and nurse education in palliative care and symptom control.

A key fundamental limitation for adequate symptom control and palliative care is found in Chilean medical and nurse education, which are very much influenced by the “disease - oriented” North American model prevalent in the last decades (2). In fact, a recent survey performed among residents of the post degree medical programs at Pontificia Universidad Católica de Chile, indirectly demonstrated a relatively poor perception that of young physicians have of the level of preparation in palliative care and symptom control. Table 1 shows the results of a preformed anonymous questionnaire distributed to 158 1st to 3rd year residents of the post degrees programs at the Faculty of Medicine of the Pontificia Universidad Católica de Chile, one of the 3 principal medical schools of the Country. The residents had performed their medical education in the main medical school of the country and approximately 20% studied in other South American countries. This questionnaire was completed by 82% of the residents at the *Hospital Clínico of the Pontificia Universidad Católica de Chile*. We wanted to estimate the subjective level of proficiency with respect to the quality of education in palliative care, use of opioides and end of life issues. Approximately 50% of the residents felt that the level of preparation on these aspects was insufficient or bad. Interestingly, only 11% of the residents had formal education on palliative care issues and 25% of them considered to have achieved a very good proficiency in the use of opioides for pain control. This preliminary study suggests that major changes should be introduced in medical and nurse school curricula to improve the professional level of palliative medicine in Chile, a step absolutely necessary to improve the quality of symptom control and palliative care among the Chilean population.

The role of voluntaries.

In Chile, there are approximately 35 organizations of voluntaries related to medical care, the majority of which develop their activities in the hospital setting and in relationship to specific diseases, or age group. Only 3 of them develop their activities in a palliative care program with good preparation and adequate proficiency: *Corporación Nacional del Cáncer*, *Hogar de Cristo* and *Clínica Familia for Palliative Care*. The 2 last organizations develop

their activities with incurable patients harboring AIDS, cancer, as well as any other chronic medical condition that might evolve with high disability and impairment of quality of life, particularly among the poor. The role of well-prepared voluntaries is considered essential for appropriate care of incurable patients in their home setting.

Towards a modern policy for palliative care development in Chile.

Since health care priorities have been maternal and children care in the last decades, insufficient resources remain for medical care of patients suffering disseminated cancer with chronic pain, AIDS, other chronic advanced medical diseases and the concurrent family anguish, usually increased by economical and social distress. It is necessary to develop comprehensive palliative care models in the medical and nurse school settings to expand the multidisciplinary programs patient and family - centered throughout the Country at the very best level possible. The initial steps should be strongly focused to change the present models of medical and nurse education, making major modifications in their curricula in the areas of symptom control, anthropology, medical ethics and the multidisciplinary approach of incurable patients and their families. Physician and nurse education should improve the teaching integrative empathic abilities to work in a multidisciplinary team patient - centered and not only oriented in the “disease cure” paradigm of twentieth century medicine.

Every body in Chile accept and ask for a humanistic and compassionate care of the incurable patient, however paradoxically, when the time comes to develop specific and concrete palliative care programs, policy makers and doctors do not give the necessary priority to this area. Money is usually directed to improve technology, infrastructure and administration of health resources, but not to support appropriate palliative care team development at the university level, as well as in the community settings, including home care and appropriate clinic and hospital facilities. A strong lobbying in support of palliative care development should be directed at different levels, including politicians, the medical academic community, the church and the media.

One of the principal steps to pursue in the short term is to achieve a high level - educational organization associated to national and international universities to concrete successful models of palliative care for the Chilean population. We must perform good research and post degree education in all the disciplines related to symptom control and palliative care, to improve efficiency and efficacy. We must demonstrate that humane and compassionate care, are very much improved and truly realistic when accompanied by the very best of science and

technology. These aspects are possible considering the degree of scientific development of the Country. This is the core challenge for the future. The key chosen instruments to multiply national efforts for the benefits of the incurable patients are education and formation at the highest level possible, to construct and apply appropriate care models consistent with the particular cultural and social characteristics of specific populations.

Two major goals for symptom control and palliative care development in Chile are first, to put into practice evaluation instruments to adequately assess the effectiveness of the different palliative care and symptom control programs according to international standards (10-12). Secondly, it is necessary to change the culture of medical schools improving the scientific basis of quality of life assessment and the teaching programs on clinical pharmacology, symptom control and end of life issues. The same emphasis should be put into work to permeate the education of social workers, lawyers, economists and psychologists. A major issue relates to the importance of education in palliative care and end – of – life issues of priests and pastors in modern pastoral care.

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Legends to figures.

Figure 1. Cancer mortality rates among Chileans. Rates are expressed as number of individuals per 100,000 inhabitants.

Figure 2. Opioids consumption in Chile during the last 2 decades.

Table 1. Physician education in palliative medicine in Chile. Perception about the quality of preparation in palliative care and symptom control among a cohort of 144 residents at the Catholic University Hospital, Santiago, Chile, 2002.

	Very good (%)	Adequate (%)	Poor (%)
Curriculum in palliative care and end of life issues at the medical school.	11	42	47
Pain control and management in the palliative setting.	40	20	40
Use of opioids For chronic pain	25	25	50
Ability to face End of life issues.	14	41	45

A preformed anonymous questionnaire was distributed to 158 1st to 3rd year residents of the Post degrees Programs at the Faculty of Medicine of the Pontificia Universidad Católica de Chile. The following specialties were chosen: Internal Medicine, Surgery, Pediatrics, Family Medicine and Obstetrics & Gynecology. Eighty two percent of the questionnaires were returned.

