Palliative Care for People with COPD

Patients with advanced chronic obstructive pulmonary disease (COPD) have worse quality of life, greater limitation of activity, more anxiety and depression than patients with lung cancer, yet access to palliative care services is rare. An approach, such as is used in other end stage diseases, especially malignancy, is valid, with emphasis on quality rather than quantity of life. For more information, see the IPCRG's Palliative Care Opinion Sheet (2 page PDF file), (Turkish Version), (Greek version) and additional comments to complement the opinion sheet from our members in several countries.

What is happening around the world

Italy

New Zealand

Sri Lanka

Turkey

United Kingdom

United States

Canada

ITALY

In Italy every year over 250.000 terminally ill patients (among those more than 100.000 affected by non-oncological diseases) die. All of these would get palliative care in the last phases of their life. The most important non-oncological causes of terminal illnesses are respiratory failure from COPD, cardiac failure from dilative myocardiopathy, neurological diseases e.g.. multiple sclerosis and cirrhosis of the liver. The rationalization of the medical, sociomedical and charitable interventions in the last phase of the life of these patients (oncologicals and non-oncologicals) has been among the most important goals of the Italian Government in the last few years. Both hospices and home care are the leading pillars of the “Palliative Care Network” in Italy since 1970. They are funded by over 190 charities. But this network still is not homogeneous all over the country (less in South Italy). The palliative care culture, like other countries, developed in Italy around the oncological patient but it seems that it is spreading also to non-oncological patient. In the meantime COPD patients generally die in hospital.

NEW ZEALAND

There is an active hospice movement operating in NZ. This is most frequently charity funded, which is outside the public (government funded) system. Palliative care is being increasingly accepted in this country as a valid concept for incurable chronic illnesses such as COPD. The approach has long been used routinely in cancer. A recent study suggested that general practitioners in Auckland New Zealand were more open that their London (UK) counterparts in discussing prognosis with patients with severe COPD

SRI LANKA

According to our culture, palliative care will revolve around the religious institutions where patients obtain spiritual benefits; non governmental organizations (NGO) eg; (Sumithrayo, Sarvodaya) where they get educational, financial and social support and the GP who is the health care provider, a leader and a communicator. Therefore a palliative care approach involving religious leaders and the village based NGO with the local GP taking the leading role will be of much benefit for our patients.

TURKEY

There is no active official service for COPD patients in their terminal phase. Family support is often available and patients stay until their death with family members. Since home visits are commonly not performed in primary health care, people in terminal phase very frequently visit emergency departments if they need pain relief or similar needs. Private health care providers provide home and palliative care. Municipalities are nowadays interested to provide similar services for disabled people in the community. NGOs like the Social and Applied Gerontological Society of Turkey is trying to enhance human service capacity in Turkey.

The Turkish Ministry of Health released a regulation on “The Provision of Home Care” in 2005 and the interest for home care is increasing day by day. A recent survey of IPCRG-Turkey members revealed a great need for evidence-based guidelines in palliative COPD care and for courses and training (unpublished data; to be submitted to IPCRG Sevilla Conference).

UNITED KINGDOM

Hospices in the UK are charities, though they receive NHS support. Historically, hospice care has focussed on the needs of people with cancer though recent policy has encouraged a broadening of their remit. Many have responded to the growing awareness of the unmet needs of people with non-cancer diagnoses by accepting people with end-stage COPD. Although they offer in-patient, day-centre and bereavement care, a key role is to support general practitioners and community nursing teams by providing advice on palliation of difficult symptoms. General practice is encouraged to use a national framework for palliative care, the Gold Standards Framework http://www.goldstandardsframework.org.uk, and there is a nationally supported pathway for the dying, the Liverpool Care Pathway.

UNITED STATES

Hospice care has been available in almost all areas of the US for over 15 years. Most hospices deal with people with end stage cancers but have broadened the groups they serve. Hospices may provide in-home services, in-nursing home services, hospital-based services or services at free standing hospice units. Services are usually restricted to 3 to 6 months and require that the patient not be receiving any active care but can receive supportive care which for COPD may include oxygen, steroids, and bronchodilators. Few hospice programs actively seek people with COPD but can accommodate them. Insurance coverage is not uniform across all states and may prohibit the use of these services. Most hospices include physical, emotional, mental health and end of life support services.

CANADA

Palliative care services in Canada have progressed greatly over the last twenty years. Initially a service that was provided in a haphazard fashion by family physicians, it is now frequently done by organized groups. Regional groups of physicians with liaisons to physicians with special expertise have allowed much greater coverage of our community palliative needs. Organized Palliative Care conferences promoting team work has improved the knowledge base across the country.

Clearly the initial focus was on comfort measures for patients and their families dealing with end of life care for end stage cancers. This has been expanded to include patients with intractable medical diseases such as end-stage COPD and CHF. Physical, emotional, mental health and end of life support services are provided in home, in dedicated hospital wards or in community run hospices run by volunteers and nurses paid for by local fundraising. Medical care is covered under the local provincial health care systems, and assistance for medications, oxygen and devices is facilitated. Intractable dyspnoea is a symptom complex that can alleviated through careful attention to respiratory secretions and individual patient anxieties.

If you have information about what happens in your country, or useful web-based resources you wish to add, please contact the Secretariat.