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Academic Foresights

Palliative Care

How do you analyze the present state of palliative care?

Palliative care, although conceived and created to reverse the neglects of dying cancer patients, is not restricted to the cancer circle of human suffering and loss. Although palliative care had undergone years of development and growth, since the pioneering work of Dr. Cecily Saunders in the U.K. in the 1960s, cancer patients themselves still face and experience kinds of death to which neither they, nor their loved ones, nor anyone else should and can agree. However, the high numbers of persons dying from cancer, and the very history of palliative care itself can, in consort, distract from palliative attention to so many people who suffer and bear intolerable kinds of dying from a range of diseases quite different from cancer. The enduring challenge of palliative care, a challenge still only minimally met in 2012, is to pursue the research needed to develop and implement the methods required for the effective relief of the multiple kinds of suffering afflicting those who are dying from other severe diseases such as cardiovascular disease, diabetes, the motor neurone diseases, chronic obstructive pulmonary disease, as well as Alzheimer's disease and the other forms of dementia afflicting the aged.

The World Health Organization (WHO) definition of palliative care offers a succinct, yet comprehensive, basis to pursue this analysis of the current state of palliative care.

This definition's nine specific statements highlight that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of palliative care;
- offers a support system to help patients live actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies

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that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage clinical complications.(1)

These nine points of the WHO definition describe an ideal programme of palliative care, a description of what palliative care should be. What palliative care, where it exists at all, actually is often falls short of this ideal.

First, *consider how this World Health Organization definition is reflected in the world situation of palliative care.* The 234 countries of the world have been classified in the following 6 levels of palliative care achievement: (2)

Group 1 countries (75) exhibit no known palliative care activity.

Group 2 countries (23) give evidence of some preparatory, capacity-building activity, but have no established palliative care programme or services.

Group 3a Countries (74) are characterized by an isolated provision of palliative care: few services, limited funding, and low availability of morphine for pain control.

Group 3b countries (17) have achieved a more developed provision of palliative care based upon availability of morphine, diverse sources of funding, and some palliative care training and educational activities.

Group 4a countries (25) have attained a preliminary integration of palliative care services into the mainstream system of health care. Key features of this attainment are: a variety of palliative care providers; health care professional and community awareness of palliative care; a substantial number of palliative care training and educational initiatives.

Group 4b countries (20) are notable for an advanced integration of palliative care into the mainstream of health care services. Several distinguishing marks of this advanced integration are: comprehensive provision of all types of palliative care; unrestricted availability of morphine and other pain-relieving drugs; academic links with universities; the emergence of a national palliative care association.

Second, *consider the worldwide limited access to palliative care.* It is estimated that less than 8 percent of the hundred million or so people who would annually need palliative care services (patients, families, caregivers) actually ever gain access to these services.(3)

Third, *consider the WHO definition's statement about palliative care relief from pain and other distressing symptoms.* There is a worldwide undertreatment of pain, particularly in countries having limited access, or no access whatsoever, to opioid medications. There is a global imbalance in the availability and use of pain-relieving medications. Europe and North America dominate the consumption of the world's available opiate medication for the treatment of moderate to severe pain. As recently as five years ago these two populations accounted for "approximately 96 percent of

the world's Fentanyl consumption, 89 percent of the world's morphine consumption, and 97 percent of the world's oxycodone consumption.”(4)

We seem to be sleepwalking through the centre of an ongoing international injustice. However it would be an illusion to think that those who suffer relentless and neglected pain live only in the very poor and resource-bereft countries of the world. In very rich and developed countries, myths about the hastening of death and the triggering of addiction, as well as doctors' fears about opiate regulatory surveillance and possible legal prosecution, continue to condition physicians to go just so far, and far from enough, in giving suffering people the pain relief they need and have every right to request and expect.

In your opinion, how will the situation likely evolve over the next five years?

As I would not hazard to answer this question for the global situation of palliative care, I will focus on a few points about the possible evolution over the next 5 years of palliative care in Canada.

According to a recent estimate, there are at least 70 percent of Canadians who have no access to palliative care.(5) I do not think that access will measurably improve over the next 5 years unless increased funding is provided for major improvements in home care palliative care services and for financial support of persons staying at home (away from work) to care for a loved one dying in the home. It is also worthy of note that for many elderly people with multiple chronic diseases a long-term care facility becomes their home. The evolution of palliative care in Canada in a positive direction over the next 5 years will very much depend upon a much increased availability of top-quality programs of geriatric palliative care.

There is also a geographic component to the evolution of palliative care in Canada over the next 5 years. Canada's population of about 34 million people is spread across the second largest landmass of the world. It is difficult to imagine that equitable access to palliative care will be achieved over the next 5 years, particularly in thinly populated communities distant from the major health care and academic expertise.

What are the structural long-term perspectives?

An attempt to forecast or predict the future of palliative care over the next 10 to 15 years should not assume that this future is governed by some central determinism controlling all the variables out of the interaction of which the future of palliative care will emerge. Neither should a forecasting attempt assume that the unfolding of the future of palliative care can be described from the vantage point of some super-observatory and that this description, as well as the unfolding of this future, will be independent of the hard questions that have to be faced and answered if palliative care

independent of the hard questions that have to be faced and answered if palliative care is to have a future. These hard questions, as well as the answers that various countries manage to construct, are the pathways to the future palliative care. These hard questions and the responses given to them, will determine the conditions for palliative care, in any one country and across the world, having one rather than another of several possible futures.(6) And I think it should be quite obvious that there will for a very long time be many quite different futures of palliative care in countries across the world.

Two pathways into the long-term futures of palliative care are set out with the two following hard questions. The questions are hard because the answers they require cannot be simply thought out; the answers have to be worked out and this will often require major intellectual, cultural, political, and structural change.

1. *How much longer will we allow so many people across the world to suffer unrelieved pain?*

The World Health Organization (WHO) estimates that there are about 5 billion people living in countries with insufficient or no access at all to medications for the relief of moderate to severe pain.(7) The convergence of outmoded fears about pain medication triggering addiction and complex narcotic laws and the fears of governments about illicit drug use is a tragic convergence. The tragedy “is that for millions of people around the globe, excruciating pain is an inescapable reality of life.” (8)

The future of palliative pain control will depend upon the emergence or the absence of deep structural change regarding the use of opioids for the relief of pain.

2. *Will palliative care remain restricted to the advanced stages of dying? (9)*

Point 9 of the WHO definition of palliative care (cited above) emphasizes that palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.

In contradiction to this powerful statement is the perception – more dominant in some countries than in others – that to receive palliative care a patient has to be dying with death expected to occur within a very short period of time. This enduring perception is reinforced in countries that define eligibility for palliative or hospice care in terms of the conditions that a patient must be willing to forego life-prolonging or curative therapies; and that physicians can certify that a patient is expected to die within a set and short period of time.

This radical separation of care into “palliative” and “curative” is clinically false and morally inhumane. Very sick people may well need palliative radiotherapy, palliative surgery, or palliative antibiotic treatment to maximize their comfort and freedom from

distressing symptoms and persistent suffering. The future of palliative care will continue to be sombre as long as this radical separation continues to exercise hegemony over the care given to very sick and dying people.

Moreover, the restriction of palliative care to the very last short period of life is medically unenlightened and damaging to sick people. A recent study has shown that early palliative care for patients with metastatic non-small-cell lung cancer as compared with standard oncologic care alone has resulted in: prolonged survival, clinically meaningful improvements in quality of life and mood, greater documentation of resuscitation preferences in the medical record, and less aggressive treatment at the end of life.(10)

This study supports and advocates the integration of palliative care with standard oncological care. The future of palliative care will take an upward turn depending on how effectively palliative care is integrated into standard oncological care and, equally so, integrated into standard care for so many other diseases, such as cardiovascular disease, diabetes, motor-neurone diseases and the dementias.

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