BARRIERS TO EFFECTIVE PALLIATIVE CARE OF TERMINAL PATIENTS
An International Perspective

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Effective palliative care has two major components. The first is the psychological and emotional care and support of the dying person and the family. The second is the relief of physical pain and symptoms, as well as the recognition and treatment of other kinds of pain, using effective and proven treatments, including opiates for the relief of pain.22 Palliative care may be provided in the course of usual health care by the patient’s usual health-care providers, perhaps with the assistance of experts in palliative care. Or, more usually, at least in the United Kingdom and the United States, it is provided in a hospice, which may provide care at home, in a nursing home or hospital, or in a free-standing inpatient unit.

The first modern hospice was founded in Great Britain in 1967. Many of the first American hospices and many throughout the world followed the British model initially. Funding, regulations, and other local influences have resulted in modifications of hospice care since then. For example, American hospices now place significant emphasis on home care partly because of Medicare regulations, and Canadian palliative care has largely separated into hospital-based palliative care services and local, volunteer-run hospices. Palliative care is widely available and used in caring for terminally ill cancer patients in much of the developed world, especially the English-speaking countries, much of the European Community, and the Scandinavian countries. Research, much of it done in hospices, has improved the degree to which palliative care is effective, especially in the

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treatment of physical pain. Cross-fertilization has been important—different models and methods tried in one country have influenced others in palliative care. However, significant barriers to palliative care remain even in developed countries, especially for patients with terminal illnesses other than cancer and for minority patients. In developing countries, not only modern palliative care but modern healthcare may not be available.

Despite the wide differences in healthcare worldwide, there are interesting similarities in the reasons why palliative care is not more widely used. In this article, these barriers are discussed which include: inability or reluctance to use opiates appropriately to relieve physical pain, the segregation of palliative care into separate hospice systems, cultural and religious beliefs, financial barriers, and the problems of providing an effective palliative care for terminal illnesses other than cancer. In addition, possible remedies for some of these problems and some of the effective programs that have been developed in other countries are discussed.

AVAILABILITY AND USE OF OPIATES

The World Health Organization (WHO) stepped-care method of pain control has been available for almost ten years. The WHO approach uses morphine or other strong opiates for those who do not, or who have ceased to respond to weak opiates. Since the guidelines were promulgated, morphine usage has increased markedly in several countries, including the United Kingdom, United States, Canada, New Zealand, Australia, Iceland, Ireland, Norway, and Sweden, all developed countries. Morphine consumption in these ten countries accounts for about 57% of the world morphine usage, and in the top 20 countries accounts for about 86%. Each study has shown that the amount of morphine and other strong opiates used for medical purposes in most developing countries is far less than the amount predicted based on the numbers and kinds of cancers present in the population. The reasons for these marked discrepancies include: lack of knowledge about appropriate prescribing, lack of access to opioids because of legal restrictions and high costs, and cultural biases against using morphine or strong opiates.

Rules and Regulations

One of the few successes of the global "war on drugs" is that legal narcotics have not been diverted in large amounts into illicit channels. The "war" has had major adverse effects, however, on the use of opiates for legitimate medical purposes, including the treatment of cancer pain. In addition to the social resistance among both healthcare professionals and patients to the use of strong narcotics even for medical use (discussed below), there has been a proliferation of rules and regulations making it difficult to prescribe or obtain strong opiates in many countries. These include such rules as requiring special prescription forms, limiting the number of pills or the dosage that can be prescribed, or requiring those

taking strong opiates to register as drug users. Among the European countries, restrictions in Germany, Spain and Portugal have generally been much stronger than those in Great Britain. Similar regulations are, of course, found in some American states, and initiatives similar to the Wisconsin Pain Initiative have been introduced in several countries. In addition to the reduced demand caused by these regulations, restrictions on manufacturing, importing, and pharmacy stocking of opiates has resulted in lack of availability in many countries. The Declaration of Florianopolis, concerning opioid availability in Latin America, noted that, in Latin American countries, availability may be limited to the mild opioids on the one hand, and to very expensive forms of strong opiates, such as sustained-release morphine preparations and pentobarbital patches on the other. The price of opioids is significantly higher in most Latin American countries than in Spain. The Declaration ended in a series of recommendations intended to improve access to appropriate pain control for cancer patients in Latin American countries.

In China, the strongest analgesics available is usually intramuscular or oral meperidine. Morphine requires additional signatures and only a few tablets are issued at a time. In Russia, opiates are often lacking also, along with other basic supplies. Morphine is not produced in Russia, and imported drugs are expensive. Weaker opiates are used instead, and there are very few oral analgesics available. In Africa, opiates may not be available because of restrictions, or they may be too expensive—partly because of regulations—for most patients. Thus, throughout major regions of the world, strong opiates are not easily prescribed or used for cancer patients, significantly affecting the ability to provide good palliative care.

Lack of Knowledge

Morphine has been shown to be very effective in controlling the pain of most cancer patients. Studies typically show that from 75% to 90% of cancer pain in terminally ill patients is well controlled using the basic stepped care approach, often requiring mean doses of 30 mg of morphine every 4 hours to maintain good pain control. However, as in America, many health care professionals do not know of the WHO approach, and many laypeople do not know that palliative care or hospice care is possible at all. It is difficult to tell whether restrictions on availability, ignorance of how to use the medications, or cultural biases are responsible for their misuse.

Even where morphine is available to physicians, appropriate doses may not be used. Despite relatively unregulated access to strong opiates, the Netherlands has had, until recently, no available hospice care, and has very low morphine consumption. This may account in part for the strong interest in active euthanasia there. A study of treatment of cancer pain in Germany found that only 322 of 16,630 cancer patients received strong opiates, that adjuvant therapy was rarely used, and treatment for breakthrough pain was not given. More than 30% of the prescriptions for sus-
tained-release morphine were written for inappropriate intervals—one time a day, four times a day or more, or as needed. Similarly, a study comparing morphine use in a palliative unit in Canada to one in South America found marked differences in the mean daily equivalent dose of parenteral morphine used—44 mg in Canada versus 9 mg in Argentina, although patients in Argentina were more likely to get narcotics “around the clock” at appropriate intervals.

The effect of teaching centers in influencing and educating other individuals, organizations, and even countries, is evident in the history of modern hospice care. Most of the hospices now existing have been influenced, at one or more remove, by Dame Cicely Saunders and St. Christopher’s Hospice. Similarly, many of the countries now trying to develop hospice care are doing so in part by developing one or more centers of excellence, with the hope of educating and influencing other institutions and practitioners. International groups have worked to develop standards for palliative care and for palliative care education, though differences in health-care systems and in access to strong opiates make the application of uniform standards difficult. Palliative care is being taught in more medical schools, especially in the United States, United Kingdom, and Australia. In the United Kingdom and Australia, palliative care is now a recognized specialty, and in the United States, some fellowships in palliative care are now available.

The effects of centers of excellence or teaching centers may also be felt, perhaps even more strongly, where there is no tradition of hospice care. In Poland, hospices are relatively new—the first was started in 1981. There are now over thirty, some developed and run by Catholic organizations, some by other charitable organizations. Although only 1% to 2% of Polish terminal cancer patients receive palliative care, the number is far higher in areas with active hospices. Approximately 45% of the patients dying in Poznan of cancer now receive hospice care, and morphine use has risen thirty-five times that of the prehospice period in that area. In order to reach others, a group of hospice doctors, many of whom have taken courses in palliative care at Oxford or at the Cancer Pain Division of WHO in Milan, has helped develop a 30-hour curriculum for the sixth year medical school students in Poznan, covering issues in death and dying, palliative care, and pain control. Problems include the introduction of these topics late in the curriculum and the lack of clinical experience.

In another example, the Tianjin Hospice Research Center has been the center of palliative care research and training in China, sponsoring conferences including expert foreign speakers and distributing information about palliative care, including translated information from the English and American literature.

Misconceptions about Opiate Use

Health care professionals may be concerned about addiction, be too concerned about respiratory depression, or think that morphine is a drug only for those actively dying. Patients and family members often have similar concerns, especially about drug addiction; for example, in Poland, myths about morphine include that it is to be used only in the very last stages of disease, that it will cause addiction, and that, if given earlier, there will be nothing stronger with which to relieve pain. Similar beliefs persist elsewhere, including in the United States, and there is often an aura of illegitimacy surrounding the use of strong opiates (including morphine), as well as a failure to distinguish between legitimate and illegitimate use. To some degree, these concerns may be the result of too-effective substance-abuse education programs that lump drugs of abuse together with drugs used for appropriate medical purposes.

FINANCIAL BARRIERS TO PALLIATIVE CARE

As with poor or minority patients in the United States, cancer and other terminal illnesses in developing countries are often diagnosed too late to hope for curative treatment, even if that were available. More than half of the new cancer cases are found each year in developing countries, and most are solid tumors, treatable even in developed countries only with massive outlays and limited success. In addition, cigarette smoking, on the decline in the United States and other developed countries, is on the rise in developing countries, so that respiratory-tract cancers are likely to increase drastically in the next few decades. Most new AIDS cases are also found in developing countries.

Health care budgets in developing countries are usually stretched thin, and may reasonably stress prevention and management of more treatable diseases than cancer or AIDS. Under these circumstances, palliative care would seem especially appropriate. However, good palliative care is not cheap, requiring as it does skilled care and, usually, medications. Opiates may be more expensive than in the developed world, because of scarcity or regulations. Modern health care resources are often available only to the urban elite in large cities, and may not be available at all to the majority of the population in rural areas. Under these circumstances, devoting scarce resources to the humane care of those who are already dying may seem an unnecessary luxury rather than an appropriate need to those administering shrinking health-care budgets. Providing effective palliative care in such circumstances will require an emphasis on palliative-care training for health care professionals, as well as making opiates available and affordable for treating pain, and most importantly, flexibility in bringing care and facilities to where there is a need, and in using the resources already available, including families and traditional healers.

In the past, it has been assumed that the poor dying patient would at least have an extended family that could provide a safety net. American hospices have long been aware that this is not always the case—poor families often face multiple stresses, are not able to afford to hire a care giver to help provide care, have less space and money, and may be unable to care for an ill adult family member at home. The same may be true elsewhere. A study of the care of people with AIDS in Uganda found
limited family care in most of the cases. Family members gave various reasons, including lack of food and money and other family responsibilities. Such problems may be especially common where the family has already sustained multiple deaths or serious illnesses or other losses, as in countries or areas where AIDS is common or the social fabric has been ripped in other ways.

However, flexibility may make it possible to assist the family in providing care without large financial expenditures. In Jamaica, a program has assisted family members in providing home-hospice care, with the support and education of visiting nurses. There are satellite programs in rural areas, but no separate in-patient facility is available. Another possibility is to involve family members in the patient’s care, but not within the home setting. In India, both patients and family members may be involved in caring for other patients and doing daily tasks in the facilities run by the Missionaries of Charity. These facilities can provide excellent basic care, but do not usually provide skilled palliative care, which would require specific training and supplies. Similarly, in Banaras in India, where, for religious reasons, many Indians go to die, houses called mukhtahavens are available in which family members care for elderly relatives while waiting for them to die. Thus, palliative care may be delivered without the full range of services available in modern hospices, but in ways that suit the needs and resources of local populations.

Terminal Illnesses Other than Cancer

Medicare regulations requiring a certification of a life expectancy of 6 months or less have probably limited hospice access for patients with terminal illnesses other than cancer in the United States, although patients with AIDS, heart disease, lung disease, end-stage renal disease, and dementias are seen in many hospices. In other countries, palliative care or hospice care may be limited more directly; for example, in Japan, for a palliative-care unit to be funded, patients must predominantly have a diagnosis of cancer. In Russia, patients with cancer may be automatically referred for hospice care, regardless of probable life expectancy. In all of these countries, patients with cancer are most likely to receive palliative care, despite the possible needs of other patients with terminal illnesses.

CULTURAL ATTITUDES TOWARDS DEATH AND TERMINAL CARE

One of the central tenets of hospice care in the United Kingdom and America has been the need to discuss death openly with the patient; however, that is not possible in many cultures, in which, at least from the Western hospice perspective, there is mass cultural denial of death, and in which physicians, families, and perhaps patients are reluctant to discuss the prospect of death openly. This taboo against speaking of death may be especially strong in Asian countries, but exists widely. In America, the emphasis on the patient’s autonomy and right to make decisions, the hospice movement, and the work of Dr. Kubler-Ross have combined to cause a marked change in attitudes over the last two decades, so that it is now considered appropriate for the patient to be given the news about a terminal illness directly. In the United Kingdom, it is also considered appropriate for the patient to be told of terminal illnesses. In Italy, the taboo against speaking of cancer or terminal illnesses to the patient is strong but may be changing.

Traditionally, Japanese patients are not told of a diagnosis and prognosis of a terminal illness—families are usually informed, and make decisions related to the patient’s care. Since hospice care is not widely known in Japan, a patient may even receive hospice care without being aware of the diagnosis or prognosis. Interestingly, this attitude may no longer reflect the wishes of Japanese patients. A study of attitudes among medical residents, cancer patients, and medical students in the United Kingdom, New Zealand, and Japan, found that a majority of people, including cancer patients, would want to know the truth if they had a terminal illness, although the majority was not as large in Japan as in the other two countries. More medical students in Japan would be willing to conceal information from the patient than in the United Kingdom or New Zealand.

It is unclear exactly what the interaction between religion and cultural beliefs about death is, and it is dangerous to draw strong conclusions in this area, but the reluctance to discuss death seems to be greatest in areas where there is no strong religious belief or ritual. Traditional customs, religious beliefs, and ceremonies have typically helped patients come to terms with death, and helped survivors deal with their loss. In many cultures, old traditions and beliefs have been discarded or questioned without anything to take their place. Many people may not know just what their religion demands or permits in the setting of a terminal illness.

The Roman Catholic Church and most mainstream Protestant denominations accept the principles of palliative care in caring for dying persons. In particular, though the Church believes that suffering may be a means of spiritual growth for some, it does not think it necessary “to impose a heroic way of acting as a general rule.” The Church also recognizes that, in some patients, relieving pain may result in sedation and may have the “double effect” of hastening death in a few patients, even though that is not its primary goal. Such an effect would not be considered murder or suicide. The Catholic Church also accepts the practice of withholding burdensome or useless therapy from someone who is dying. In other words, it may be acceptable not to give artificial nutrition and hydration to a dying patient.

In Jewish law, human life has infinite value, and therefore one may not do anything to hasten death, including, in one orthodox interpretation, withdrawing or withholding artificial nutrition and hydration. On the other hand, one need not prolong the dying process, so if a therapy is not effective in prolonging life, it need not be offered, and palliative care, including hospice care, is acceptable.

In the original British mode of hospice care, pastoral counselling is
considered essential, and chaplains are valuable members of the interdisci-
niplinary team. Pastoral counselling is considered similarly important
elsewhere, except in Japan and mainland China. In Banaras, at the
mukhbares, families provide physical care, while the priest-workers
care for the dying person's spiritual well-being by praying, chanting, read-
ing religious stories to the dying, and conducting rites of purification.

SEPARATION AND SEGREGATION

In the United States and elsewhere, hospices often represent a com-
pletely different health care system for the patient and family, often with
different nurses, doctors, home health aides, hospitals or inpatient units,
and reimbursement mechanisms. This represents a problem of contin-
unity of care and a major psychological stress at a time when patients and fam-
ilies are already being stressed. It may also represent "giving up" or "be-
ing dumped" to the patient and family, as in Russia, where the hospice
may be considered "like a morgue." On the other hand, expert pallia-
tive care in many places is available only in hospices. This again represents
a problem for health care professionals—the lack of contact and cross-
fertilization means that many health care professionals may perceive pal-
tiative care as being out of the mainstream. They may be reluctant to refer
patients until late in the patient's illness, and will be unlikely to learn and
apply principles of palliative care in their own practice.

One possible solution to this problem may be a palliative-care ser-
vice—a service provided by an interdisciplinary team, usually in a hos-
pital setting to inpatients, either in consultation to others or as a primary
care service. Palliative-care services are most common in Canada, where
terminal care has, to some degree, evolved into a two-pronged ap-
proach—volunteer, community-based hospices which often supplement
home-care services, and hospital-based palliative-care services. There are
no enforced standards for palliative-care services, and funds are not spec-
ifically allocated for palliative care, so there is wide variability in staffing
and services. Financial support is a significant and continuing problem
for most palliative-care services. Palliative-care services follow several
models, and many do not provide home-care components. Thus, there
may still be a break in continuity of care when the patient is discharged
home. On the other hand, palliative care services such as the one at Ham-
ilton Civic Hospital in Ontario spend significant proportions of time on
education and outreach, which may improve the level of palliative care
offered by primary care providers.

CONCLUSION: BREAKING DOWN BARRIERS

The barriers to effective palliative care, are, not surprisingly, similar
worldwide. They include lack of education in palliative care, especially
pain control, for many health care providers. In many countries, strong
opiates are not available, are strongly regulated, or are very expensive.

Cultural and religious beliefs may limit the ability to talk about and deal
with terminal illness and the dying process. Financial barriers to palliative
care are very strong in the developing world, where basic preventive care
is often not available. Finally, even where palliative care is available in
hospices, it is often in a separate health care system from the one usually
encountered by patients, families, and health-care providers, making com-
unication, early referrals, and cross-fertilization difficult.

Education in palliative care is essential for health-care providers, and
programs are being developed in many medical schools. Many countries
have developed centers of excellence, which sponsor education and research
in palliative care. Regional and national pain initiatives have been
developed, often on the model of the Wisconsin Pain Initiative, to improve
awareness of appropriate cancer-pain control, and improve the availability
and affordability of the medications needed. Palliative care services
have been developed in hospitals, and may improve the level of com-
unication and education there, but continuity of care into the community
may not exist, and financial support is often tenuous. Flexibility in
adapting models of care from one country to another is essential in over-
coming barriers. The British free-standing hospice model has already been
adapted in a multitude of ways to countries in the developed world. It
may need to be adapted again, or other models altogether developed, to
meet local conditions in other countries.

Palliative care is essential for the humane care of the dying, and no
country is free of barriers to that care. We can learn from each attempt to
break the barriers that prevent that care, whether successful or not, wherever
they occur.

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