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The challenge of palliative care

Palliative care is patient-centered, rather than disease-focused; accepts the inevitability of death while simultaneously is life-affirming; addresses psychological, social, and spiritual concerns as well as physical ones; and is best delivered by a multiprofessional team working in partnership with patients and their families. Palliative care stresses the importance of “appropriate treatment” and the need for doctors not to prescribe a lingering death. Even though there is no chance of cure, there is much scope for psychosocial and spiritual healing, and often some scope for physical rehabilitation. Palliative care is emotionally demanding for professional carers, and strategies for personal support are necessary. The World Health Organization has played a major part in the ongoing campaign to improve cancer pain management and to make medicinal morphine more widely available. A systematic approach to pain and symptom management is essential, and there is need for specific training for all health professionals. In most countries, for palliative care to take root, there is need for charismatic “champion”. However, for palliative care to flourish, there is need for a governmental commitment to its development. Charisma continues to be necessary to prevent palliative care being strangled by an over-rigid bureaucracy, but incorporation into existing health delivery systems is necessary to prevent it being stillborn through lack of resources.

Key words Appropriate treatment · Pain management · Palliative care · Symptom management

Introduction

Palliative care is the term used to describe the care of patients whose disease is incurable and whose life expectancy is limited to weeks or months. Its main goal is to help patients live as actively and creatively as possible until they die. “Palliative” is derived from the Latin word “pallium”, a cloak. Thus, in palliative care, symptoms are “cloaked” with treatments whose primary purpose is to promote patient comfort. However, palliative care extends far beyond symptom relief. Its essence is poignantly reflected in sentence from the Qur’an: “May you be wrapped in tenderness, you my brother, as if in a cloak.”

Modern palliative care began 35 years ago in the United Kingdom as a result of the vision and enthusiasm of Dr. Cicely Saunders, who established St. Christopher’s Hospice in London. Palliative care soon spread to the United States and the “white” Commonwealth countries. Subsequently, palliative care has spread to other countries in all five continents, particularly in Western Europe. In the United Kingdom, palliative medicine has been a recognized medical specialty since 1987, and a major expansion of specialist posts is planned to take place over the next few years. The Association of Palliative Medicine presently has over 700 members. Specialist palliative care is now available in all parts of the United Kingdom (Table 1).

In contrast, most countries still have little or no palliative care provision. Palliative care is mainly the preserve of wealthier countries, despite the universal need for this type of care. Deaths from cancer worldwide now exceed 6 million per annum and deaths from AIDS are rapidly increasing, mainly in sub-Saharan Africa, but also elsewhere. Further, it is now generally accepted that patients with any end-stage disease should be offered palliative care. Looked at this way, the number of patients worldwide who would benefit from palliative care is enormous. Indeed, the only way that the need will be satisfied is if palliative care becomes an accepted responsibility of all clinicians, and not just those in specialist services.

However, such a vision may well be utopian. Many doctors become doctors because they want to cure. Consciously or subconsciously, death is the enemy which must be defeated, sometimes seemingly at all costs. Such doctors find it hard, if not impossible, to recognize the approach of inevitable death and continue to promise improvement or
Clinical ethics

The cardinal principles which underpin all clinical practice are:

• respect for patient autonomy (patient choice)
• beneficence (do good)
• nonmaleficence (minimize harm)
• justice (fair use of available resources). ²

These four principles need to be applied against the background of respect for life and an acceptance of the ultimate inevitability of death. Thus, in practice, there are three dichotomies which need to be held in balance:

• the potential benefits of treatment versus the potential risks and burdens
• individual demands versus the needs of society
• striving to preserve life, but, when the burdens of life-sustaining treatments outweigh the potential benefits, withdrawing or withholding such treatments and providing comfort in dying.

Derivative from the second dichotomy is an attitude of partnership between the professional carers on the one hand and the patient and family on the other. Both the classic and modern forms of authoritarianism should be eschewed:

“I know what’s best for you”.
“You must decide for yourself”.

Give options, yes, but seek to gently guide the patient towards what you as a professional regard as the most appropriate form of action, given all the patient’s circumstances, physical and otherwise.

A proper understanding of the principle of double effect is also necessary. This states that an action having two possible foreseen effects, one good and one harmful, is not always morally prohibited if the harmful effect is not intended. This is a universal principle without which the practice of medicine would be impossible. It follows inevitably from the fact that all treatment has an inherent risk. However, most discussions of the principle of double effect focus on the use of morphine or similar drugs to relieve pain in terminally ill patients. This gives the false impression that the use of morphine in this circumstance is a high-risk strategy. When correctly used, morphine, and other strong opioids, are very safe drugs, safer than non-steroidal anti-inflammatory drugs, which are widely prescribed with impunity. ³ The use of both classes of analgesic is justified on the basis that the benefits of pain relief far outweigh the risk of serious adverse effects. Indeed, clinical experience suggests that those whose pain is relieved live longer than would have been the case if they had continued to be exhausted and demoralized by severe unremitting pain.

The situation in the United Kingdom is encapsulated in a classic legal judgment:

A doctor who is aiding the sick and the dying does not have to calculate in minutes or even in hours, and perhaps not in days or weeks, the effect upon a patient’s life of the medicines which he administers or else be in peril of a charge of murder. If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. ⁴

Similar sentiments have been expressed in other countries, and reflect a broad international consensus. However, the intended aim of treatment must be the relief of suffering and not the patient’s death. Although a greater risk is acceptable in more extreme circumstances, it remains axiomatic that effective measures which carry less risk to life should normally be used. Thus, in an extreme situation, although it may occasionally be necessary and acceptable to render a patient unconscious, it remains unacceptable and unnecessary to cause death deliberately (euthanasia). Indeed, palliative care and euthanasia are essentially mutually exclusive philosophies.

Appropriate treatment

There is much discussion about the ethics of stopping or withholding treatment. However, an understanding of the

### Table 1. Palliative care provision in the United Kingdom in 2002

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient units</td>
<td>208³</td>
</tr>
<tr>
<td>Beds</td>
<td>3029</td>
</tr>
<tr>
<td>Home care services</td>
<td>334⁴</td>
</tr>
<tr>
<td>Specialist community nurses</td>
<td>&gt;2000</td>
</tr>
<tr>
<td>Extended nursing care (“hospice at home”)</td>
<td>78</td>
</tr>
<tr>
<td>Day centers</td>
<td>243⁴</td>
</tr>
<tr>
<td>Hospital support nurses/teams⁵</td>
<td>321</td>
</tr>
<tr>
<td>Number of patients seen by specialist professionals</td>
<td>&gt;120 000 p.a.</td>
</tr>
<tr>
<td>Number of new patients admitted to an inpatient unit⁶</td>
<td>≈40 000 p.a.</td>
</tr>
<tr>
<td>Number of deaths in palliative care units</td>
<td>≈29 000 p.a.</td>
</tr>
</tbody>
</table>

Notes:

⁴ Data supplied by Hospice Information Service, St. Christopher’s Hospice, London SE26 6DZ, UK
⁵ Fifty-six in National Health Service; the rest independent. Mean number of beds, 15 (range, 2–63); in addition there are 22 units for children, with a total of 186 beds
⁶ About 40% are based at an inpatient palliative care unit
⁷ About 70% are situated in an inpatient palliative care unit
⁸ Offer an intensive consultation service but have no dedicated beds
⁹ Malignant disease accounts for 96%, with AIDS and motor neurone disease comprising most of the rest

p.a. Per annum

Even cure when an objective assessment would conclude that these outcomes were totally unrealistic. On top of this, in Western countries, most people seem to want to believe that death can be kept at bay indefinitely. In consequence, they will overtly or tacitly encourage doctors in their unthinking that risk is perceived as being only in days or weeks, the effect upon a patient’s life of the medicines which he administers or else be in peril of a charge of murder. If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.¹ This task will be facilitated by reconsidering the ethical basis of clinical practice.