

Looking Back and Looking Forward

PATIENT CARE: PAST, PRESENT, AND FUTURE

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ABSTRACT

The 40 years since St Christopher's Hospice opened has witnessed a burgeoning international interest in palliative care. Its key characteristics comprise a focus on the whole-person (physical, psychological, social, and spiritual), patient-centeredness (partnership with and empowerment of the patient and family), openness and honesty in communication, an acceptance of the inevitability of death coupled with improvement in the quality of life, multi-professional teamwork integrated with community (volunteer) involvement. Although much has been achieved, much remains to be done. Both in resource-poor countries and in more wealthy ones, the scope of palliative care has changed. Initially in the United Kingdom, palliative care was mostly limited to cancer patients but now strenuous efforts are being made to extend coverage to other patient groups, e.g., those with end-stage heart disease or renal failure. In India, with a dearth of chronic care facilities, palliative care services increasingly embrace those with chronic disability as well as progressive end-stage disease. In Sub-Saharan Africa, the devastating impact of AIDS is having a major impact on the development and delivery of palliative care. To maximize the benefits of limited financial and other resources, a strategic approach is necessary. The World Health Organization emphasizes three essential foundation measures: health service policy, public awareness and professional education, and drug availability. However, at the end of the day, if we are truly to honor Cicely Saunders, palliative care must remain *a movement with momentum*, combining creative charisma with inevitable bureaucratic routinization.

INTRODUCTION

As the founder of the modern hospice movement, and thus of palliative care, Cicely Saunders was without doubt *the* initial major influence in the latter part of the 20th century in relation to compassionate-cum-scientific “end-of-life care.” With the opening of St Christopher’s Hospice in 1967, she fanned the flames in what has become a global movement for improvement in the care of people with progressive end-stage disease. Obviously, there is a limit to what one person can do, and credit also goes to an expanding number of enthusiasts in more and more countries.

The second major catalyst to the global development of palliative care was the Comprehensive Cancer Control Programme initiated by the World Health Organization (WHO) in 1980 [1]. This three-pronged program comprises:

- prevention
- early detection and curative treatment
- pain relief and palliative care [2, 3].

The incorporation of the third component prompted the founding of the European Association for Palliative Care (EAPC) in 1988, the State Cancer Pain Initiatives in the United States in the 1990s [4], and many national and regional bodies, including the International Association for Hospice and Palliative Care. Palliative Medicine has achieved specialty or sub-specialty status in several countries, and academic departments have been, and are being, established. Journals and academic courses (diplomas and Master degrees) abound. The 4th EAPC Research Forum in 2006 attracted >500 abstracts. Looking back over 40 years, the progress has been truly remarkable. Even so, paradoxically, in many ways we are only just beginning. When viewing the global scene, we find that:

- the provision of palliative care is still patchy
- it is not available for most of those who need it
- it is not fully accepted by the medical profession in most countries
- it is not a core component of most national health systems
- the need is still increasing because the global prevalence of cancer is still rising
- the HIV/AIDS pandemic affecting Africa and many parts of Asia is increasing the need for palliative care still further.

So, although the light at the end of the tunnel is glowing brighter, there is still a great deal to be done.

FROM THE PAST TO THE PRESENT

In the early days, “hospice” was seen almost exclusively as *inpatient*, *cancer*, and *terminal*. However, it is now regarded more widely as a concept of care for people in the end-stages of progressive disease of any kind (Table 1). Thus,

Table 1. Key Characteristics of Palliative Care

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| Whole-person (holistic) care: physical, psychological, social, spiritual |
| Patient-centered, not disease-focused |
| Partnership with and empowerment of the patient and family |
| Openness and honesty in communication |
| Death accepting, but also life enhancing |
| Improving the quality of life, not quantity |
| Concerned with healing, not curing |
| Multi-professional teamwork and community (volunteer) involvement |

hospice (palliative) care can be defined as the active total care of patients with life-limiting disease, and their families, by a multi-professional team when the disease is no longer responsive to curative or life-prolonging treatments [5]. The essential task in palliative care is to help patients (and their families) make the transition from fighting death to seeking peace. This is greatly facilitated by achieving as high a degree of physical comfort as possible, thereby enhancing the patient's quality of life.

A key characteristic of palliative care is a patient-centered approach. The focus is on a **PERSON** with end-stage disease, rather than on a person with **END-STAGE DISEASE**. On paper this may seem a small difference but in practice this change of focus has a big effect. *Good communication* between health professionals and the patient and family is essential. Indeed, palliative care should be seen as *a partnership between experts*. In relation to the disease process, the clinicians are the experts but, in relation to the impact of the illness, the experts are the patient and family. It is vital to recognize this because, through listening to their story and their problems, the patient and family begin to shift from being passive victims to empowered persons.

PARADOX

Those visiting a hospice for the first time often comment that it is not the depressing place they had imagined it would be. Instead they find a place permeated by life, and even joy. A strange discovery, but it is perhaps in this paradox that the "secret" of palliative care resides. Life and joy in the midst of death and distress can result from relatively ordinary professional activities—like nursing care, pain and symptom management, and psychological and spiritual support—when motivated by *practical human compassion*. This, in turn, is the outworking of an attitude of respect for the patient and of corporate activity in

which individualism is balanced by teamwork and vice versa. The "House of Hospice" model is a good way of expressing this (Figure 1), with its foundation stones of *acceptance* ("Whatever happens, we will not abandon you") and *affirmation* ("You may be dying but you are important to us"). Honesty and hope make up the cement which binds the various components together.

Caring for the dying is not easy. One doctor described it as "extremely harrowing but very rewarding." It is difficult but, again paradoxically, it generally has a positive dimension [6]. Thus, a patient dying of motor neuron disease (amyotrophic lateral sclerosis, "creeping paralysis") spoke of terminal illness as *coming together illness*. After many weeks as an inpatient at St Christopher's Hospice, he said, "I've seen it time and time again. Patient and family; patient and patient; patient and staff—coming together illness."

Relief of pain and other distressing symptoms is rightly seen as the primary goal of palliative care. Where palliative care is available, competent symptom management means that patients can generally expect to be largely free of pain [3]. A high measure of relief can also be expected with many other symptoms. No longer distracted and exhausted by unrelieved pain, patients may become distressed emotionally and spiritually as they contemplate their approaching death. Few do this with equilibrium. Most defend themselves psychologically in various ways, but some are overwhelmed with anguish, rage, or fear about what

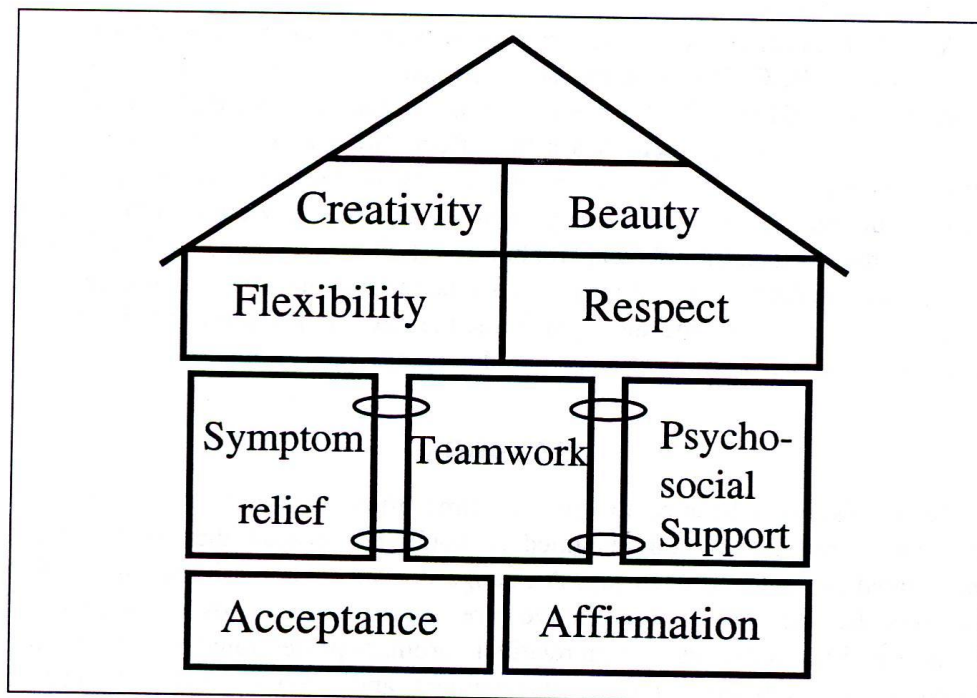


Figure 1. House of Hospice

is happening to them. In consequence, it has been suggested that hospice should be thought of as *a safe place to suffer*, a place where people can come to terms with their own death as easily, fully, and constructively as they have it in them to do [7].

PALLIATIVE CARE AND HEALING

You can't die cured but you can die healed [8].

These words, by a dying doctor, sum up much of the existential dimension of palliative care. This is reflected in what a widower wrote after his wife's death:

Of course terminal cancer is unspeakably awful. That aspect needs no emphasis. More difficult to imagine is the blessedness which is the corollary of the awfulness. . . . I think my wife learnt more of our love during those dreadful months than she did at any other time, and we of hers. . . . The suffering of a long and terminal illness is not all waste. Nothing that creates such tenderness can be all waste. As a destroyer, cancer is second to none. But it is also a healer, or an agent of healing.

Healing is about restoring right relationships with self, others, the environment, and God. The aim of healing is not to be cured or to survive, but to become whole. Dying healed includes being able to convey five important messages to one's nearest and dearest: I love you; forgive me; I forgive you; thank you; goodbye [9].

PAIN AND SYMPTOM MANAGEMENT

The message that you do not have to die in agonizing pain is what most people associate with Cicely Saunders. She was the pre-eminent practitioner and teacher of "efficient loving care":

- attention to detail
- the thorough evaluation of symptoms [10]
- the regular prophylactic use of analgesics and other symptom relief drugs [11]
- continued monitoring of the impact of the prescribed treatment
- the exploration of the patient's fears and anxieties, and also those of the family.

She was an inspirational teacher. Her now classic teaching model of "total pain" took health professionals, almost without effort, from a narrow physical outlook to a holistic approach in which the unit of care is the family (Figure 2).

In the 1960s, Cicely prepared a four-page handout for use with her lectures. Now, as befits a full-blown medical specialty, the handout has been superseded by the 1,244 pages of the multi-authored Oxford Textbook of Palliative Medicine,

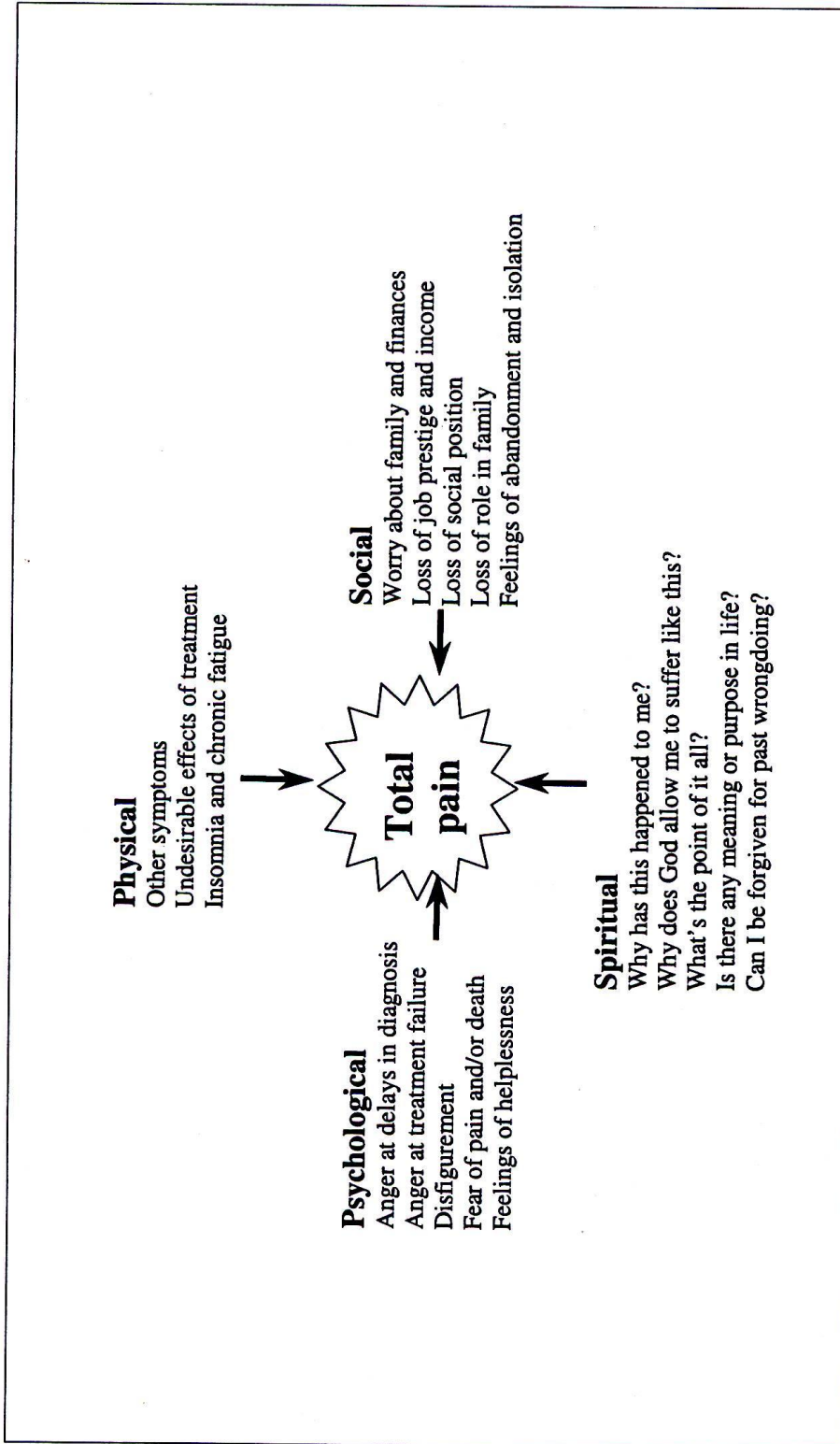


Figure 2. Factors influencing perception of pain.

and by numerous other books. But whether just four pages or 1,244, the core message remains the same:

You matter because you are you,
and you matter to the end of your life.
We will do all we can not only to help you die peacefully,
but also to live until you die.

FROM THE PRESENT TO THE FUTURE

The challenges facing countries where palliative care services are reasonably well developed (the minority) and those for other countries (the majority) differ considerably. However, there is one major challenge common to all countries, namely the need for truthful communication between health professionals and patients. This is basically an ethical challenge, but it is related to the underlying attitude of health professionals toward their patient; openness and honesty stem naturally from a patient-centered and partnership approach to care.

Worldwide, good communication skills are still the exception rather than the norm in the medical profession. In *Truth may hurt but deceit hurts more* [12], examples are given of deliberate attempts to withhold the truth from patients, together with cases of unintentional deception created by ambiguous language. The evidence all points to the conclusion that, although truth may hurt, deceit hurts more. The challenge has been succinctly summed up as follows:

Truth is one of the most powerful therapeutic agents available to us, but we still need to develop a proper understanding of its clinical pharmacology, and to recognise optimum timing and dosage in its use [13].

Being sensitively honest with one's patients has always been a key characteristic of palliative care—all part of responding to the patient's "total pain." Unfortunately, there are still those who say that allowing patients to learn that they are terminally ill will destroy hope and leads to irreversible despair and depression. However, in reality, the opposite is more often the case—lies and evasion isolate patients behind a wall of words or silence that prevents them from sharing their fears and anxieties [14]. Palliative care demands a commitment to openness and honesty:

A promise we can keep and a hope we can give is the certainty that no man or woman will be left to die alone. Of the many ways to die alone, the most comfortless and solitary must surely take place when the knowledge of death's certainty is withheld. . . . Unless we are aware that we are dying, we cannot share any sort of final consummation with those who love us. Without this consummation, no matter their presence at the hour of passing, we will remain unattended and isolated. For it is the promise of spiritual companionship near the end that gives us hope, much more than does the mere offsetting of the fear of being physically without anyone [15].

These words, penned by an American surgeon, echo the sentiments of Cicely Saunders. She would have agreed that the ultimate tragedy is not death but depersonalization—and that one potent cause of this is isolation from the spiritual support of other human beings, leading to a sense of desolation and helplessness. Unfortunately, globally, a “conspiracy of silence” and a “conspiracy of misleading words” are still major causes of suffering.

FOUNDATION MEASURES

For countries beginning to think about the need for palliative care, the WHO stresses the need for three “foundation measures”:

- policy
- education
- drug availability.

Unfortunately, there can be a wide gulf between a policy statement and a program of action. Thus, for example, some 15 years ago, India became the first country formally to adopt the WHO’s Comprehensive Cancer Control Programme. However, only now (2007), for the first time, will palliative care feature in a five-year Action Plan.

Generally, there is always resistance to change. In relation to palliative care, those most resistant to or indifferent to the need for change are often oncologists. Palliative care is seen as an admission of failure (something which is very hard for most doctors), but also as a threat to their earnings. The fact that most major cancer centers around the world still do not fully integrate palliative care is a black mark on the medical profession.

Limited drug availability, specifically of morphine, continues to be a major obstacle to the development of palliative care [16]. The ability of Drug Regulatory authorities to block or hinder the ready availability of cheap generic oral preparations of morphine has to be seen to be believed. David Joranson, Director of the Pain & Policy Studies Group, University of Wisconsin Comprehensive Cancer Center, and Head of the WHO Collaborating Center for Policy and Communications in Cancer Care, has helped local palliative care activists in many countries over the last 10-15 years. But it seems that one has to be a Houdini to escape from the ensnarement of bureaucratic (and indifferent) red tape. This is another black mark, but more for government agencies than for the medical profession.

MOVING GOALPOSTS IN DEVELOPING COUNTRIES

Regrettably, most people in the developing world who need palliative care have no chance whatsoever of accessing it. For them, it just does not exist. In such countries, the government Health Departments struggle to fund their public health programs and acute medical services. There is literally no money for palliative

care. One way of circumventing the impasse is to develop a truly community-based and community-owned palliative care service: “for the people, by the people, with the people.”

Thus, in Kerala, a state in South India with some 30 million inhabitants, Neighborhood Networks in Palliative Care are being established. This resulted from the realization that doctor-led palliative care clinics, many functioning just one to two days per week, could never provide holistic palliative care for all those who needed it. As a consequence, it was decided to set up “neighborhood networks” of trained non-professional volunteers. The volunteers identify people in their locality who would benefit from palliative care. As a result, many patients are being included in addition to those with an end-stage disease. Patients in the following categories are now being supported socially (including financially), psychologically (extending to spiritually), and physically by the local palliative care network:

- stable chronic disorder, such as post-traumatic paraplegia
- fluctuating chronic disorder, such as lymphedema, sickle-cell disease
- slowly progressive disease, such as peripheral vascular disease, HIV/AIDS
- end-stage progressive disease, such as cancer.

In these localities, the definition of palliative care has become *the active total care in the community of patients with a chronic disorder or advanced disease, and their families*. Already, after just five to six years, there are >70 functioning groups, with plans for state-wide coverage and support from at least one major political party. Remarkably, one group has extended its services to chronic psychiatric patients. In the Districts served by a Neighborhood Network, in just a few years, estimated coverage of those in need of palliative care has risen from about 30% to >80%.

Hospital-based Pain and Palliative Care Clinics, already established in several major hospitals (mainly by anaesthesiologists), are of course still necessary for patients with intractable pain or other refractory symptoms, and for patients with non-malignant chronic pain. Such centers are also necessary for teaching and training purposes, and for “hosting” diploma and other postgraduate courses.

A similar reliance on community volunteers is also true of parts of sub-Saharan Africa, although the focus there is still end-stage disease. In this region, HIV/AIDS has overtaken cancer in terms of numbers and social impact. In some African countries, between 30% and 40% of the adult population is HIV positive. Often it is the main breadwinner who is struck down. Thousands of children have become “AIDS orphans.” As a result, it has become necessary to redraw the diagrammatic representation of palliative care (Figures 3 and 4).

These local developments in India and Africa—and no doubt elsewhere—have broadened and deepened the scope of palliative care. It is exciting that, globally, palliative care is increasingly breaking out of its original cocoon, and is imaginatively and compassionately responding to neglected and unsupported

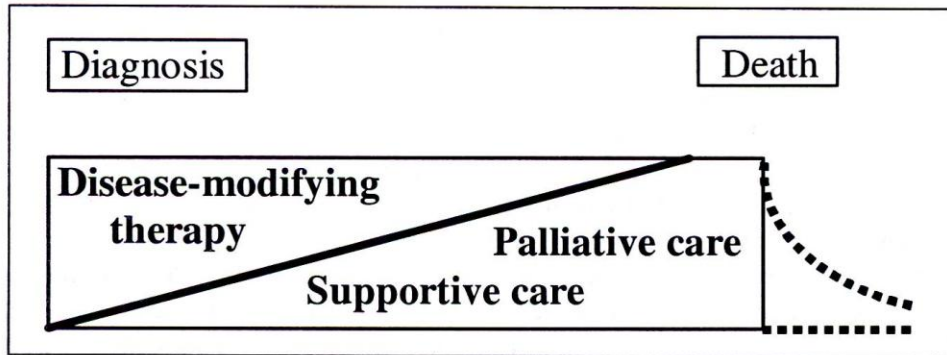


Figure 3. Traditional diagram illustrating the relationship of palliative care to disease-modifying/curative treatment.

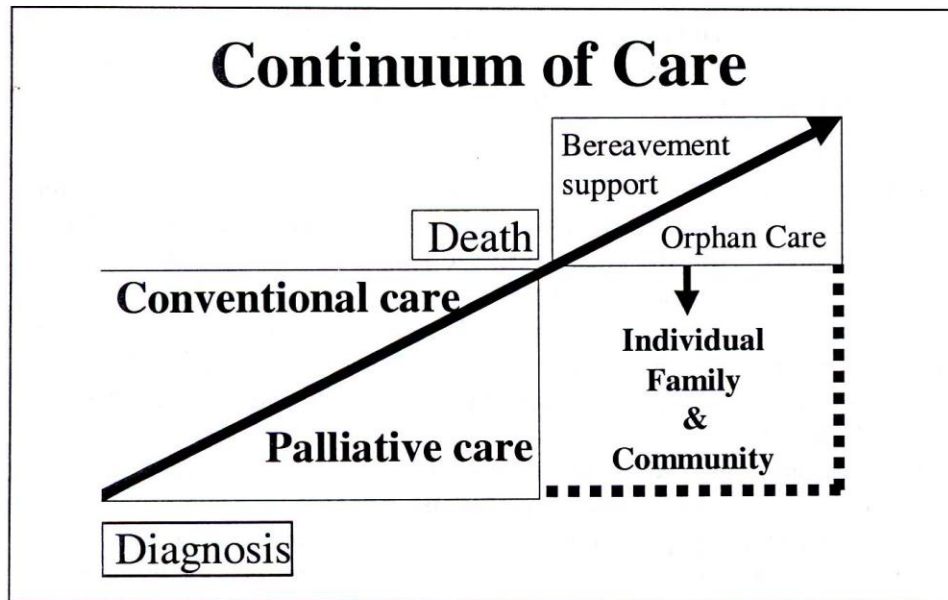


Figure 4. Modified diagram illustrating the extension of palliative programs in sub-Saharan Africa (Kath Defilippi, South Coast Hospice, KwaZulu Natal, South Africa).

suffering of many kinds in the wider community. It calls for inspired leadership—and a true partnership between the community and the health professionals. The bulk of the “active total care” will be provided by trained non-professional volunteers in the patients’ homes, with health professionals involved only with patients who have a persistent problem in relation to symptom relief or psychosocial support.

MOVING GOALPOSTS IN DEVELOPED COUNTRIES

Generally, in developed countries, a short prognosis is the entry ticket to specific palliative care services. However, unlike with most cancers, prognostication is not straightforward in other end-stage disease. Fortunately, there is a pragmatic way forward through the morass of uncertainties, and that is to ask the “surprise question.” “Would I be surprised if this patient died within the next year?” If the answer is “No,” then it is time to adopt a palliative approach to care.

Paradoxically, despite its seeming unscientific nature, the question is in fact the only scientifically acceptable one in this context, and it provides a satisfactory basis for a pro-active change in the overall direction of care. Unfortunately, most doctors are not prepared to adopt this strategy. In consequence, globally each year, millions of patients suffer unnecessarily because they are subjected to increasingly futile, and increasingly burdensome, life-sustaining treatment. However, there are encouraging developments. For example, in the United Kingdom, a cadre of specialist nurses is being built up. Each nurse specializes in one specific type of progressive disease, e.g., diabetes, or COPD, or heart failure. They monitor the impact of the disease on the patient and the family, act as trouble-shooters, and provide the all-important listening ear and empowering presence. Because such nurses adopt a holistic approach, they are well-placed to provide an effective link between the cure-oriented specialties and Palliative Care.

However, if traditional cancer-oriented palliative care services are to care optimally for patients with, say, end-stage heart failure, they will need to develop what, for them, is a novel approach to care. For example, cancer patients receiving chemotherapy often feel worse for their anticancer treatment, and the default position in palliative care is to encourage its discontinuation if the burdens of treatment appear to outweigh any benefits. In contrast, the patient with heart failure generally feels better for disease-specific treatment, and it needs to be continued, judiciously adjusted, perhaps simplified, and closely monitored [17]. Further, palliative care in heart failure could be intimidating because of the need to enter a Brave New World littered with interventions which may significantly improve the patient’s physical status, and even prognosis—a world which includes CRT, ICD, LVAD, CPR, and even heart transplantation. But here again, particularly with input from a Specialist Nurse, the traditional cancer-oriented palliative care team could rapidly learn to negotiate their way successfully through the mine-field of additional treatment possibilities.

The corresponding challenge for cardiologists is to make sure that their most needy patients do not miss out on the added benefits of a palliative approach to care. Those in greatest need will include those who are being considered for a “high-tech” intervention. But it is these who perhaps are least likely to be referred to a palliative care service because “We’re not at that stage yet—there’s still a lot more we can do.” In consequence, the myriad other problems contributing to the patient’s misery fester unaddressed on the sidelines.

CHARISMA VERSUS ROUTINIZATION

It has been said that history alternates between charisma and routinization. In this context, charisma refers to the ability of exceptional individuals to act as a catalyst for social change, and acknowledges the impact of personality in bringing about radical innovation in institutions and established beliefs. Thus, in countries where palliative care is well-established and fully integrated into the health systems, the challenge is to prevent palliative care moving from the creative and disruptive influence of charisma to the cozy ambience of routinization.

This is important because movements which become routinized tend to become monuments, rigidified by bureaucracy. Even in the United Kingdom, palliative care services generally have not yet reached their full holistic potential. So the best tribute we can give to Cicely Saunders, and to other charismatic leaders in this field, is to make sure that palliative care remains *a movement with momentum*, combining creative charisma with inevitable bureaucratic routinization.

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