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Palliative Care in the 1990s: Special Issues*

Derek Doyle, MD†

My views on hospice, though based on British experience, are not unrelated to hospice care in the United States. I believe that in order to prepare ourselves for the future, we need to understand something of our past and the influences which molded us. The first such influencing factor in the field of hospice is public opinion.

Social historians will surely record how the general public enthusiastically accepted and helped to develop and influence hospice care. While the public undoubtedly appreciated the continuing advances in modern medicine, people often felt that care offered to the dying was less than satisfactory. Many studies of public opinion reported disquiet about the communication skills of medical professionals as well as dissatisfaction with the incidence of unnecessary suffering of terminally ill patients. As a result, the public applauded the initiatives of the medical pioneers of hospice care, contributed both to founding and funding such services, and came to view hospice care as an expression of consumerism.

Others who watched with interest the development of hospice care were the health care managers and economists. They were interested in whether hospice care was cheaper than conventional hospital care and were no doubt attracted by the prospect of high-quality care provided at reduced cost by professionals apparently characterized by unlimited dedication despite grossly limited income and often lukewarm acceptance and recognition by their professional peers. Presumably these administrators, like some medical colleagues, saw the possibility of extending hospice or palliative care beyond the ranks of cancer patients to geriatric care and in particular to domiciliary care of the dying.

The medical profession itself has played a major part in the development of hospice. Not only was the philosophy of skilled, compassionate care of the dying defined by our pioneers, but so was the emphasis on "total" care of body, mind, and spirit; the reaffirmation that all such care must be scientifically based and evaluated and due attention paid to the needs of family and professional colleagues.

I have been privileged to see firsthand the hospice/palliative care services in many different countries. What is most striking is the professional and personal caliber of so many of the doctors and other caregivers who have selected this work as a career. Contrary to the opinion of many critics, these people have not chosen an easy path, have not come into it because they could not succeed in academic circles, and are not unscientific, religious zealots. Many are choosing a hospice career because it is academically and professionally satisfying and personally demanding. They bring to this field outstanding sensitivity to the deepest human needs coupled with personal, management, and teaching skills of the highest order.

No one can fail to notice that hospice care has developed almost exclusively and most extensively in the West and in Westernized countries such as Japan, Australia, and South Africa. In such countries medical care is universally available, sophisticated, and advancing rapidly. Those who receive hospice care usually have had the benefit of high-technology investigations and the best surgical and oncological opinions. Hospice care for the dying is the cherry on the icing of an already rich cake. Inevitably it may have already come to be seen as "luxury" care, the right of any patient who has already had all that money can buy.

Hospice care is a product of the affluent West, a response to pressures from a sophisticated, articulate, consumer-conscious public. It is attractive to doctors who see in it a worthwhile challenge to restore dignity to a system of medicine which may have lost sight of quality of life in its striving for cure as the only acceptable goal.

Problems in Hospice/Palliative Care

Public demand for hospice care seems to be insatiable, little different from the demands faced everywhere in the provision of health care. In Britain we have the impression that were sufficient resources available, both to found services and to fund them, the public would have a hospice service in every town and city. Little thought is given to continuing revenue needs and even less to the scarcity of adequately and appropriately trained doctors to provide such services. Little attention is paid to strategic planning and cooperation with neighboring units and national guidelines. The public, which feels helpless to challenge or change a monolithic health service, sees in hospice care something it can initiate and, to some extent, control or influence. However, the future of hospice care does not lie in the uncontrolled proliferation of units and services but in infusing the

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The future of hospice care does not lie in the uncontrolled proliferation of units and services but in infusing the principles of such care into the mainstream of medicine, in hospitals and family practice. Consumer drive must not be allowed to become consumer direction... only the medical profession can set guidelines, establish appropriate training, and ensure the highest medical standards.

Some blame lies with us, the senior professionals in hospice care. If some members of the public and some cost-conscious health care administrators misunderstand what we offer and how we operate, we must accept the blame for their ignorance. The onus is on us to define hospice care, to describe its essentials, to research and audit what we do, and to invite our peers to replicate it to their own satisfaction—in a word, “scientific evaluation.”

One subtle, adverse effect of consumer interest and acclaim is its effect on our professional attitude to this work and to our colleagues in other disciplines. Members of the public who were so disappointed with the care previously offered to the dying, who were so critical of the communication skills of oncologists, and so specific and articulate in their criticism, seem to lose this critical faculty when they comment on hospice care. We who come in at the end seem to do nothing wrong. The quality of care is good, the ambience of our units just right, the skill of our communication with patients and families what they had always wanted—or so they would have us believe. This is reassuring, but it is also dangerous. Too readily we can be lulled into believing them, forgetting that we often face fewer ethical dilemmas, have to make fewer difficult decisions, and, after all, that we ought to be able to offer better care when we work as integrated, specially-trained teams in well-endowed, well-staffed units. Consumer satisfaction with our work does not give us license for complacency, nor freedom to criticize our colleagues whose work is often so much more difficult and demanding. It would be churlish of us to dismiss their grateful comments, but the ultimate test of our work and its value should be whether it is so recognized and approved of by our colleagues that they want to emulate it.

Hospice care is almost an exclusively Western phenomenon, but we must ask if this should remain so. If we mean by “hospice” a brick and mortar building, the answer is probably yes. If, on the other hand, we see hospice as a philosophy of care—the total, team caring of patients with advanced disease and a predictably short prognosis for whom cure is impossible and the focus of care is the quality of life—then it would be better to call it “palliative care.” These two terms are now being used worldwide and gradually the professionals are preferring palliative care while the public remains more familiar and comfortable with hospice care.

The relevance of this terminology to the rest of the world is now clear. Millions of people have no means of obtaining curative care yet need access to relief of pain and suffering. They would suggest this is possible, and in the case of doctors desirable, by making greater use of volunteers. To do so would diminish our essential professional input and change the fundamental nature of hospice care. Few would deny that volunteers have a role, particularly if their professional and personal skills can be utilized, and hospice care might rightly claim to have demonstrated the contribution they can make. However, the role of the volunteer is a complementary one. Volunteers cannot replace professionals who have committed themselves to this discipline and extended their skills through advanced training and who bring the unique benefits of coordinated continuing care to their patients.

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The relevance of this terminology to the rest of the world is now clear. Millions of people have no means of obtaining curative care yet need access to relief of pain and suffering. They
need palliative care. For decades to come, palliation is all they can hope for, yet millions do not even have that. As the World Health Organization has so eloquently shown, the availability and the use of morphine is abysmally limited in all but 13 countries, with little increase in availability in some and diminishing availability in most others. Even some of the major countries of the world have nothing stronger than codeine and no doctors whatsoever trained in or committed to providing adequate pain relief. To suggest that the first priority throughout the world is the establishment of modern cancer services staffed by oncologists with access to radiotherapy equipment and our present armamentarium of chemotherapeutic agents is nonsense. Before that is achieved, scores of millions will have died after months or years of suffering which could have been dramatically alleviated had they had access to palliative care. Should this be any concern of ours?

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Pressing Issues in Palliative Care

We must begin by defining palliative care, by defining what we do and who we are. This is important in relation to the public but even more important for our professional colleagues. We must not complain if we are not understood or respected, but instead set out to demonstrate that palliative care is nothing new. We have not invented anything but rather rediscovered something which has long been at the heart of medicine, long before we had the means either to cure or to put diseases into remission. Palliative care and curative care are not incompatible. The best doctors have always hoped to cure but been equally skilled and ready to relieve when cure was impossible. We are not in opposition to traditional medicine but surely are a part of mainstream medicine. We are, ourselves, ordinary physicians from many backgrounds and specialties, using standard drugs, reliant on modern diagnostic aids, interested in every aspect of our patients' lives, but focusing on the time when quality has replaced quantity.

We have no right to be accepted by our peers. We must earn their respect and shall do so only if we define, research, and publish what we do, if we show our respect for them and share our knowledge and skills with them.

Sadly, palliative medicine has a poor record of research and publications. Much of the fundamental work on which our practice is based was done by colleagues in other disciplines, particularly pharmacology, neurology, oncology, and anesthesiology. We owe them a tremendous debt but must recognize that, with a few notable exceptions, there are too few from within our own ranks who are committed to research. Why is this? Do some feel research and palliative care are somehow incompatible, endangering the privacy and dignity of our patients? Surely not, for we are not necessarily speaking of experimentation but rather observational research and data collection. Could it be that some physicians have come into this work to avoid the pressures to research and publish, usually associated with our teaching hospitals? Are many of us not trained in simple research methodology and too proud to ask for help? Are we inadvertently creating a cadre of doctors which is not attractive to the research-minded colleagues who might otherwise wish to join our ranks? This issue must be addressed.

Here I must declare my British experience and state my conviction that palliative medicine must be recognized as a full specialty as has now happened in my country. Its knowledge-base, track record, and declared objectives merit it. Certainly in Britain this recognition has given it a standing, a credibility, which has to be seen to be believed. Its practitioners are increasingly accepted as equals by other colleagues. Its voice is being heard and apparently respected on committees and in colleges. Its input into patient care, whether in the home or in major teaching hospitals, is being welcomed and appreciated. It is now attracting some outstanding young doctors who previously would have brought credit to whatever specialty they entered but have positively elected to devote their lives to palliative medicine. Like the pioneers I referred to, they have not opted out of academic medicine for something easier and less demanding but rather have chosen this field for the challenge it presents and the rewards it so clearly offers. This, too, is an issue we must address.

Whether or not we seek recognition as a specialty (with its rigorous training program), we cannot evade the obligation to teach the doctors of tomorrow. The principles of palliative medicine are not absorbed by passive osmosis nor easily taught in lecture theaters. They require charismatic teaching and demonstration. This will necessitate a formal input into undergraduate and postgraduate programs, the presence on staff of palliative medicine physicians not only prepared to teach but trained to teach, and nationwide courses for family physicians and hospital specialists who want to update their skills. The necessity for medical input of the highest quality is therefore undeniable. The
need for sufficient such teachers is obvious. In some countries a
start has been made. There are now four Chairs of Palliative
Medicine and in Britain it is included (albeit in a modest way) in
the curriculum of each medical school. If palliative medicine is
as important as we say it is, it must surely be taught in every
medical school in the world. Are we addressing this issue?
The ethics of palliative care are not different from those of
other disciplines or specialties, though we more often seem to
find ourselves wrestling with some of them. One challenge we
face is that our work can easily be misunderstood by the public,
particularly with regard to euthanasia. Presumably all of us
would deny that we ever intentionally abbreviate a patient’s life.
Very occasionally it may perhaps be shortened if we have to re-
sort to heavy sedation (as distinct from skilled analgesia with
opioids which often appears to prolong life and bring its own
problems), but what matters is our intent. Similarly, we may oc-
casionally not exhibit antibiotics in the final days when their use
would neither improve the duration nor the quality of life. We
would not unquestioningly use intravenous rehydration in the
final days when simpler palliative measures were open to us.
The intent is not to abbreviate or end life but some observers
might see this as passive euthanasia. So long as the public (and
even some ill-informed doctors) continue to believe that life is
always shortened by opioids, so will they see us as agents of eu-
thanasia. There is, I suggest, a real danger that palliative care
will be seen by some as passive euthanasia. They are wrong but
the onus is on us to declare why we do what we do.
The public which increasingly calls for “Living Wills” will be
attracted by what we do. As our population of old people in-
creases as projected, and ever greater demands are made on geri-
atric services, even some of our own profession who, like us,
would never subscribe to euthanasia may see our units and ser-
dices as better places for the elderly. We are faced with the need
to repudiate most clearly any suggestion that we are involved in
passive euthanasia or that we are a cheaper, more “Living Will”-
friendly place for geriatric care. Unless we come out with clear,
unequivocal statements of our work and its intent, we must not
be surprised if the public see some hospices as pro-euthanasia.
Debate must continue about the care of patients with the ac-
quired immunodeficiency syndrome (AIDS). Can they, should
they, be assimilated into our existing services? That the prin-
ciples of palliative care apply to AIDS patients is beyond ques-
tion, but we must resist public pressure for us all to become in-
volved unless our services, and we the physicians, have the re-
sources, the skills, and the knowledge to care for these patients
as they deserve. My understanding is that many AIDS patients,
until a very late stage in their illness, need diagnostic and care
facilities quite different from most cancer patients. I offer no an-
swer but only caution that, once again, the public may bring
moral (and even financial) pressure on existing hospice services
to become involved when they are not professionally equipped
to do so.
I have asked many questions but proffered few answers. I
have welcomed consumer interest but cautioned against it. I
have urged that we define our work and heighten our profession-
alism; that we face up to ethical misunderstandings and eco-

one pressures; that we explore specialization and do not ne-
clude education and research; and have challenged us to look be-
yond our present boundaries to the needs of a world crying out
for palliative care.
We are one of the most privileged groups in modern medi-
cine. We must demonstrate our blossoming maturity and our in-
debtendness to many colleagues by our attention to these issues.
If we fail to do so, no one else will do it for us.