Appropriate palliative care: when does it begin?

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The transition between a curative and a palliative approach to the care of a patient with cancer may be filled with uncertainty for patients, their families and health care professionals. A conventional model of treating the patient with cancer through curative, palliative and terminal phases is examined. The boundaries between the phases of care are blurred. A model of care based on respect for patient autonomy ensures that the timing of the switch from curative to palliative care is appropriate.

Keywords: curative, palliative, terminal, autonomy, multidisciplinary, informed consent, decision making.

Vex not his ghost: 0, let him pass! he hates him much
That would upon the rack of this tough world
Stretch him out longer.
King Lear, V, 3

INTRODUCTION
At first glance, it seems that the care of a patient with cancer may be divided conveniently into different phases, each determined by the primary aim of treatment and care: curative, palliative and terminal (Ashby & Stofell, 1991). This paper challenges the model and explores the ethical dilemmas encountered at the interface between curative and palliative care. Ethical debate of these issues has practical implications for the quality of patient care. George & lennings (1993) suggest that clinical decision making and planning is more difficult when it is certain that the patient will die despite our best efforts. However, it may be that greater uncertainty exists at an earlier stage of disease, when clinicians may be caught in a dilemma between over-treating patients on the one hand or neglecting some remote chance of cure on the other. Practical ways of reducing this uncertainty will be discussed.

THE PHASES OF CANCER CARE
Curative
In this phase of care there is a realistic chance of cure or long-lasting remission. The aim of care is survival of the patient. Ashby maintains that some harmful side-effects of treatment may be acceptable to the patient in return for a good chance of cure (Faithfull, 1994; Ashby & Stofell 1991). However, ‘cure’ may have different meanings for doctors and patients. Doctors may measure a cure in terms of a 5-year disease-free survival. For the patient, however, a cure is more than survival and implies a return to the normality which existed before the onset of the cancer (Faithfull, 1994). Nowadays, doctors may be concerned with applying a sophisticated technology to remove disease: the current concept of cure. This scientific approach to curing provides a stark contrast to palliative care. Here, care is concerned more with the subjective feelings of the patient, and the impact of the illness on the social, emotional and spiritual aspects of his life than with the pathology of the physical disease.
Palliative

The aim of treatment in this phase is to maximize the quality of life of the patient by promoting his capacities to make and take responsibility for his own choices. Health is not seen as the absence of disease, but as the expression of the individual’s body, mind and spirit to its own maximum potential. Ashby’s risk-benefit analysis model implies that treatment side-effects should be less harmful than the effects of cancer itself (Ashby & Stofell, 1991). Palliative care involves more than the control of distressing symptoms; it aims to relieve suffering, a subtle concept which extends to the way in which the illness affects the whole individual. In the palliative phase there are shifts in emphasis from quantity of life to quality of life and from pathology to person (George & Jenning, 1993). These shifts have an important consequence: a requirement to listen to the patient’s views and to respect his autonomy.

Terminal

In this phase, the aim of care is to enable the patient to die with dignity. Harmful or distressing side-effects of treatment are not acceptable (Ashby & Stofell, 1991). Doctors may, however, be placed in a difficult situation by relatives who equate continuing active treatment with maintaining the patient’s hope and morale (Faithfull 1994). These attitudes are one consequence of the medicalization of death. Death is no longer a familiar natural event. Dying is often perceived to be a frightening, painful process, which should occur in hospital, rather than at home.

The curative–palliative interface

In Ashby’s model, the nature of ‘appropriate’ care changes as the condition moves from one phase to another (Ashby & Stofell, 1991). This model assumes that the boundaries between these phases are clear and the focus of change is the progression of disease pathology. How do we know when to change from a curative to a palliative approach? Clinicians offer differing definitions of the starting point of palliative care. Calman (1988) states that palliative care begins when

‘the diagnosis of cancer is established, death is certain and likely in the near future, and a curative approach to care has been abandoned’

This statement does not help us in deciding when to abandon a curative approach. It also seems to exclude situations where ‘aggressive’ chemotherapy is given with apparent curative intent to patients with widespread cancer. A recent definition states that,

‘Palliative medicine is the study and management of patients with active, progressive far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life’ (Doyle et al. 1993).

The speciality of palliative medicine is thus defined in terms of the stage of disease progress rather than on any particular pathology (Doyle, 1993). Predicting when death is going to occur may be difficult. Specialist palliative care nurses and hospice units emphasize the importance of early referral of patients if the highest standards of care are to be achieved. On the other hand, general practitioners are often faced with uncertainty about the rate of progress of the disease and defer referral to such specialists until ‘the end’.

The timing of the change from a curative to palliative approach to caring is a complex clinical and moral dilemma, which is fundamental to the care of patients whose cancers have advanced. Delay in making the decision may result in a patient receiving inappropriate therapy designed to maintain hope rather than offer a chance of prolonged remission or cure. On the other hand, doctors do not want to stand accused of neglecting patients when further curative treatments might be possible.

We are left with a clinical impression which infers that these divisions between the phases of cancer care are artificial. Because the boundaries of care are blurred, it may be more appropriate to shift our attention to respect for the patient’s autonomy.

When the stated goal for a patient is cure, professionals have greater confidence in their capacities to work toward that goal. However, when the diagnosis and prognosis is uncertain or thought to be incurable, then doctors and nurses may become less assured of their skills and roles. The doctor may feel or say ‘There is nothing more I can do’ (Calman, 1988). Much of clinical medicine involves handling uncertainties. It is therefore useful to explore the uncertainties surrounding the change from a curative to a palliative approach to care. The uncertainties involve doctors, nurses, patients and their relatives.

UNCERTAINTIES FOR DOCTORS

Doctors treating a patient with a potentially fatal cancer, may feel that they have failed the patient if curative attempts are unsuccessful. Modern medicine seems so powerful that there is a risk that we lose sight of the cancer’s
potential to cause death. For instance, in widespread metastatic disease, to what extent should we spend resources hunting for the primary tumour? Estimating the prognosis for an individual patient is notoriously difficult. How much of this uncertainty should be shared with the patient? Who should make the decision to switch from curative to palliative care? Palliative care demands a team approach to care. To what extent should the patient be included in decision making? Reaching a moral consensus within a multidisciplinary team may be difficult.

A conflict often exists between technical care and personal care. In the busy context of modern medicine, time to listen to patients may be perceived as a luxury. Medical training concentrates on clinical competence. There is a danger we may forget that compassion is a vital part of caring.

Ethical dilemmas form one of the most challenging aspects of medical care. Struggling with questions which have no obvious answer is an essential part of our professional role. In striving to act with integrity, honesty and a sense of moral responsibility we define what lies at the heart of what it means to be a doctor.

UNCERTAINTIES FOR NURSES

Nurses work in a different management structure from doctors. Nurses are organized in a hierarchy whereas doctors work in a collegiate system. This can mean that a nurse may be faced with loyalties divided between patient, doctor and manager.

Much of palliative care is nursing care. Traditionally, nurses are closer to patients and more aware than doctors of the wider needs of the patient. These needs, which may be psychological, social or spiritual, may be of greater significance to the patient than his medical problem. Nurses may be placed in a situation where they have to act as an advocate for the patient. Advocacy is a useful mechanism for power sharing within the team, but all too often it is perceived in a negative way, as a threat or implied criticism of medical care. Doctors need to listen to their nursing colleagues who often have a more accurate view of the patient’s concerns. It is illogical to speak of equality for patients but not for colleagues who happen to work in a different discipline.

Nurses may also feel uncertain if there is no clear team philosophy. A patient with advanced cancer may ask a nurse how serious his condition is. How is the nurse to respond if she knows that the consultant always gives an optimistic prognosis? We need to respect the autonomy of colleagues and take time to listen to their views.

UNCERTAINTIES FOR PATIENTS

When a cancer is no longer thought to be curable, the patient’s world becomes filled with uncertainty. The word ‘cancer’ implies lack of control. Cancer is widely regarded as inevitably involving a painful and undignified death. On the other hand, patients may have unrealistic expectations of medicine’s power to cure. Calman defines quality of life in terms of the gap between a person’s expectations and the reality of his situation (1984). Where there is a wide discrepancy between expectation and reality, then quality of life is low. Calman’s model serves to emphasize that part of a doctor’s role may be to help patients to have more realistic expectations, particularly at the point where the focus of care is changing from curative to palliative.

Palliative care aims to maximize patient autonomy, so long as it does not adversely affect the autonomy of others (Jeffrey 1993). Taking responsibility for his choices may mean that the patient will blame himself if events turn out badly. When curative measures are failing and the switch to palliation seems likely, doctors may be tempted to make decisions for their patients. This behaviour derives from a duty to do good and is described as paternalism. When faced with an uncertain patient and a complex clinical dilemma which demands a decision, the doctor may act in a paternalistic way and do what he feels is best for the patient. This type of paternalism excludes the patient from decision making and threatens autonomy.

At the interface between curative and palliative care it is particularly important to give patients their final opportunity to exercise their autonomy by giving as much information as the patient needs. Respect for patient autonomy demands that patients be given honest answers to their questions. Without honesty, moral discourse becomes impossible and communication pointless. Without honest information a patient becomes more uncertain and is unable to make decisions about his future. Patients need just as much information to make rational decisions about their medical condition as they do for any other sphere of their lives. If the doctor is uncertain at the transition of curative to palliative care, he needs to acknowledge his vulnerability, and seek to share his concerns with the patient and his colleagues.

Patients are tougher than we think. Professional carers who wish to give appropriate care need to make some evaluation of the quality of the patient’s life. It is important to remember that the most reliable assessor is the patient himself. Quality of life relates both to objective features of disease, and to subjective feelings, hopes and fears. The concept of quality of life extends beyond a balance between the impact of a treatment and its side-effects to recognize
and respect the autonomous individual—the patient—in the social context of his relationships with family and friends (Fallowfield 1990).

**UNCERTAINTIES FOR RELATIVES**

There may be a feeling of helplessness and a perception that their loved one is suffering. Relatives often fear the harm of giving honest information to the patient. They may insist that the doctor must not tell the patient that cure is no longer possible. ‘The news would kill him, doctor’. Thus, collusion is born, and grows to isolate the patient from his loved ones, doctor and nurses.

Relatives need time to share their fears and distress. We need to acknowledge that they are acting from the best of motives—to preserve their loved one from harm. Relatives need to discover for themselves the cost of maintaining deception, a distancing from the patient. Finally, they need help and support in sharing the truth with the patient (Maguire & Faulkner, 1988).

Collusion is difficult to manage, but is easier to prevent. If doctors resolved to discuss the diagnosis with the patient and the relatives together, then collusion would be less likely to occur. Respect for autonomy demands that the patient should be the first to know what is happening to his body. Professionals can help by suggesting that relatives are present at these discussions.

The relatives may insist that ‘something must be done’. Doctors need to explain that good palliative care does not mean giving up care. Medical care has the power to harm, as well as to heal. We can mutilate, make patients vomit or lose their hair. We need, therefore, to be certain that these risks are accepted and understood by the patient, who can then weigh them against potential benefits.

**PALLIATIVE TO TERMINAL CARE**

The phase of terminal care involves the last days of someone’s life when death with dignity is the aim of care. Relatives may express their distress in terms like ‘I would not let a dog suffer like this’. This may surprise the professional carers who sees a patient who seems to them to be dying peacefully. Carers may also become distressed if dying seems to be prolonged. Perhaps patients die as they have lived, some with quiet acceptance, others ‘raging at the dying of the light’ (Thomas, 1992). We have duties of care to ease suffering, but not to hasten or prolong the process of dying.

Active euthanasia is now being debated in the UK. The debate is beyond the scope of this paper but doctors working in palliative care need to make a clear public statement of their position on this issue (Jeffrey, 1994). Plausible arguments for active euthanasia, based on particularly difficult individual cases, have been advanced (Institute of Medical Ethics, 1990). However, I believe that even the slightest erosion of a doctor’s duty not to kill would cause irreparable harm to patient care. Furthermore, the fact that the euthanasia debate has resurfaced at a time of reduced and inadequate resources for health care, is a reflection on the values of our society. We must not confuse our attempts to measure the quality of a patient’s life with the value of that life. Whatever our religious beliefs, we share a general notion of the special value of human life. We need to accept that death is a part of every life, it may come as a relief, but it is not an option for doctors as a means of achieving relief (George & Jennings, 1993).

On the other hand, ‘letting die’ differs from active euthanasia since it acknowledges that cancer has a lethal power. When further resistance becomes futile, then letting die is I believe justified. Doctors do not have a duty to prolong life indefinitely at whatever cost to the patient.

**COPING WITH UNCERTAINTY**

The key to coping with the various uncertainties which arise in beginning and ending palliative care lies in the process of sharing information and thus respecting patient autonomy. Doctors need to share their uncertainty with patients and families, and with their nursing colleagues. Informed consent is a mechanism for sharing the power of the doctor and the patient, and thus protects patient autonomy from well-meaning medical paternalism. Gillon defines informed consent as a voluntary uncoerced decision made by a sufficiently competent or autonomous person, on the basis of adequate information and deliberation, to accept rather than reject some proposed course of action that will affect him or her (Gillon, 1985). If treatment is aimed at controlling symptoms rather than cure, then patients need this information. Only then can they determine what choices to make. The central function of informed consent is to ensure a sharing of knowledge between the doctor and the patient. The process of seeking informed consent is a powerful way of demonstrating respect for a patient’s autonomy. Through this sharing process patients receive appropriate care from doctors they trust and doctors gain deeper understanding of the real needs of the patient. Informed consent is a dialogue between a patient and his doctor in which both become aware of the potential harms and benefits for the patient. It is much more than a granting of permission.
SUMMARY

No individual has the skills or strengths to meet all the needs of the dying patient. Multidisciplinary teams of doctors, nurses and other professional carers can have the resources to meet the challenge of caring for patients with advanced cancer. Doctors and nurses need to face the moral challenge of sharing access to the patient. The alternative is to see care directed to maintaining interprofessional boundaries rather than respecting the autonomy of the patient. Sharing information within a team is a means of sharing power and of respecting the autonomy of one’s colleagues. Much of palliative care is nursing care and we should protect and preserve this vital caring element of our work. Medically defined interventions, made without input from nursing colleagues, risk neglecting the social, spiritual or psychological needs of the dying patient and tend to focus on disease pathology. Research offers another mechanism for coping with uncertainty. There is a need for qualitative research to explore the process and effects of medical, nursing and patient decision-making at the interface between curative and palliative care.

Appropriate palliative care depends upon the formation of a caring partnership between doctors, nurses and patients. This partnership will ensure that resources are not wasted on unnecessary treatments, that patient autonomy is respected and professionals are better equipped to avoid burn-out.

A patient writes

‘Patients want to be able to trust doctors. We need drugs for symptom control. We want to remain clearheaded to be able to attend to our own affairs and relate to family and friends. We want to use our gifts and talents to the end. We want to be treated lovingly, knowing that we may become unlovable. Most of all we would like to die at home in our own surroundings and hope that we will still have friends there when we do’ (Jolley, 1988).

CONCLUSION

Rapid advances in cancer treatments and the search for cures have created a division between scientific technical care and personalized palliative care. These differing approaches have evolved their own philosophies, and created a boundary between curative and palliative care. Palliative care has changed over the past 30 years to become a more scientifically rigorous discipline. It is now time for those adopting technological curative strategies, to assimilate some of the skills of a palliative approach which focuses on the choices of the autonomous person rather than on the disease from which he happens to suffer. If health care professionals work together with the patient in a true partnership of care, respecting his autonomy, and seeking his informed and understood consent, then we shall have a better chance of achieving our therapeutic aims, whether curative or palliative.

ACKNOWLEDGEMENTS

This paper was presented at the First International Conference of the Indian Association of Palliative Care, Hindustan University of Benares, January 1994. I am grateful to Cancer Relief India for their invitation and to the Royal College of Physicians of Edinburgh for a Myre Sims Travel Bursary.

REFERENCES


