Ethical issues in the treatment of cancer patients*

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Nineteen speakers at the International Conference on Supportive Care—More than Medicine, which was cosponsored by WHO and held in Château Montebello, Quebec, Canada, 18–21 July 1988, presented short introductory lectures and led the Ethics Working Group's discussions on the following ethical issues relating to cancer research and the treatment of cancer patients: telling the truth; allowing to die and practice of euthanasia; clinical research; and limited resources leading to hard choices. This article presents the discussions and recommendations of this Working Group.

Introduction

Over the past several years it has been recognized that one can no longer resolve the multiple and complex ethical issues of contemporary medicine by direct and simple appeal to the doctor–patient relationship. This is particularly true if that relationship is conceived exclusively in terms of the patient's trust and the physician's conscience. The shift today is away from this paternalistic model, acceptable as it may have been in simpler times, towards a doctor–patient partnership in shared decision-making. However, this model based on dialogue between individual physicians, patients, and families in taking decisions and making choices has implications for the medical profession and society as a whole.

A society's ethos and values are today more frequently at stake in the decisions and practice of health-care professionals than ever before in the history of the healing crafts. Rapid advances in the basic sciences and parallel developments in medical technology, have vastly expanded the pathways of

diagnostic and therapeutic intervention into the bodies and psyches of sick people, and into their lives. The number, kinds, and complexity of decisions to be made have increased, now that more can be done. It is equally important to note that the matrix of these decisions has also changed. Societies are now morally more pluralistic than they were several decades ago, and it is, consequently, not always easy to perceive clearly the difference between right and wrong, particularly in situations that display radically new kinds of clinical intervention.

Although the ethical questions and dilemmas of contemporary medicine are inevitably bound up with the circumstances of each individual case, other wider issues exert a critical impact on the common good of nations and of peoples across the globe. Thus, ethical issues raised by the goals and methods of preventive medicine, by resource-intensive innovations in medical science and technology, and by the correlative need to evaluate innovative as well as established treatments are intertwined with matters of science, medicine, economics, law, and public policy. The analysis and resolution of these macroethical issues requires an interdisciplinary method and collaboration quite different from the approach appropriate for the resolution of value conflicts at the bedside. We rightly expect that physicians will battle for the best interests of their patients. We face chaos, however, if those who are responsible for the good of the entire community fail to measure their decisions and policies against the community's governing ethics and the standards of distributive justice (see below). This wider macroethical perspective focuses on issues of a different kind and difficulty from those a physician encounters at the bedside.

* This article is based on the report by the same author, which is published in *Journal of palliative care*, 5(2): 56–61 (1989). The 19 speakers in the Ethics Working Group were: M. Boisvert, J. Cantin and B. Dickens (Canada); T. Haga (Japan); S. Husebo (Norway); T. Kashiwagi and R. Kimura (Japan); R. Levine (USA); W. Mackillop, R. Margolese, A.B. Miller, and B. Mount (Canada); R. Nicholson (United Kingdom); W. Parasiuk, D.J. Roy and H. Schipper (Canada); J. Van Eys (USA); V. Ventafridda (Italy); and P.A. Voûte (Netherlands). A French translation of this article will appear in a later issue of the *Bulletin*.

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A community's governing ethics encompasses what the people believe and perceive to be of the highest importance. The critical question here is: how wide is the perspective we adopt to gauge the scope and depth of our responsibilities to other human beings? Despite the existence of "international law", we are only beginning dimly to perceive that ethics transcends national boundaries. We are a long, long way from full consciousness of our planetary ethical responsibilities; a long way from realizing what the dictates of distributive justice mean when they are applied to the human community across the globe. The right to health care means at least a claim in justice to a fair share, and to a decent standard, of health, medical, and hospital care. It is, indeed, reasonable to argue that this standard can never be identical in all places, or at all times in the same place. Nevertheless some disparities in the share people enjoy within communities and within a nation are clearly recognized as morally intolerable. Clearly there are tremendous disparities in the share of health, medical, and hospital care that people receive within the international community. But do we perceive these disparities as *morally* intolerable? Or do we perceive them as tragic, and relatively unchangeable, facts deriving from nature's laws and the behavioural laws governing relationships between nations?

Though science is largely transcultural, the human community has not yet developed a corresponding transcultural ethics. Some even fear that a so-called "transcultural ethics" could never be anything other than the imposition on some peoples of the ethical views of dominant peoples. Informed and voluntary consent has, at least since the Second World War, increasingly become a standard of doctor-patient and clinical research-subject relationships. Both physicians and patients in a culture that places great emphasis on trust in the physician as an integral part of the healing process may find the situation of open admission of ignorance and uncertainty in a physician to be therapeutically damaging or even absurd. North American culture, for example, emphasizes the value of individual autonomy. Other cultures emphasize the value of the family and the community in resolving disputes and in decision-making. The approach to informed and voluntary consent may therefore be quite different in each of these cultures. Sensitivity to the ethos and values of other cultures is an essential requisite of international collaboration in working towards an international baseline of ethics in science, medicine and health care.

At the Conference the participants experienced how difficult and simultaneously how exhilarating it was to discover where and why people of high moral

standards and very different cultures and histories both differ and agree on matters of vital importance.

Discussions

Telling the truth

Deficiencies in communication between doctors and patients not only cause anguish for those already burdened with more than enough suffering, but also set the stage for ethical conflicts and dilemmas. The latter arise inevitably when decisions of vital importance have to be taken mutually by people who do not really know each other. Reduction of uncertainty and anxiety, which is one of the prime goals of a fruitful patient-physician relationship, increases the ability of both physicians and patients to decide and to act.

Studies and anecdotal experience indicate that problems of communications between physicians and patients are frequent. These problems may arise from the failure of both patients and physicians to realize that truth-telling is a two-way transaction. The physician needs information from the patient, e.g., for accuracy in clinical diagnosis, which is all the more necessary if decisions about appropriate treatment are to take into account the patient's strengths and weaknesses, hopes and fears, desires, interests, and life plans. There is an essentially subjective component to truth-telling when physicians and patients are involved in decision-related communication about health and disease, life and death. The patient's truth may often not be the physician's truth and vice-versa. A genuine relationship is the only way in which each will discover the truth of the other.

Though physicians and patients may say quite different things to one another in different cultures, what is indispensable, even across cultures, is the physician's ability to listen to patients sensitively, to grasp the patient's truth, and then to honour that truth. To be effective in therapy and support, physicians and care-givers have to be masters, in a sense, of each patient's personal language. This ability to listen and communicate is a very important clinical skill which has to be learned, preferably from those who are already experts. Mastery of this skill in listening and communicating should be valued for its high worth and rewarded accordingly in medical and professional schools.

Teaching the clinical skills of communication, however, should rest upon a solid basis of research into the multiple varied expectations and requirements of informed and voluntary consent in different clinical situations. We now face a dearth in the empirical research required to add precision to the

currently general guidelines governing informed consent.

Life and death decisions: euthanasia

Over the past decade, people in many countries have come to accept the notion that aggressive life support, i.e., prolonging life to the bitter end, is frequently not the right thing to do. The ethic has evolved, and is now widely accepted, of allowing terminally ill patients to die with dignity. In practice, this may involve withholding or discontinuing such interventions as respirator support, chemotherapy, surgery, and even assisted nutrition and hydration.

Those in favour of active euthanasia, however, argue that a rapid, painless death is more humane than the slow, lingering one that often occurs even after the decision to withdraw active life-supporting measures. Others who argue against any legalization of active euthanasia base their rejection on one or several of the following considerations: active euthanasia is in principle morally wrong; or it is against the basic tenets of medical ethics; or this act is unnecessary if adequate palliative care is available; or this act would invite us to reduce our efforts to organize adequate supportive and palliative care; or active euthanasia, if legally approved, would inevitably lead to abuse and to a social climate that would exercise subtle pressure on people to choose euthanasia when they really do not want to die. Over the past several years, ethical and legal thinking demonstrate the following stages of progression regarding decisions affecting the prolongation or ending of patients' lives:^a

- (1) Medical dominance: the physician decides.
- (2) A terminally ill patient may reject "extraordinary" means of life support.
- (3) A terminally ill patient may reject "ordinary" means of life support.
- (4) A terminally ill patient may reject nutrition and hydration.
- (5) A non-terminally ill patient may reject ordinary medical care.
- (6) A non-terminally ill patient may reject nutrition or hydration.
- (7) A family may reject "extraordinary" life-supporting procedures for a terminally ill relative.
- (8) A family may reject ordinary life-supporting measures and nutrition for a terminally ill relative.
- (9) A family may reject "extraordinary" and "ordinary" life-supporting measures for a non-terminally ill relative.

^a These stages come, with modifications, from Bernard Dickens' presentation.

(10) A physician may help a terminally ill patient to end his or her life rapidly and painlessly.

(11) A physician may rapidly and painlessly terminate the life of a patient who requests this.

(12) A physician may rapidly and painlessly terminate the life of a patient who is unable to make the request.

The representatives from various countries in the Working Group could not reach a consensus on the above scale of progression and few of them were prepared to endorse all twelve steps.

Although euthanasia—the rapid, painless termination of human life, deliberately done to release someone from pain and suffering—is not legal in the Netherlands, doctors who administer euthanasia will not be prosecuted if they follow certain rules, notably those set down by the Netherlands Medical Association. While this was quietly practised for many years, there is only now open discussion of this matter.

The doctor need not be the one who directly terminates the life of a suffering terminally ill person. In the view of some, the person who seeks release from intolerable suffering should terminate his or her own life if he or she desires. When patients do not know how to do this effectively, the doctor can be instrumental in procuring the needed drugs to effect a rapid and painless death.

A high court decision in Japan in 1962 identified the following conditions (all of which must be met) to render euthanasia an acceptable exception to the general ethical and legal condemnation of homicide:

- The patient must be suffering from an incurable disease, and death must be close at hand.
- The patient must be in a state of intolerable suffering.
- The purpose of euthanasia must be only to release the patient from pain and suffering.
- If the patient is competent, euthanasia must not be administered without his/her consent.
- Euthanasia should be performed by a physician, unless circumstances render this impossible.
- The patient's life must be terminated in a painless, humane fashion.

Some participants emphasized that the wish to die must always be looked upon as the patient's need for a better life. The question then becomes: what do patients really want when they ask to die? Even with optimal symptom control, profound suffering can be found in dying patients. It is incumbent upon doctors to relieve that suffering, which is often caused by poor communication. It can be a problem for the doctor, especially if he knows the patient only slightly, to know the patient's own perceptions of a "good life" and a "good death". Therefore, when is

the appropriate moment to let a patient die? A further question is also raised: should doctors with poor communication skills have the power to decide that euthanasia is appropriate for those patients who ask to die?

Some persons in favour of euthanasia emphasized that it should be considered for only three conditions: (1) only in terminal illness; (2) only in profound suffering; and (3) only if life expectancy is limited.

Under U.S. and Canadian law, active euthanasia is a criminal offence equivalent to murder/homicide. Although the motive is compassion, the intent is still to kill, and cases are prosecuted. Legal thinking, however, could conceivably evolve in the following direction. Attempted suicide has been decriminalized in many jurisdictions. Suicide is then seen as a liberty, if not as a right. People give power of attorney to others to ensure that what they want to do will indeed be done when and if they are no longer personally able to realize their desire and will. Could such powers of attorney be considered to cover active euthanasia in the law?

Those working in palliative medicine take a stand against active euthanasia because of their dedication to the physical and psychosocial control of symptoms till the end of life. Patients' needs at this time call for increased support and comfort, and skills have to be targeted to the control of specific symptoms without killing the patient. It is only when symptoms cannot be controlled that patients request euthanasia. A peaceful death should become the goal.

Pain is only a part of the suffering. Adequate and effective palliative care comprises more than symptom and pain control; it dictates the need for compassion. This means the mobilization of persons who can help a patient carry suffering that would otherwise be intolerable. We are now not directing enough of our resources to this kind of care. There is a lack of balance between the proportion of resources given over to treatments that iatrogenically often increase a patient's misery as compared with the resources directed to assuring a delivery of effective palliative care and palliative medicine.

Clinical research

The leading speakers focused attention on a range of ethical issues in cancer research. There is, for example, uncertainty about what to tell patients who are invited to participate in trials (Phase I trials) designed to evaluate the safety and efficacy of new therapeutic agents. One ethical dilemma is: how to

be honest without losing patients to the trial by telling them about possible toxicity and without gaining their consent by raising false hopes. In randomized clinical trials, the usual disclosures to trial candidates may be inadequate, particularly when consent forms are incomplete or slanted to encourage participation. There is a link here between the situation in clinical research and health care. In all clinical research, it is essential that the goals of health care be clearly identified in the patient-doctor relationship. Otherwise, the patient's alternatives and choices will be obscured. As a consequence, a patient's decision to participate in a trial or to refuse may suffer from diminished awareness and freedom.

There seems to be fairly widespread confusion among physicians and clinical investigators about the purposes and requirements of informed consent for participation in medical research and clinical trials. Clinical investigators sometimes speak as though consent is something they need for *their* research. They fail to grasp that adequate information is primarily a need of the patient and a moral requirement in a human relationship. The goal of adequately informing patients and of seeking their voluntary consent is not primarily the protection of the investigator and his or her institution.

In the context of research with children, it was pointed out that there is a misconception that children reason like adults, even if with less knowledge, but have childish feelings. Rather the opposite is true. Children reason childishly and process information according to their developmental stage, but they have the same feelings as adults. They know the fear of abandonment, loss of control and anxiety, and have a deep dread of non-existence (death).

The discussions revealed wide variance in the practice of research ethics in different countries. In countries where there is a strong cultural bias against open communication about cancer, clinical investigators may find it very difficult to accept or achieve the ideals of informed consent espoused by their colleagues elsewhere. In some countries, clinical trials are being conducted without adequate scientific justification. Some countries overemphasize the scope of therapeutic privilege and may dispense with the need for informed consent when the clinician feels that informed consent is not in the patient's best interests. The examples mentioned suggest the need to revivify the principles of true voluntary and informed consent as articulated at Nuremberg.

Limited resources and high costs

The participants experienced considerable difficulty in focusing on precisely who should be making

precisely what hard choices since societies are faced with limited resources and seemingly limitless innovation. There was general recognition that we cannot return to a simpler period when fewer decisions had to be made because less could be done for those threatened by crippling disease and death. Thus, proliferating health care technologies and services as well as their high costs are the two major problems associated with limited resources.

Many participants voiced the contention that money is being wasted on treatments that cause suffering and bring the patient little counter-balancing benefit. There was a related emphasis on the need to evaluate the outcomes of treatments and considerable support for a policy of restricted diffusion of, and access to, innovations based upon reliable scientific knowledge about safety, efficacy, effectiveness, and appropriate indications.

Adequate assessment of technologies and services, though morally and financially necessary, will never solve all the problems associated with limited resources. Difficult choices will always have to be made, since there is no possibility in open societies of ever totally matching resources to needs. Moreover, the perception of need evolves as new technologies and services become known. It is essential, in this respect, that people are adequately informed about what doctors can and cannot really do. One participant suggested, only somewhat jokingly, that we would all benefit from a new publication, updated regularly, that would precisely identify what doctors cannot achieve. This might contribute to the deflation of overinflated expectations and demands.

If major strides are going to be made against cancer over the next few years, it will probably be in the area of prevention. Those strides will not be made if increasing resources are not shifted from useless therapy to effective education and prevention. In many developing countries the chance for curing some cancers is slight and detection is often too late for prevention. The emphasis in these countries should be on pain and symptom relief and on the broad spectrum of palliative care measures.

Recommendations

As regards recommendations 1 to 5, given below, it should be noted that in dealing with persons who are very ill and/or dying, honesty and compassion are essential in all communication and in the presentation of medical facts. To communicate effectively, health workers require appropriate verbal and non-verbal skills. However, from our discussions, it

appears that in many instances such skills may be lacking. Hence, this problem requires attention. Doctors in particular need to possess and utilize this ability to communicate because of the pivotal role they play in the management of patients' treatment and the coordination of the treatment team.

The following recommendations of the Ethics Working Group should be adapted to the national, cultural and ethnic milieu in which they will be applied.

(1) In the education of all health care personnel greater emphasis should be placed on communication skills in order to facilitate the crucial interaction between patients and health care providers.

(2) Health care personnel should be trained in the provision of hospice, palliative or supportive care.

(3) Educational institutions for health care professionals should appoint as faculty members in clinical departments persons who are exemplars of ethical professional practice.

(4) Doctors should be encouraged to acknowledge both their personal limitations and those of medical science, in making clear to individual cancer patients the limits of medical treatment that can be offered, and in educating the general public on what physicians cannot do today as well as what they can achieve.

(5) In all countries there should be recognition of the right of patients to the truth about their illness including diagnosis, therapeutic alternatives and prognosis.

(6) Palliative, hospice and supportive care should be recognized as an essential part of health care and be financed accordingly.

(7) Only regimens of therapy that have been shown to improve survival and maintain quality of life should be incorporated in routine clinical care.

(8) Phase III clinical trials of cancer therapies should include assessment of the quality of life of all subjects in the trials.

(9) Informed consent to clinical trials of cancer therapies should include clear statements of the expected effects of participation on the quality of the patient's life as well as a comparison with the expected effects of alternative therapies, including palliative therapy outside the clinical trial.

(10) In view of potential benefits stretching into the next century, measures to apply existing knowledge to prevent the development of cancers should be widely promoted.

(11) National medical research authorities should actively encourage clinical researchers in their countries to comply with accepted international

guidelines, for example those of CIOMS (Council for International Organizations of Medical Sciences), on the ethical conduct of research.^{a,b}

(12) There should be a legally enforceable duty to obtain the voluntary informed consent of the subject to all cancer research procedures.

(13) Countries should review their laws to consider allowing individuals to give in advance directives for their care in the event that they become legally incompetent and terminally ill.

^a Bryant, J.H. & Bankowski, Z. *Health policy: ethics and human values. An international dialogue. Highlights of the XVIIIth CIOMS Round Table Conference, Athens, 29 October–2 November 1984.* Geneva, Council for International Organizations of Medical Sciences, 1985.

^b Bankowski, Z. & Bryant, J.H., ed. *Proceedings of the XVIIIth CIOMS Round Table Conference: Health policy, ethics and human values—an international dialogue.* Geneva, Council for International Organizations of Medical Sciences, 1985.

(14) Helping patients achieve a timely and dignified death should take precedence over mere prolongation of life.

(15) Since patients have a right to receive, and health care professionals have a duty to provide, adequate relief of pain, countries should review their laws to eliminate legal impediments to the achievement of adequate pain relief.

(16) Studies should be undertaken to assess the frequency of, and to determine the reasons for, patients' demands that their lives be terminated.

(17) In the light of our recognition that we, as a working group, are unable to recommend for or against active euthanasia, countries should establish appropriate task forces to study the issue of active euthanasia.

(18) The special needs of children should never be forgotten within the adult-oriented structures of cancer care and research.