Quality of Life:

Mr. Maurice Nouvelle went to the heart of all quality of life concerns when he said, "I am afraid everything will be over and I won't have had anything. Does a dinosaur, I mean a dinosaur's daughter, understand that?"[1] This anxious quest for understanding comes from a man who thinks he is a dinosaur, and who sees his psychiatrist, Dr. Susan Baur, as a dinosaur's daughter.

Mr. Nouvelle is quite mad, his thoughts all mixed up, his memories a mish-mash of delusion. He is as helpless as a child. Yet, as Dr. Baur explains, his feelings and suffering are utterly sane. He seeks love and esteem. He seeks to be understood and treasured. He seeks, as do we all, someone who would "catch the sound of our soul singing as it did before it lost its courage and its love."[2] In that search, all those threatened with biological and personal disintegration – the insane, the broken people, the dying – join the common human condition. A mark of this condition is that quality of life for anyone depends on the presence of others.

The expression "quality of life" refers both to experiences that make life meaningful and conditions that allow people to have such experiences.

Multiple interventions of curative medicine and Palliative Care centre on quality of life in the second sense: they deal with conditions enabling people to have experiences that make life endurable and worthwhile.

Survival is obviously one of these conditions, the sine qua non for all experience. It explains massive past and current efforts to develop and expand technology of drugs and surgical operations for the one purpose of saving lives. Individuals and their families have learned all too painfully that being biologically alive is necessary, but not sufficient for meaningful, worthwhile living. Other requisite conditions must be satisfied, if sick and dying people are to be ready and receptive for achievements and experiences that give meaning and interest to their remaining life.

Emancipating sick people from pain and unendurable symptoms is one of the conditions that sick, dying people most need in order to live their remaining time as fully as possible, true to themselves and family. Unrelenting pain, persistent symptom distress, and crushing fatigue bind consciousness to the loss of one's own time. A person's time cannot then be used for anything else. It cannot bring joy, peace, promise or hope which might momentarily counter, weaken or even dispel haunting threat of disintegration. Great efforts of Palliative Care to control pain and manage symptoms serve deeper existential purpose in freeing a sick, dying person's time. Freeing a dying person's time? For what? For any meaningful act or personal experience powerful enough to demonstrate "that for a short moment there is no death and time does not unreel like a skein of yarn thrown into an abyss."[3]

These lines from Czeslaw Milosz's poem *Earth Again* symbolize the kinds of events and experiences that bring the unconditioned into people's lives. The unconditioned here refers to experiences of grace, gift, or presence that can redeem tragedies of the past, fill a present threatened by absence and emptiness, and illuminate a future seemingly short and dark. This is a first meaning of quality of life and measurement has nothing directly to do with it. Such experiences cannot be guaranteed or measured, and medical, nursing, and other health care professionals cannot provide them.

But this is only part of the quality of life story. One tragedy of the human condition is that people can live and die without ever experiencing even a short moment "where there is no death" and where time holds together with transcendent peace and joy. Others fall into such deep misery that they cannot remember experiences when they have, indeed, occurred nor return to them for strength, light, and hope. Experiencing the unconditioned in the sense of the Milosz poem, or rediscovering such experience, depends primarily on freedom from abject misery of body and mind.

Quality of life in a second sense consists of such freedom. Multiple interventions of health-care professionals have much to do with provision of that freedom. Quality of life measurements control the degree to which that provision is occurring. During delivery of care, quality of life studies and measurements prevent devastating separation of a person's body from a patient's biography. Such separation, as A. Feinstein insisted, blocks scientific attention to a person's pain, discomfort, distress, insomnia, fatigue, anxiety, joys, sorrows, and other component conditions of a genuinely human life.[4]

The purpose of scientific, measured attention to data, deriving from both a person's body and biography, is to humanize medical and health care technology. Humanization requires two kinds of excellence from those who care for the sick and the dying: that expressed in effective relief of pain and symptoms, and that expressed in ability to read and respond to messages and quests between unwritten lines of each person's biography. This is where unique, personal suffering is so often found. This is where we can catch the sound of someone's soul singing as it did before it lost its courage and love.

REFERENCES

1. Baur S. The dinosaur man: tales of madness and enchantment from the back ward. New York, NY: Edward Burlingame Books, 199, 1991.
2. Baur S, op. cit.; 106.
3. Milosz C. Unattainable earth (translated by the author and Robert Hass). New York, NY: The Ecco Press, 8, 1968.
4. Feinstein AR. An additional basic science for clinical medicine: I. The constraining fundamental paradigms. Ann Int Med; 99: 394, 1983.

Ethics

> *"Clinical ethics concern decision making and the resolution of certain doubts, dilemmas or value conflicts which arise at the patient's bedside. There are also on occasion conflicting perceptions, presuppositions, and beliefs. Clinical ethics should lead to a practical judgement of what is best done now to help one particular patient survive or die, in a way which respects the patient's dignity as a man or woman."* [1]

To care effectively for those living with HIV/AIDS, approaches to ethical issues such as decision making, assisted suicide and euthanasia on demand must be understood.

Solutions to these ethical dilemmas can only emerge from a global view of the person living with HIV/AIDS, considering the person's clinical condition, personal values, aspirations, perceptions, beliefs, relationship with family and caregivers.

Global understanding of a person and his/her experience begins when the caregiver enters a therapeutic relationship. Opposing points of view emerge, challenging the art and science of clinical ethics and medicine to find an acceptable consensus. This is the ideal, but some caregivers have difficulty with therapeutic limits and failures, viewing death as a barrier.

Controversies surrounding major existential questions – the meaning of life, reasons for suffering and death – force society to question utopian ideals of a society free of suffering, pain, misery, evil, and death. We search for the meaning of life, the significance of suffering and death, yet answers elude us.

TREATMENT OPTIONS AND RESUSCITATION

Treatment options and resuscitation pose some of the most difficult questions encountered by professional caregivers. The caregiver must demonstrate moral strength and sensitivity when discussing ethical issues with the person living with HIV/AIDS. It is difficult for young individuals and caregivers to accept that nothing more curative may be done. Confronting personal limits overwhelms some caregivers with paralysing helplessness, preventing them from finding other uses for their skills.

Some clinicians react to an individual's refusal of treatment as if it were a personal rejection, repudiation, or accusation of incompetence. But if refusal of treatment follows frank, open dialogue, and if the individual is made to feel that the caregivers respect his/her decision and will carry it out, mutual respect and trust ensue.

> *Persons living with HIV/AIDS generally value autonomy and self-determination, asserting their right to be included in decision making*

These issues should generally be discussed in advance with the person living with HIV/AIDS. Increasingly, individuals are making a living will and/or giving power of attorney with instructions for the time of their death. However, lack of a living will or power of attorney does not mean that the person desires excessive therapeutic treatment at the end of his/her life. In fact, resuscitation efforts at the end of life may not only be futile but damaging. This highlights the importance of having frank discussions about these issues in advance.

Canadian jurisprudence has established the principle of self-determination and freedom of choice. It has freed the physician and other health professionals from risk of criminal lawsuits by removing legal and judicial ambiguities governing refusal of treatment and cessation of treatment on demand.

TABLE 1

Guidelines for Arriving at a Clinical Decision Concerning Resuscitation, Unjustified or Excessive Treatment, Refusal of Treatment, or Cessation of Treatment [2]

☐ evaluate the clinical condition of the person living with HIV/AIDS

☐ evaluate his/her decision making competence (see *Legal Issues*)

☐ if he/she is competent, explain the facts necessary to make an informed decision (see *Legal Issues*). If he/she is not competent, speak to family

☐ evaluate how the individual currently perceives the quality of his/her life, and how it may be affected by decisions being made

☐ evaluate the ultimate objective of the specific treatment in question: maintaining life and/or maintaining a quality of life

☐ obtain the opinion of the care team

☐ keep a clear record in the individual's chart of all conversations and decisions concerning treatment

☐ respect any change in the wishes of the person living with HIV/AIDS

☐ periodically re-evaluate all decisions

☐ frankly discuss any unreasonable demands made by the person living with HIV/AIDS or his/her family

☐ provide Palliative Care to improve the individual's physical and psychological comfort, and to provide support for family

ASSISTED SUICIDE AND EUTHANASIA

A person living with HIV/AIDS and severe diabetes develops a bronchopneumonia for which he refuses treatment. He progresses to a semi-comatose state and you question yourself on the appropriateness of continuing insulin. This question has never been discussed with the person. Is insulin now fulfilling the objective for which the person had been taking this medication all his life?

Debate continues concerning assisted suicide and euthanasia, particularly within the HIV/AIDS community. While individuals have the accepted right to refuse specific treatment, even by advanced directive, the right to aid or abet a suicide is not legally recognized (see *Legal Issues*). The third party (physician or other) who assists with suicide or provides euthanasia is not insulated from criminal and civil culpability.

Persons living with HIV/AIDS often involve caregivers in questions about euthanasia and assisted suicide. It is difficult to answer such questions frankly without dodging the issue. Most requests for euthanasia and assisted suicide are generated by one or more of the following reasons:

- fear of suffering
- loss of mental faculties
- physical pain
- disfigurement
- affirmation of the personal right to self-determination over the act of dying and moment of death
- loss of control
- loss of dignity
- dementia
- rejection of dependence

Again, the caregiver must be honest with the person living with HIV/AIDS. Whether or not assisted suicide and euthanasia are decriminalized or are morally acceptable, the caregiver must understand, respect and support the person living with HIV/AIDS through the decision process. The caregiver's attitudes and availability of Palliative Care may often reduce the perceived need for assisted suicide and euthanasia.

TABLE 2

Basic Guidelines for Handling Requests for Assisted Suicide or Euthanasia

- ☐ do not evade controversial questions. Listen actively
- ☐ ask open, non-judgemental questions about motives behind the request. Allow the person to express him/herself freely
- ☐ ensure that an informed decision is made voluntarily. The person should be free of external social pressures and family constraints, and internal factors like depression
- ☐ attempt to decode the request for death. It may mask other silent requests for things he/she might want more than death, like assurance that he/she will not be abandoned
- ☐ do not assume that all requests for death can be decoded as a request for something else. Some requests for death are genuine and mean exactly what they say
- ☐ ensure that the person has your professional and personal support by providing the best possible Palliative Care
- ☐ reassure the person of your respect for his/her choice
- ☐ when an explicit, repeated request conflicts directly with the caregiver's moral conscience, or is illegal:
  - – do not abandon the person but maintain the dialogue
  - – express your perception of the situation, including one's own right to freedom of conscience and any legal constraints
  - – seek advice from a trustworthy colleague

Caregivers have the moral obligation to relieve suffering in all its forms, respecting the individual's right to self-determination as much as possible, while facing their own social, personal and professional responsibilities. Compromises are inevitable. Caregivers cannot ignore or elude extreme cases where life can no longer be good in itself, where to live becomes a relative, subjective, or objective burden. In therapeutic decision making, caregivers can no longer avoid weighing the changes in the present and future quality of the person's life occasioned by their decisions.

However, it would be disquieting to see assisted suicide and euthanasia become expedients which allowed society, the individual's loved ones, and the health care team to shirk their duty and fail to provide excellent Palliative Care.

CONCLUSION

How are we to solve the ethical dilemmas which we must increasingly confront? Who will make the decisions? Using which criteria and principles? Resources are scarce and our pragmatic society, with its pressures for efficiency at any price, is inclined to place increasingly relative value on human life.

Dignity comes from the person, as a caregiver once put it. But it also comes from the view others have of that person. The subjective nature of individual perceptions of dignity and quality of life is influenced by the perceptions that others have of one's own dignity and quality of life. Bearing these concerns in mind will help us resolve many value conflicts which we will encounter. Our personal and social consciences will be tested, no matter what legislative and judicial framework happens to be in place.

> *"How can we help the individual live and die in such a way that we respect his/her dignity as well as our own?"*
>
> Dr. David Roy[3]

REFERENCES

1. Roy D.J. Au chevet, 1994; Vol. 1, No. 1
2. Reprinted in part with permission from: Centre Hospitalier de l'Université Laval. Avis du Comité de bioéthique – Ordre de cessation de traitement, de réanimation ou non-réanimation et de mise en oeuvre de traitements disproportionnés, 1989. (Available from *CHUL*, Comité de bioéthique, 2705, boul. Laurier, Sainte-Foy, Québec G1V 4G2)
3. Roy DJ (ed). Ethics in palliative care – part I/ when suffering persists/need they sleep? Sedation in PC/life-prolonging treatment/quality of life/when the sick request death (a special thematic issue). Journal of Palliative Care, Summer;10(2), 1994.

SUGGESTED READING

Baudoin JL, Blondeau D. Ethique de la mort et droit à la mort, PUF, Paris, 1993.

British Columbia Persons with AIDS Society. Position statement on euthanasia, Vancouver, 1994.

Flanagan, N. The right to die: opening communication, making decision. AIDS Patient Care, October 1988; 2(5):34-37.

Latimer EJ, McGregor J. Euthanasia, physician-assisted suicide and the ethical care of dying patients (a position statement). Canadian Medical Association Journal, October 15 1994; 151(8):1133-1136.

Miller FJ et al. Regulating physician-assisted death. New England Journal of Medicine, July 14 1994; 331(2):119-123.

Morissette MR. Un regard "médical" face aux demandes d'euthanasie. Memoire presented to the Special Senate Committee on Euthanasia and Assisted Suicide, Québec, 1994.

Ogden RD. Euthanasia, Assisted Suicide and AIDS. Vancouver, BC: Perreault/Goodman Pit Meadows, 1994.

Tindall B. Attitudes to euthanasia and assisted suicide in a group of homosexual men with advanced HIV disease. Journal of AIDS, September 1993; 6(9):1069-1070.

Van Delden JJM. The Remmelink study/two years later. Hastings Center Report, November 1993; 23(6),24-27.

Williams JR, Lowy F, Sawyer DM. Canadian physicians and euthanasia: 3. arguments and beliefs. Canadian Medical Association Journal, May 15 1993; 148(10), 1699-1702.