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CANADIAN CATHOLIC BIOETHICS INSTITUTE

Bioethics Update

Ethical and Spiritual Issues at the End of Life: The Relevance of Spiritual Care to Bioethics

This Bioethics Update is a contribution to the Canadian Catholic Bioethics Institute's larger project of identifying ethical issues in the care of the elderly and the dying. The first article presents a model of spirituality in persons near the end of life that identifies three developmental stages. The second places our local efforts to care for the elderly in a global context.

For a person at the end of life who is suffering from an illness for which there is no medical cure, the only healing possible may be spiritual. 'Spiritual' is here understood in terms of an individual's quest for ultimate meaning. The developmental stages to be considered here are: (1) reconciliation, which involves the acceptance of the reality of death and the need to review one's spiritual life; (2) orientation, which involves prioritizing one's values toward an ultimate end and discerning spiritual tasks that are necessary for the time that remains; and (3) thanksgiving, which involves communicating to others the meaning of one's life. This model connects the spiritual challenges particular to each stage of development with the dilemmas in medical and ethical decision-making as a terminal illness progresses.

Health as the Quality of Relationships

We can understand the health of an individual and a family as involving a harmony within and between various levels of relationships. Such relationships connect the various body systems; the body with the psyche and mind; the individual with his or her environment; the individual with others, and the individual with the transcendent. Illness entails a disruption of this harmony in our relationships at some level of our being (Sulmasy, 2002). The effects of this disruption are rarely restricted to one set of relationships. They can affect the experience of oneself and one's world. Such disruptions can influence one's appreciation of the meaning and purpose of one's life. A life-threatening illness can lead a person to re-evaluate his or her relationship with the transcendent, in whatever way this may be understood and expressed, and to ask questions about the ultimate meaning and significance of one's life and legacy.

Spiritual Health

The human person can be characterized as an *embodied yearner* whose ultimate wholeness or health involves his or her spiritual dimension. The "spiritual" denotes ways in which we transcend ourselves that are not based on reason alone (Dunne, 2001). It is one's capacity to seek and to discover, in one's life journey, transcendent beauty, understanding, truth, goodness and love. By contrast, spiritual illness or distress is the experience and awareness of a significant incongruity between one's transcendental yearnings and the actual history and patterns of one's life.

Spiritual and Other Types of Care

What does it mean to 'care' for an individual with a terminal illness and his or her family so that they may be able to cope and be well? Healing is effected not only by acts of 'curing', of which modern medicine is justifiably proud, but also by acts of 'caring for' people. Following Edmund Pellegrino's account, we can distinguish five senses of care: compassion, activity replacement, assurance, competence, and curing (Pellegrino and Thomasma, 1997). To these medical senses of care, we can add

spiritual care that involves assisting individuals who encounter specific spiritual challenges and/or opportunities. In the face of a terminal illness, opportunities arise during distinct stages of reconciliation, orientation and thanksgiving. At each stage, there is an opportunity to assist a person to review his or her life and vocation, to complete important unfinished tasks, such as mending relationships with others, and to focus on his or her relationship with the transcendent. People at the end of life and their families often describe these tasks, and the healing that comes about through completing them, as important to 'dying well'. I maintain that the particular spiritual challenges at each of these developmental stages provide the context for medical decision-making. In addressing bioethical issues that arise near or at the end of life, we will not understand the basis for a person's decisions unless we understand something about the nature of his or her relationship with the transcendent, even if this person happens to ignore or reject the transcendent. Moreover, good spiritual care, understood as providing help to a person to progress in his or her relationship with the transcendent, can often enable him or her to make good medical decisions at each of the following stages.

Stages of a Terminal Illness and Related Bioethical and Spiritual Challenges

Reconciliation Stage

The reconciliation stage is at the beginning of a terminal illness. During this time the main personal issue is to become aware of and to accept that one's earthly life may be drawing to an end.

Bioethical challenges are apt to arise during this stage if acceptance of the truth of a terminal diagnosis has not been achieved. These can range from insisting on medically inappropriate or futile care, on the one hand, to rejecting what is normally considered to be useful and appropriate care, on the other hand.

The main challenge in providing spiritual care at this stage is to encourage people to face up to the truth that their lives may be drawing to an end and to make the appropriate personal and medical decisions in light of this truth. This may require the person providing spiritual care to avoid colluding with someone's denial of death in some cases. It also entails that the person providing spiritual care should console but avoid giving false reassurances or minimizing the suffering that a dying person experiences in accepting the brute fact of his or her approaching death.

Orientation Stage

The orientation stage falls somewhere between the beginning and the end of a terminal illness. Following some degree of reconciliation with the fact of one's dying, the next main personal issue for the dying person is to orient his or her life to ultimate concerns in this new context. This orientation involves picking up of the trail of his or her life journey and discovering the mystery and meaning of life that, for Christians, lies in and through the image of the cross. Such an orientation provides a dying person with the opportunity to set his or her heart on ultimate things that will endure. With this new orientation, the dying person can consider what needs to be done with the time he or she has remaining. This includes learning to navigate the medical world, setting goals, making decisions consistent with these goals, and coping with losses.

Bioethical challenges are apt to arise if this orientation to ultimate concerns has not taken place. These can include the selection of medical treatment goals and burdens that may undermine personal and spiritual goals.

The main challenge in providing spiritual care at this stage is to encourage persons to attend to things that will last and to make medical and personal decisions in light of these ultimate ends.

Thanksgiving Stage

The thanksgiving stage corresponds to the final stage of a terminal illness. In some sense, this stage can also be regarded as the *leitmotiv* of a dying person's entire life. The opportunity of this stage is to respond to all of a person's life experiences in a spirit of gratitude for the many gifts received along his or her journey, especially the gift of life. Thanksgiving involves understanding one's own experiences in a positive light, learning to trust God and to let go, and being a source of blessing to others by means of one's gift of self in living with a terminal illness, and after death, through one's legacy.

Again bioethical challenges are apt to arise if a spirit of anger and resentment, rather than one of gratitude, dominates this stage. These could include requests for euthanasia or physician-assisted suicide, and enmity or isolation in one's relationships with others.

The main challenges in providing spiritual care are to affirm or engender genuine hope in the life of the person who is dying and his or her family, and to help them to discover meaning and community even in the midst of their losses. To experience the life of a loved one who is enduring suffering in a spirit of complacency and gratitude is to experience, concretely and personally, God's victory over death.

Conclusions

Spiritual care addresses a person's relationship with the transcendent. Such care assists a dying person with the bioethical and spiritual challenges that arise during distinct but related stages of his or her coping with a terminal illness. These are the stages of reconciliation, orientation and thanksgiving. Care and promoting caring relationships are at the centre of medicine and bioethics. This includes attending to the deepest of all human relationships, a person's relationship to the transcendent. Spiritual care of persons with a terminal illness and their families facilitates their quest for ultimate meaning in the context of illness and approaching death. It also enables them to make medical decisions in light of that ultimate meaning. Providing good spiritual care for those with a terminal illness and their families ought to be a priority for faith-based healthcare. It is the stone on which such healthcare has built its foundation and legacy. This legacy today provides an original and important witness to our death-denying culture in its search for ultimate sources of meaning and hope.

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The Global Horizon of Local Efforts to Care for the Frail Elderly

Globalization is the modern phenomenon of worldwide communication and trade that has bound the peoples of the globe together into an increasingly unified economy . The phenomenon of globalization is morally ambiguous: (1) it creates great promise for helping those formerly beyond the reach of most humans (and so thereby increases the reach of everyone's moral responsibility); (2) it increases the capacity of people to learn from one another, and the opportunity for all to correct the distortions of their limited perceptions by conversation with people who are culturally and economically different and far away; but (3) it is based on human transactions that are not readily accountable to national authority and are often driven by market considerations devoid of moral concern. The reach of the promise for humanity of globalization is restricted by the moral limitations of the economic motivations that make globalization possible.

Globalization has become a central concern of Catholic social teaching, and, increasingly a matter of concern for bioethics. The mandate to share expensive drugs and procedures with suffering societies in the developing world is one area of serious concern; the need to regulate the increasingly worldwide undertaking of scientific research and to prevent its exploitation of poorer peoples for research purposes is another. But the globalization of biomedicine affects other, seemingly local areas of bioethical concern.

One such area is that of care for the frail elderly. What role should the globalized horizon of modern health care play in our in thinking about how we are to care for the frail elderly in a morally responsible way? Helping such people seems to be an inherently local, not a global undertaking. We can and morally must help those at hand needing our help; we alone can provide them the care they need. Plainly, this does not remove the real responsibilities those in wealthy societies have to those further away–to share our wealth to support them and those who are on the scene to help them. This important global responsibility must be reasonably balanced with the local neighbourly responsibility we bear to those whom we alone can readily reach and to whom we are bound by kinship, proximity and a web of commitments. The question is: how should the global horizon of moral

thinking affect our dealing with such a local implementation of the second love commandment?

I believe this question must seriously challenge our conscience: we have a serious responsibility to care for our immediate neighbours who need our help, and yet we may not ignore our responsibilities to those who are farther away, but not so far away that we can use our resources to help them. Moreover, it is a question that does not admit of a quick or facile answer. It is difficult to discover the correct balance of responsibilities.

Here are a few preliminary ideas relevant to addressing this challenging and difficult question:

First, we are bound to use private charity to help others far away even if it stretches our resources for other good purposes, including helping those near and dear. Still, much of what needs to be done to help the people of poor countries deal with their health care issues must be done through governmental action – aid and regulation – as the African need for help in dealing with AIDS shows. Our uneasy conscience about the level of support for poorer peoples by wealthy nations such as Canada should not, therefore, undercut our resolution fully to use the resources presently available to help our own frail elderly.

Second, even if our solidarity with the poor were closer in practice to the ideal articulated in Christian teaching, there would remain the need to deal with the distinctive problems faced by people in advanced countries such as Canada, problems that arise because of the economic and social structures of these societies. Helping the frail elderly live well, and caring for them when they become too frail for independent life, has a distinctive shape in a country like ours. Globalization implies interaction, the capacity to reach, not global uniformity.

Third, it is altogether possible, as was suggested by some of the Third World participants in the International Colloquium held by the Canadian Catholic Bioethics Institute in July 2003, that the distinctively first-world shape of problems such as dealing with the elderly might make some people such as these elderly worse off than many in poorer parts of the world. For example, the availability of work outside the home and the economic imperatives for all adult family members to work outside the home reduces the human resources available in many societies for caring for the frail elderly. That in itself need not make the frail elderly worse off, but it does challenge us to consider how institutions and professionals can cooperate properly with family members to provide that part of care which family members in other societies – and in ours until recently – have substantially provided.

Fourth, one implication is that among the chief roles of our newly globalized sensibilities in bioethics is to put our local problems in a wider perspective, to learn how other societies deal with these issues, and to ponder how the lessons we can learn from them might actually foster human dignity in our cultural context. So, the lessons of globalization are not limited to the increased responsibilities of the richer nations and peoples to help the poor without patronizing or colonizing them; they include the responsibility of all to learn from others of the various ways to promote human good and respect human dignity.

This is not to suggest that solutions from other societies are likely to solve our problems. Rather, this larger perspective helps remove the sense of the inevitability of our *status quo* and reminds us that our society has made trade offs that, however beneficial, all things considered, do involve real costs and do present real challenges to our humanity.

The moral of this story is not utopian or revolutionary: it is evident that to help the vulnerable actually in need of our support, we must operate within the social world–the economy, social structure, health care system, etc. which we have – even if we judge it desperately in need of repair. For unless we do at least this–act with what we have – we won't help those vulnerable people. But we are liable for our blindness if we fail to learn the lessons others have to teach us. And that blindness may cause us less intelligently to care for them and for those who will soon be in their situation.

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