

The Ethno-Cultural and Spiritual Impact on Ethical Consultations for End-of-Life Decision Making: An Inter-Pathetic and Pluralist Approach

Philip Crowell, M.A., M.Div., Ph.D.

Co-chair of British Columbia Women's Hospital Ethics Committee

Director, Department of Spiritual Care, Children's and Women's Health Centre

Canada

How do cultural/religious concepts, values and beliefs correlate with the language of bioethics discussions of autonomy, beneficence, and 'do no harm'? What do we mean by the term culture? How is the diversity of religious cultures appreciated and acknowledged in the ethics consultation process? This paper explores how the "thick" concepts of religious cultures are a primary lens for patients who adhere to a particular religious tradition. The concepts and clinical language of medicine becomes incorporated into the interpretive process of determining the meaning of this illness and the end-of-life (EoL) ethical decision making for the patients and families.

In this investigation we ask how are Muslims, Aboriginal/First Nations, Christians, Jews, Hindus, Buddhists, to respond personally and/or collectively to EoL decisions, based upon their own respective commitments to: Qur'an, harmony with nature, Gospel, Torah, Ahimsa, compassion, or Dharma. There is a natural desire for healthcare professionals to create a 'shopping list' or 'cookbook' in order to better anticipate patient needs, and to 'tidy up' culture, as the same as other epidemiologic variables, such as smoking, age, gender or fertility rates. On one hand, this is a positive move in trying to respond to cultural and religious diversity in ethical consultations, however, on the other hand, this article identifies some of the significant hazards in this approach and suggests another 'way' which enters into the experience of the 'other.'

As a starting point we need to ask, 'what is culture?' It is not simply an inconvenient barrier to a rational, scientifically based health care system or a feature of ethnic "others." Culture includes, but is not restricted to, age, generation, gender, sexual

orientation, occupation, socioeconomic status, ethnic origin, migrant experience, religious-spiritual belief or disability.

Culture is dynamic. Culture is constantly re-created and negotiated. Individual and community negotiation is a complex process from the 'bottom-up.' Data shows individual differences can be most profound within ethnic groups. Culture is embodied and expressed in language, art, history, literature and science. The German philosopher H.G. Gadamer argued that cultural traditions are being interpreted as they are interpreting us. He articulated traditions as "effective historical consciousness" since they are the parts and the whole of living traditions that are still effective in human consciousness.¹

Culture is what we do every day, every week and every year– it is embodied in our way of seeing the world, seeing other human beings, assessing "goodness" or risk and understanding our past, present and future. We all have a culture. We have a medical culture which informs us and we shape its future trajectory, in terms of how we talk about life and death issues, and how decisions are made by the family or individuals and this impacts our religion and spirituality. I refer to spirituality as distinct from religion or culture. Generally speaking, "religious beliefs" refer to beliefs that are formally articulated by a recognized religious tradition or faith community. By contrast, "spirituality" represents a personal view of one's relationship with other people, the natural world, and a larger framework of meaning or purpose that may or may not be understood theistically.² Spirituality as is often defined as being universal, shaped by culture and by individual experience and personality. However, religion may also embody a high level of spirituality as well which impacts on ethical decision making. In order to appreciate the ethical interpretations there is a need to deal with conceptual and philosophical context in which ethical dilemmas arise.

How does Hindu concept of "moksha" 'see' withdrawal of treatment? What is Buddhist wisdom on 'right action' for EoL decisions? How is suffering (dukkha) viewed in EOL cases? If life is suffering when is it time to release and let go? How does Judaism understand quality of life in EOL cases? What is deemed 'futile' in Christian values and beliefs? If a faith-tradition believes in miracles, when is it okay to let go? What is Islamic teaching on withdrawal of life supports? What do Sikhs mean when they speak of "the community as Guru" and God as Guru? Does the community help frame ethical

decisions? I am not attempting to answer these questions, but simply juxtaposing the ethical questions with relevant religious concepts, which inform patients and families, in order to demonstrate the need for broad thinking in this area.

In responding to cultural and spiritual/religious perspectives different from our own there are two basic approaches. First, there is the resources specific approach in which you reduce culture/religions to a simple formula a virtual “cookbook” response. A second more promising approach is that of interpathy suggest by the theologian David Augsburger.³ Interpathy is an intentional cognitive and affective envisioning of another’s thoughts and feelings from another culture, worldview and epistemology. In interpathy, the process of knowing and “feeling with” requires that one temporarily believe what the other believes, see as the other sees, value what the other values. In interpathy, I seek to bracket my assumptions and learn a foreign belief, take a foreign perspective, base my thought on a foreign assumption, and feel the resultant feelings and their consequences in a foreign context. It is experiencing what is truly other. The expression that the “person who only know his religion doesn’t understand religion at all” entails and requires an openness to the other. This movement may suggest relativism or pluralism.

Diana Eck, puts it slightly differently in advocating pluralism. “I would insist that pluralism is not simply relativism. It does not displace or eliminate deep religious commitments, or secular commitments for that matter. It is, rather, the encounter of commitments.”⁴ Augsburger would suggest the true encounter means entering into another’s world. However, there may be occasions, as well, when we can only imagine, or maybe not even imagine, what the suffering and the dying is like. The challenge is how to enter in and/or the willingness to let go of one’s world in order to enter or encounter another. And so in our clinical context we correctly ask: why do “minority” families in North America and especially, the US demand you must do everything possible in the face of the futility of treatments?

Barbara Koenig explores the issues of cultural diversity in decision-making about care at the End of Life” citing new cases which consist of “minority” families demanding further care in the face of healthcare professional’s definition of futile treatment.⁵ In my Canadian context the mistrust of Aboriginal Peoples towards the establishment is rooted in a long history of political, economic deprivation, deception and

broken promises by government which extends into the clinical setting as well. There are the practical issues of what kind of care do families and patients want at the end of life when it is clear that life is closing. Can we be cultural sensitive to how they want the end to be? This is more than a question of rituals, which is integrally important, but also the ethical/ religious questions as to who will decide when is the appropriate timing in all of this and what does this mean? In other words, it is respecting people, doing good, avoiding further harms and suffering, acknowledging the struggle that has gone on long enough. Are certain religious group more ready to face the ending of life? Some groups belief that death must be delayed as much as possible, consequently, suffering is unnecessarily prolonged. K. Jones identifies the differences in British experience, this study contends that the 'cookbook' approach creates more stereotypes, compounding with inaccuracies the expectations and the necessities of the situation.⁶ M.E. Baker in an article entitled "Economic, political and ethnic influences on end-of-life decision-making: a decade in review" for the Journal of Health and Social Policy,⁷ contends that minority populations in the UK complete advanced directives less frequently than white populations and minority subjects tend to indicate that they do want aggressive, life-sustaining medical interventions.

The "how to" literature abounds in this climate of cultural sensitivity. Nursing times (1989-1992) ran articles on Death with Dignity citing 13 different religious traditions: from Islam, Hinduism, Sikhism, Rastafarianism, to Zoroastrianism. The Canadian Medical Association Journal from 1996-2000 ran similar articles on Islamic bioethics, Hindu bioethics through to Aboriginal bioethics trying to provide orientation. Ethical care for EoL will entail both ethical and religious reflection and engagement. To appreciate the depth of world religious traditions requires more than introductory articles but a lived-experience and entering into another person's world and engaging the depth of such ultimate concerns. The cautionary note is that there is wide variation of beliefs and behaviours within traditions, folk beliefs and folk medicine, generational differences within, and historical trends. In the context of clinical consultation the performative aspect often proves to be most challenging and exhausting. It requires such skills as clarifying the questions to be answered, determining how best to obtain required information, ascertaining which individuals need to be involved and which do not, mediating conflict, and "keeping more space open" and "creating moral space." In strict religious traditions which appear to have ready-made-answers as opposed to the more philosophical religious traditions how does

one have an ethics conversation respecting the priority of the theological convictions and conceptual beliefs which direct actions? In other words, the ethical emerges from the beliefs and values and the clinical context.

My composite clinical case involves a devout religious couple who were only open to the ethics consultation after the felt their spiritual concerns had been addressed. Their newborn had been in the NICU for almost two weeks with few signs of improvement. The kidneys are not functioning well, there has been a brain bleed and the child is without much normal response. Respiration is weakening and because of the brain bleed there is a feeling that the newborn should be extubated, however, the couple believes this is giving up and is resistant to the idea.

This is a family/ couple in distress. They are refusing to converse with the doctors. They seem to be exaggerating the few positive signs that they see, as well as minimizing the negative indicators observed by the doctors. But in the father's word, "we are very open to the spiritual and the unexpected." This devout couple believed that if they keep up their positive thoughts and energy that their baby will have the energy to make it. They are conflicted by the realization that the child is obviously not well and the hope that good thoughts and prayers will keep the child alive. Their belief that the universe is organized by energy-forces confirms what the healing Gurus are telling them that this baby will be okay. This message is their conviction. But after they have described in detail their values and beliefs they are ready for the negotiation and discovery of an ethics consult with a doctor that they feel extremely comfortable with. Four days later they agree to the extubation but with the proviso that if it fails that they will re-intubate. The physician declares we do not re-intubate babies in this condition. Then the couple refuses to extubate. The physician in response agrees to re-intubate if necessary but they will do another extubation in 24 hours which will be final. They all agree on this process after weighing the risk and benefits and acknowledging the importance of taking the next step in good faith.

Barbara Russell and Deborah A. Pape recommend that ethics consultations are a knowing-to-act-in-the-moment such as knowing when to listen and when to ask questions, knowing when to invite an elder to speak and who to address in the family and religious circle.⁸ Or knowing how to move the conversation along in negotiating, and how much people can handle in a given bad day. Churchill and Schenck invoke Taoist concepts in

their role as ethics consultants. A couple deciding about their at risk fetus seek “to discern their proper place in the scheme of things,” and the task for most parents and families is “to find the path...to locate the right way.” Also Taoism, like many religions, invites humility. Discovering the most fitting way may involve other people, not the consultant herself or himself only.⁹ With this couple it was finding the “right” doctor and finding a “way” to slowly move this couple in the appropriate direction without taking away their hope.

Heidegger remind us that nothing is as individuating like dying and the awareness of death. In the clinical context Roberto Dell’Oro argues that we may suffer of the same disease, yet we undergo the experience of suffering and dying in different ways, radically left to our own individuality. Even as empirically reducible entity, the fact of illness exists only as interpreted fact, experienced and recounted by a particular patient. From the moment in which medical data are collected often it is the patients’ tendency to inadvertently shift their language from the pure enumeration of symptoms to a kind of self-inferred diagnosis. Insofar as it represents a spontaneous tendency, however, it throws into relief our need to interpret illness, to “translate” its brute facticity to meaning.¹⁰

The interpretative nature of the patient’s experience becomes evident in the language used by the patient, in the emotional mood underlying his/her narrative of symptoms and pain as well as the interpretive experience of what it means to being dying and to contemplate one’s own death. It is important to stress that narratives of illness are never purely descriptive: as they are embedded in the life-world of patients- bespeaking their beliefs, fears, uncertainties- they are already value laden in culture and/or religious meaning. The patient’s narrative has not only a diagnostic, but even a therapeutic significance. According to Drew Leder the very ability to bring the disease to the level of language causes resistance to two primary features of illness that give rise to suffering: senselessness and isolation; the fact of translating disease (and EoL/death) into “a language begins to overcome this twofold alienation. What was a private pain is now made public, what was senseless and random is woven into a meaningful tale. The narrative context itself can have healing force,” even at the end of life.¹¹

The Kelner study looks at 126 patients in Eol care. There are 48 dialysis patients, 38 long-term care, 40 people who are HIV/AIDS.¹² Their message is that they wish to: receive adequate pain control, avoiding inappropriate prolongation of dying process, achieving a sense of control, relieving burden on loved ones, and strengthening relationships with loved ones. This last point is strengthened by the use of narratives which pull together individuals affected by the health crisis. These are personal narratives but they may also try to connect their narratives with the narratives of their cultural religious tradition generating a sense of objective meaning.

Bioethics in North America tends to value autonomy, other cultures value beneficence and avoidance of harm, and the latter message suggests, instead of scrabbling for a treatment that will probably prove to be futile, provide comfort and allow for meditative rituals. For example, native aboriginals may request aboriginal drummers and Hindus may want a reading of some portion of the Gita. Where will the decision making come from when to slowly withdraw treatment? Cultures that place a higher value on beneficence and non-maleficence relative to autonomy have a long tradition of family centered care decisions. Many culture and Asian cultures see family based medical decisions as a function of filial piety with an orientation toward the extended family indicating that illness is a family event.

It is interesting that investigators in the U.S. find significantly lower rates of advanced directive completion among Asians, Hispanics and blacks. Low rates of completion may reflect mistrust of the system, health care disparities, culture perspectives on death and suffering, discrimination and specific concerns about having a “good death”¹³ There are times families will “protect” their family member who is seriously ill from the bad news because they believe that disclosing bad new is disrespectful or impolite. Some cultures believe that open discussion of serious illness may provoke unnecessary depression and anxiety and that explicit disclosure may eliminate hope. Even discussing the possibility makes it real, viz., self-fulfilling prophesy expressed in the Navajo Indian Act of Nevada. Studies show that many Japanese and African physicians, when discussing cancer with patients choose terms like ‘growth,’ ‘mass,’ ‘blood disease’ rather than specifying.

There are many points of cultural diversity in healthcare which impact EoL ethical decision making:

- Emphasis on individualism versus collectivism,
- Definition of family (extended, nuclear)
- Common view of gender roles, care of elderly
- Views of marriage and relationships
- Communication patterns (direct, non-direct; emphasis on nonverbal, meanings gestures)
- Common religious and spiritual-belief systems
- Views of physicians, views of suffering, views of afterlife

These are the “thick” cultural and religious values, beliefs, customs and practices which we mentioned at the beginning of this article. It requires prior understanding to orientate oneself in another’s world and it also requires openness to see the unique appropriation of culture by the individual and it takes courage to enter into unknown territory. A capacious attitude is required in order to move into another’s world and is a tremendous resource to the patient and provider as they deal with EoL ethical decision making in the light of the dynamics of culture, both, western and eastern, modern and ancient. The capacity to use these resources is part of the process in which individuals make meaning in the face of death as well as discover meaning not even intended. Meaning making helps patients with the goals of remembering, reassessing, reconciling, and reuniting—all goals which seem to be translatable cross-culturally.

“The suffering human being needs a place where he/she can rest, a place which breathes genuine hospitality, where fear and hope are permitted to exist side by side... a place where the naked face appeals for compassion and finds response.” (Eriksson & Lindstrom, 2003)



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Correspondence

Philip Crowell, M.A., M.Div., Ph.D.

Director, Department of Spiritual Care
Children's and Women's Health Centre of BC
Rm 2N34 4500 Oak St.
Vancouver, British Columbia V6H 3N1
Canada

