
Expanding Notions of Culture and Ethics in Health and Medicine to Include Marginalized Groups: A Critical Perspective

Peter H. Stephenson *University of Victoria*

Abstract: I am concerned with the manner in which an almost exclusive focus on the individual has been part of a more general process that increasingly marginalizes the most vulnerable people. A highly individual view of what constitutes the realm of ethics stems both from the cultural value of extreme individualism expressed in the industrialized west and a narrow conceptualization of culture itself. I will argue that this has profound consequences not just for groups like minorities and the poor, but also ultimately for our species itself. This is because a failure to attach ethical discussions to groups cannot adequately critique ecological disasters. Ultimately, it is our species that is threatened by a medical ethics narrowly bound to the notion of individual rights rather than to ideas of responsibility and human rights. I will illustrate this with examples drawn from the evolution of increasingly virulent diseases created largely by the pharmaceutical industry and the obsessive quest for individual longevity via organ transplantation that has led to a profound misunderstanding of cancer.

Résumé: La façon dont l'individualisme actuel marginalise de plus en plus les êtres les plus vulnérables m'inquiète. Une vision si fortement centrée sur l'individu dans le domaine de l'éthique peut provenir de deux sources: premièrement la valeur que l'ouest industrialisé accorde à l'individualisme radical et deuxièmement un concept trop étroit de la culture elle-même. Je soutiens que cette situation a de profondes conséquences, non seulement pour les groupes minoritaires et pour les pauvres, mais aussi pour toute l'humanité. En effet, on ne peut condamner les activités qui engendrent des désastres écologiques que si les évaluations éthiques portent sur les groupes humains affectés. En fin de compte, c'est l'espèce humaine qui est mise en danger par un code médical étroitement lié à la notion des droits de l'individu plutôt qu'aux idées de responsabilité et des droits humains. Ceci sera illustré par des exemples venant de l'évolution des maladies de plus en plus virulentes, largement créées par l'industrie pharmaceutique, ainsi que par la quête obsessionnelle de longévité au moyen de transplantations d'organes qui a conduit à de profondes méprises au sujet du cancer.

Par le même acte, grâce auquel il tisse la langue hors de lui, [l'homme] s'y tisse lui-même.

— (Von Humbolt, cited in Cassirer, 1973: 18)

The prevailing ethos of North American jurisprudence, marketing, business and entertainment are all highly similar—they valorise the individual as decision maker, arbiter, and consumer.¹ Not surprisingly, a similar construction of ethics predominates in many domains ranging from commerce to medicine. After participating in the discourse on ethics and medicine for many years, Renee Fox summarizes this well: “the conceptual framework of bioethics has accorded paramount status to the value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of privacy” (1990: 206). In this paper I maintain that a culturally entrenched focus on the individual in medical ethics, is deeply implicated in the ongoing reproduction of poor health for marginalized minorities. In my view there are some groups who are subordinated by other groups in the name of individual rights held to be sacrosanct, and that ethics can either veil this process or, if dilated, can serve in a more critical fashion to reveal it.

In deeply troubling contexts involving great pain and suffering, medical uncertainty, and competing cultural values; where individuals are at odds and their rights and obligations collide, there are almost never clear answers. Yet, in practice contemporary medical ethicists attempt to project a logical and moral order onto decision-making processes in just such ambiguous circumstances, with results that are generally not critically examined from a wider cultural perspective.

In these situations, rationalistic thinking and a deductive, utilitarian orientation to problem solving provide an illusion of objectivity and logic. Informed by the legacy of Cartesian duality, the analytic style of

bioethics contributes to a distancing of moral discourse from the complicated human settings and interactions within which moral dilemmas are culturally constructed, negotiated and lived. In this discourse, issues of personhood, body parts, organ replacements, genetic cloning, and the like are confronted as abstractions rather than experienced realities. (Marshall, 1992: 52)

The dilemmas most often examined as moral quandaries in the discourse of contemporary medical ethics are generally restricted to issues of individual control and rights, and consequently social justice issues are shunted out of the way. Social justice is rooted in understanding basic inequalities and these are rendered invisible through a construction of ethics that I maintain often reproduces its own fundamental contradiction, rather than resolving any recurrent dilemma with which it may engage. Thus, for example, the end of life ethical dilemmas on which medical ethics focusses presupposes a relatively long life and hospitalisation, both of which are commonplace for only some income groups in society. An end to life in early childhood is far more likely for poor, isolated indigenous populations but neither their poverty nor their disastrously high infant mortality rates are generally construed as an ethical issue; instead it is viewed as a medical, public health, or social problem (Burgess, Stephenson, Ratanakul and Suwonnakote, 1999).

Notwithstanding the effective sidelining of social factors, it has become regarded as especially useful in discussions of health promotion to include “culture” among a cluster of variables to be accounted for in the decisions that people make when they become ill.²

This is generally advanced as a means *to deliver* “culturally sensitive” or “culturally appropriate” care. The verb *to deliver* strongly suggests a commodification of both health (which is left undefined) and of caring behaviour (however that may be measured) consistent with an extremely high level of individuation. The delivery of health care equilibrates it with ordering a pizza, or receiving your morning paper.

Culture has found its way into the clinical concerns of medical ethicists, health administrators, nurses, and physicians coping with highly a plural clientele. However, it is the instrumental clinical value of the concept of culture in the treatment of individuals (or sometimes “families,” whatever they may be) that has become attractive to ethicists, not its explanatory power in social contexts such as those involving class, ethnicity, age and gender. Given the clinical imperative to treat individual suffering this is hardly surprising but in my view it is now critically important to expand the manner in which the concept of

culture is used and understood in the realm of ethics. This can be accomplished by showing a variety of ways in which culture has been used as a concept that constrains understanding rather than expanding it. Examples have been selected to illustrate a series of points that, when taken together, illustrate the need to use the culture concept in a complex, critical and multidimensional way. This is not a linear argument, and I certainly do not argue that we should exchange one particular definition of culture for another. Nor do I wish to imply that we should ignore the needs of individuals or shrink from trying to make very difficult decisions; I strongly advocate a broader understanding of how collective and individual problems are entwined in the hope that it may benefit us all.

Many influential writers in medical ethics uncritically accept culture as a kind of quasi-analytical category used to explain variation in behaviour. However, since most ethicists received their training in analytical philosophy, they do not view their own analytical categories as contestable (cultural)—instead, they are givens. In this respect they differ little from most academic fields, which begin with an episteme. Much of contemporary anthropology, however, strives to contest its own categorical assumptions in a highly reflexive manner where almost nothing is a given—except, perhaps, the very notion that we should not begin with givens. Between 1995-97 I met regularly and intensively with a group of medical ethicists to try and see how these two very different ways of working through difficult issues might fruitfully engage one another.³ This was sometimes very difficult for all of us, chiefly for two reasons: (1) most of medical ethics is concerned with individuals whereas most of anthropology is concerned with groups; (2) cultural relativism of some sort is a prerequisite of ethnographic work in cultural anthropology but what ethicists generally term “cultural ethical relativism” is anathema to the field of medical ethics. Consider the following quote from Soifer (1997: xxi) in his introduction to the second edition of his classic, *Ethical Issues: Perspectives for Canadians*,

[relativists] make the claim that what each of these cultures believes to be right *is* right. . . . Indeed, if relativism is correct, it becomes hard to see how people can engage in ethical debate even within a single culture. One might wonder how we are to determine what a culture believes . . .

I hasten to add that Soifer’s view is (relatively) enlightened. Characteristic of this kind of discourse is a highly reified notion of culture; Culture believes, thinks etc. Any contemporary notion of culture as a dialogic pro-

cess containing many different voices contesting assumptions is entirely lost; any notion that ethics itself is imbedded in this process remains almost unthinkable.

We may initiate a critical review by observing first that an operational view of culture as simply constituting one intervening variable among many is actually the hallmark of a particular kind of culture whose members tend to see virtually everything in purely instrumental and functional terms. Therefore, an initial reluctance towards establishing a working definition is a precondition for actually expanding our understanding of culture to include the wider and multiple contexts within which people operate during communication in culturally plural situations. Appreciating how culture (as ideology) obscures as well as reveals certain connections from people in various contexts related to healing and illness is the goal.

However culture might be defined, as a universal feature of human social life it must apply to the world of health care providers and clients equally (as well as to both researchers and their subjects). In the realm of health and illness this means that how clinicians and ethicists create meaning when interacting with their clientele interests us at least as much as the illness experience. Most importantly, it is the dominant cultural group in these encounters that may be especially difficult to understand. This is particularly the case where medicine and ethics come together because there it is often assumed that such a quintessential realm of science and logic has become a privileged site where culture (in its ideological and subjective sense) does not play a role. Or, if it does play a role, it is simply viewed as a contaminating variable to be excluded from analysis if it cannot be included in a highly controlled manner. I think this view is actually basic to how the most central ideological constructs of industrial Western culture are reproduced; by asserting that they are not ideological in the first place. Much of medical science manifests an unwavering belief system (an ideology) in which it is maintained that it is not an ideology, but instead constitutes the truth revealed through experimental methods. In a similar fashion, much of medical ethics asserts itself as a moral arbiter based on hard logic and absolute categories. From a critical and reflexive perspective these represent ideologically loaded core assumptions reflecting a Western post-industrial world view: the individual, consent, choice, worth and goodness (as opposed to evil) and control. More arcane terms such as autonomy, beneficence and non-maleficence are employed in ethics instead of culturally imbedded terms like “good” and “evil.” The phrase from the constitution of the United States, “life,

liberty and the pursuit of happiness” captures nicely the essence of the notions held as givens in much of contemporary American ethics. Supra-individual elements of social organisation such as kinship groupings, membership in disadvantaged groups (women, children, the disabled, etc.) or sub-national ethnicities (indigenous peoples, visible or auditory minorities) are difficult to handle in this construction of ethics. Furthermore, notions of group rights, as well as more environmental notions of cause of all forms of pathology (including crime) become either unthinkable or even anathema in the individuated realm of contemporary medical ethics.

Culture is understood in this general framework to be a controlled factor in experimental modalities rather than the comparative experimental method seen to be a cultural form where certain ideas are reproduced, most especially the notion that means are justified by ends and that individuals are the explanatory nexus of social events. Ethics is likewise viewed as somehow endogenous rather than a peculiar cultural product, which is based on a set of intuited eternal verities.

The form of ethical debate is usually a decontextualized case study phrased as a dilemma. Case by case resolution reproduces the narrative assumptions of the debates over and over again; it does not change the context that creates the events in the first place. I have used the case method in this paper in a contrary manner meant to complicate rather than to resolve, and to expand rather than limit, the discourse. If an intercultural ethics is to ever develop in pluralist societies my contention is that such privileged and hegemonic orientations will have to be subverted through an expanded self-awareness on the part of practitioners and researchers in ethics and medicine. The realm of ethics—concerned as it ultimately must be with both the examination and creation of alternatives—seems a likely if not an easy place to start.

Example #1: The Death of Sandra Navarrete

On March 28, 1989, five-year-old Sandra Navarrete died of chicken pox, a childhood disease that is rarely fatal in the United States. Her parents, recent undocumented immigrants from Mexico, did not seek medical care for Sandra until it was too late for successful intervention. Their comments indicated that they did not seek care because they did not know where to go, they did not speak English, and they had little money (Jones and Reyes, 1989: II,1). A few days after this occurred; I received a phone call from a reporter who asked me,

“What is it about Mexican culture that prevented Sandra’s parents from taking her to get health care?” (from Chavez, Flores, and Lopez-Garza, 1992: 6-7)

Like the reporter who telephoned Leo Chavez in this example, researchers from biomedicine interested in cultural pluralism and health issues greatly restrict the notion of culture by defining it as a collection of “cultural beliefs” usually assessed through questionnaires containing several items dealing with respondents’ ideas about health (Millard, 1992: 4). The resultant trivialization of culture as unarticulated elements of traditions, to which others blindly adhere, nicely deflects our attention from our assumptions about knowledge and how these “lie at the heart of contested domains concerning responsibilities, rights, authority, and power” (Millard, 1992: 4). Clearly, Sandra Navarrete did not die of either chicken pox or her parents’ health care beliefs; she died because her family is desperately poor and isolated. Furthermore, they are impoverished because they are part of a large group of undocumented and unorganized Mexican labourers exploited to keep the California agricultural and textile industries profitable. A broader definition of culture would be concerned primarily with the web of economic and political relations that subordinate the Navarrete family, with their despair, and the experience of illness that stems from these. It should also bring into sharp relief a question which I would take as central—whether the lack of access to care experienced by the Navarrete family is not also a matter which medical ethics should bring forcefully to address.

When culture is reduced to a manipulated variable called “cultural beliefs” considerable damage is done to the people to whom the narrowed concept is applied. Where culture is simply a residual and manipulated category, the subject population (patients or clients) are understood to have “health care beliefs” (culture), while professional ethicists and physicians are seen as the bearers of wisdom and medicine—supposedly value free entities which are accepted as entirely “good” and objectively “true” (as logical and as science). In the many intercultural health-care contexts of international development, immigrant and refugee issues, or the struggles of indigenous people around the world, this rapidly becomes a case of “western minds and foreign bodies” (Hepburn, 1998: 59). This is where healthy rationalism is expected to triumph over ignorance and disease because biomedicine and bioethics are advanced as neutral, scientific, and objective descriptions of a reality uninfluenced by social forces. This widespread view is taken for granted and so is not often recognized as part of

the reproduction of inequity . . . including inequities in the provision of health care itself. That it is also a deeply colonialist point of view is barely recognized.

What role does the restriction of notions of culture to a few questions in a medical history, or several variables on a needs assessment questionnaire, play in the death of Sandra Navarrete and the suffering of people like her? To begin addressing these questions, we must briefly summarize the thrust of most bioethical concerns over the past several decades. I wish to emphasize from the very beginning that I think we should understand these as predominantly the broadly defined concerns of our dominant cultural elite; that is, as ideological productions rather than as an uncontested progressive chronicle of the distilled truths of logic and science.

Fox (1990: 202) outlines three distinct phases in the evolution of bioethics in the United States, to which we in Canada are also heir. I have appended some significant social and demographic commentaries to her categories.

Late-1960s to Mid-1970s: Preoccupation with informed consent from human subjects involved in scientific research

These concerns continue to be important but have shifted from concern with individuals who may be easily exploited (prisoners, children, incompetent aged, mentally and physically handicapped) to the ramification of experiments with genes and frozen embryos, and foetal tissues (culminating in a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, est. 1978). This period was consistent with wider societal shift from concern with social deviance to a legal approach to the conflict between individual and civil rights which preoccupied Americans at the time.

Mid-1970s to Mid-1980s: Concern expanded to involve definitions of life, death and personhood.

It should also be noted that the demographic underpinning of these concerns reflects a middle-aged “baby boom” generation simultaneously coming to terms with children and ageing/dying parents. The issues of life, death and personhood reflect everything from the meaning of senile dementias to abortion but are also consistent with the growing commodification of people and their body parts. (The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, was established in 1981.)

Mid-1980s to present: Discussion of cost containment in health care and the allocation of scarce medical resources

This is consistent with wider concerns about high taxes and deficit financing of government debt in an ageing population during a period of economic recession.

All of these concerns mirror both technological shifts in biomedicine and alterations in the economic circumstances of an ageing population. Marshall (1992) summarizes this nicely as a major interest throughout recent years concerning the nature of personhood. When does individual life begin and end? To a great extent bioethical concern embodies a fundamental concern of our culture, which is to gain personal control over "events that accentuate individual powerlessness" (Marshall, 1992: 51). This is true of everything from weight control and associated disorders (*Anorexia nervosa*) through cosmetic surgery, to the ageing process and most especially to death itself. Individual powerlessness is a bleak feature of life in industrial society, which is, ironically, maintained by emphasizing the rights of individuals without acknowledging the importance of group processes in supporting and maintaining those rights. Weakening or even severing the social bonds that might truly grant individuals some measure of power and efficacy in their lives does this. However, there is also a fundamental contradiction at work here which stems from every advance in control, and which leads to great ambivalence on the part of the general public. Biomedicine grants the physician or scientist an increasingly finer control over the time of death, or the beginning of life, but simultaneously it often denies these to the individual patient and their family. It is thus that even individual rights become subordinated by the principal of individual rights to life when it is understood as a temporal commodity.

Example #2: The Configuration of Mortality and Ethics: Native Health

If the concerns over when life begins and ends, the moral quandaries associated with placing baboon hearts into infant human beings, and the sex of frozen fetuses have preoccupied parts of both our scientific and ethical communities, they have not proved to be of all-consuming interest in the rest of the world. In Islamic countries, for example, these are widely viewed as the decadent and absurd cultural productions of the self-absorbed infidel West. To critics within, this cultural preoccupation is rather akin to the number of angels who can dance on the

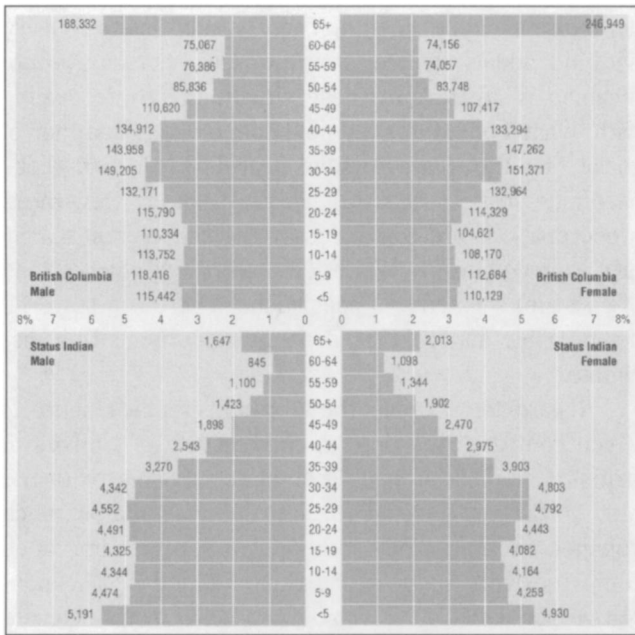
head of a pin. What certain cultural obsessions (the sexual identity of our unborn children, the exact time of our departure from life) seem to reveal is a profound concern with individuals divorced from the social domains where meaning is created. In these situations we are dealing with what constitutes personhood on the margins of social life: those pre-persons nearing birth, and those becoming post-persons through death. In my view these preoccupations are configured by the concerns of mainly urban, predominantly White, economically privileged (and often male) segments of populations. There is a powerful demographic and political dynamic underlying this discourse.

Regard, for example, the following graphic (Figure 1) which compares the population structure of Natives in British Columbia, Canada (non-status Indians) with the rest of the province. The Native population is much younger, and has almost no population of seniors when compared with the rest of British Columbia. The non-Native population is extremely top-heavy with a considerable segment of the population over 65 years of age. This latter population is almost completely urban, mainly White, intensively utilizes hospitals, and is generally far wealthier than their Native counterparts. Much of the practice of medical ethics concerns the latter stages of life and is taken up with this population and very large expenditures of funds are associated with them. Yet, the mortality statistics for Aboriginal people indicates a much poorer health status rooted in limited access and further constrained by a set of beliefs and practices which define their suffering, like Sandra Navarrete's, as a social problem surrounded by an aura of inevitability.⁴

The fact that the Native population is much younger stems from the appalling mortality experienced by the group from birth onwards as Figures 2 and 3 graphically demonstrate. The relatively younger Aboriginal population is then far more than a reflection of higher birth rates; it exists because the rest of the potential age pyramid has been eroded by constantly higher mortality from just about every cause we have managed to study. Indeed, when one measures this in terms of a comparative statistic known as potential years life lost standardised rates (PYLLSR), we find that the Native population of British Columbia (whether male or female) loses more than three times as many years as the rest of the population from all sources combined. I want particularly to draw your attention to the measured rates of Sudden Infant Death Syndrome (SIDS) in Figure 2 which initiates the simply appalling mortality curve found in Figure 3.

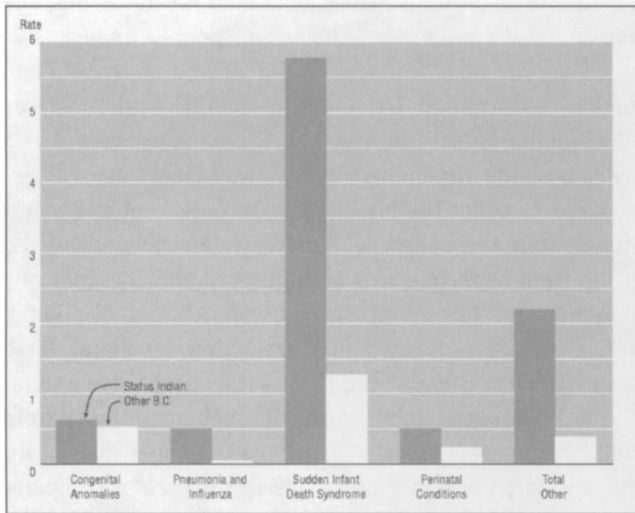
There are many risk factors associated with deaths of all infants in their first year, clustering around the 4th

Figure 1



Population comparison: Native (status Indian) vs. non-Native pyramid profiles in British Columbia, 1992 (Foster et al, in Stephenson et al, 1995: 51).

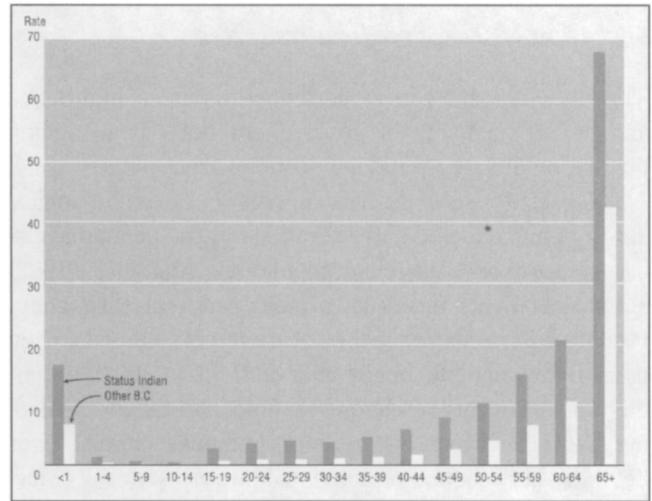
Figure 2



Major causes of post-neonatal infant mortality: Native (status Indian) vs. non-Native populations in British Columbia, 1987-1992 (Foster et al, in Stephenson et al, 1995: 70).

and 5th month of life (maternal smoking, low birth weights, maternal anaemia, youth of mother, alcohol and drug use, single status, and lower socio-economic status). The last of these, poverty, is implicated in virtually all of the others because poverty too often means poor

Figure 3

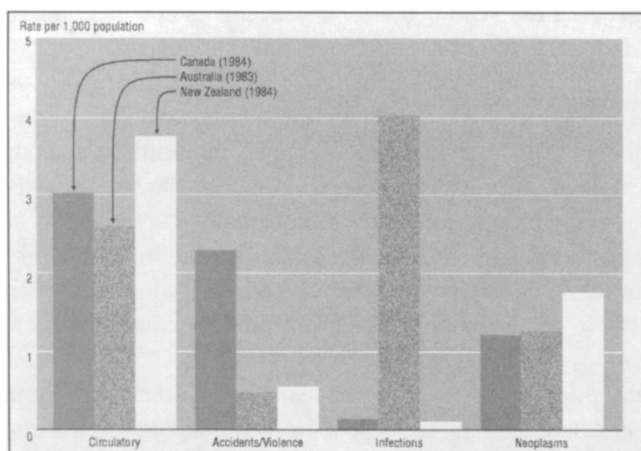


Age-specific mortality rates comparison: Native (status Indian) vs. non-Native in British Columbia, 1987-1992 (Foster et al, in Stephenson et al, 1995: 72).

maternal nutrition, absent partners, despair and addiction. If this childhood and maternal poverty is where the higher mortality trajectory begins in Native populations, then we must wonder why this is not of greater concern to the world of medical ethics? Well, of course the Native population is far more rural and has poorer access to care, maternity programmes, and all manner of public support. In particular, relatively little money is actually expended upon them compared to the dominant groups in Canadian society. To reduce mortality in the first year of life of babies also means focussing on social supports, mothers, jobs and income for partners, etc. These are all public health issues; they are deeply social and imbedded within a fabric of systemic racism and economic neglect. To deal with them in ethical terms means conceptualising and using an expanded notion of group rights; to understand why they are not now broadly configured as ethical issues we must also look deeply into the culture of the dominant group in Canadian society. We do not need another superficial set of generalizations about the culture of Native people which becomes just another way to blame the victims for their problems. We certainly do need to understand why this sadly graphic illustration of disastrous and appallingly high numbers of dead Native babies is not in the forefront of medical ethics instead of frozen foetuses and transgenic farmed organs from pigs. I suggest it will have to become so if we are ever to develop an intercultural ethics in medicine and health care which deals with more than the pre-occupations of the most powerful cultural groups in our plural society.

The Canadian example of high mortality among Native peoples repeats itself around the globe with colonized populations of indigenous people everywhere. Typically, the leading causes of death in such populations are: (1) circulatory diseases, particularly Non-Insulin Dependent Diabetes Mellitus (NIDDM) associated with loss of land and resources, relocation and dietary shifts from varied high protein/low carbohydrate diets to limited low protein/high carbohydrate diets (Heffernan 1995, Hopkinson, Stephenson and Turner 1995); (2) violence (including suicide) and accidents, often associated with poverty, substance abuse and a history of residential school systems and missionization (Cooper, 1995, Wade, 1995); (3) high rates of untreated infections associated with poor housing, poor diet, lack of access to care and isolation. Elliott and Foster (1995) graphically depict this situation (see Figure 4) for Australia, Canada and New Zealand using data compiled by Shah and Johnson (1992). Note that death from Neoplasms (Cancers) are roughly the same for each group and much lower than the leading causes of death for each respective group. Cancer kills mainly in older age categories and relatively few of these people ever reach anything like old age (Hislop and Band 1995).

Figure 4



Age standardized mortality rates of the leading causes of death for Indigenous peoples in Canada, Australia and New Zealand (Elliott and Foster, in Stephenson et al, 1995: 107)

What kind of distractions and enthusiasms contribute to the political economy and limited attention span of a world filled with starving children living in abject poverty who die in droves of common childhood diseases like chicken pox; their suffering somehow construed as inevitable? Their deaths have somehow become too easily viewed as the sadly unavoidable product of their own cultural inadequacy and degradation

brought on by mixture of corruption and poor hygiene. They are not often viewed as a creation of international agribusiness, which has alienated much of the world's food growing lands in less than a century, and turned them into coffee, chocolate, citrus, tea, poppy, coca, copra, sisal, cotton or other plantations. Neither is the destruction of food species habitats by rapacious mining and manufacturing industries generally seen as causal. My point is simply that it is rather easy to do this if we insist that our most powerful science (medicine) and our reified market (economics) are both value-free and objective while our ethical/moral assessments of health turns on questions of life extension for the privileged few. Other cultural realities are either reduced to a few beliefs which must be surmounted in order to provide them with hegemonic ideas of "modern" health care or are ruled out as based in a morally repugnant cultural relativism that applies to everyone but the ethicists themselves. This is done while simultaneously moving poor people away from kinship-based collective responsibilities and into the free-market system as entrepreneurial individuals. That these are assimilationist and neo-colonial ideas is simply too obvious to need much elaboration (Bodley 1985, 1988, 1990). A basic issue for consideration in an intercultural ethics is then the rights of groups and the distribution of basic resources needed to sustain life within them.

Example #3: The Problematic Concept of "Post-Traumatic Stress Disorder"

It is generally assumed in Psychiatry that Western diagnostic categories and standards of measurement are scientific, and hence, minimally affected by cultural values. This is type of category fallacy can be well understood through a critical examination of so-called Post-Traumatic Stress Disorder, or PTSD as it is most commonly known. The symptoms of this "disorder" are reasonably well known and need no elaboration here, but one wonders how it can be claimed that the same terminology applies equally to the victims of torture and the torturers themselves? How is it that Vietnam War veterans and Vietnamese refugees both have PTSD? Those who survived a catastrophic earthquake and those who lived through the process of "ethnic cleansing" in Bosnia are said to suffer in the same way in a common syndrome (Madaakasira and O'Brien, 1987, Young, 1988, 1992). When we focus on healing, which is an interpersonal process, it becomes clear that the fact that some people suffer as a result of human brutality while others suffer from natural disasters must play a role in the therapeutic pro-

cess. It is, after all, the bonds of human trust that must be refashioned in the former. Including the tortured with their tormentors under the same rubric begs all kinds of questions about what is obfuscated through a medicalized acronym like “PTSD.” If torture has the moral valence of an earthquake two things happen: torture is viewed as natural (or human nature) and nature is viewed as malevolent. In this instance, as in the earlier discussion of agribusiness, the culture of the observer tends to obscure something important from our view—human agency in the creation of immense suffering and a moral discourse imposed upon the natural world.

This analytic view of culture emphasizes what is hidden within the ideological structure of culture as well as what is revealed by it.

... the emphasis has shifted from what culture allows and enables people to see, feel and do, to what it restricts and inhibits them from seeing, feeling and doing. Further, although it is agreed that culture powerfully constitutes the reality that actors live in, this reality is looked upon with critical eyes: why this one and not some other? And what sorts of alternatives are people being dis-abled from seeing? (Ortner, 1984: 152)

This is not simply the conventional Marxist formula of mystified power relations; something much more personal and perceptual is implied by Ortner. If we fail to recognize our own beliefs as cultural productions while insisting that others’ problems stem solely from forces at work in their cultures, what happens to nature itself in the equation? My view is that so-called natural disasters become viewed as inevitable, capricious or even malevolent—as accidents—and the fundamental and essential human involvement in the form of everything from flawed and cheap architectural design to toxic effluvia and radiation is made invisible (Stephenson, 1997: 363).

The “aura of factuality” (after Geertz, 1973) in a culture which is conveyed by medical and ethical research and practice must become the object of scrutiny precisely because it so powerfully asserts itself as having reached a set of unassailable scientific bedrock truth. Critical analysis begins with the observation that, as Keesing (1987, 161) put it, “Cultures are webs of mystification as well as signification.” This mystification only begins to dissolve when we come to understand that, as Alan Young succinctly puts it, “in industrial societies the most powerful ideological practices are ones which claim that their facts are non-ideological because they are scientific” (1983, 209).

Example #4: Ageing and the Fallacy of Reproductive “Loss” in Menopause

It takes what Martin (1987, 52) describes as a “jolt” to better understand the “contingent nature” of biomedical description and analysis, and this can happen when one’s own assumptions are revealed in another cultural context. For many anthropologists, working in cultures other than their own with older individuals as cultural interpreters has revealed, quite unbidden, the nature of age stratification in their own societies. The stratification and stigmatization of the elderly is grounded in an ideology of ageing within biomedicine itself as the medicalization of old age. The process is particularly gendered and simultaneously yields the view that men inevitably die young due to constitutional deficiencies and that women live longer but essentially unproductive lives. Both of these are ideological constructions based upon social forces at work upon men and women in industrial societies. The discussion here relates to women’s health but a similar deconstruction of men’s socialization into highly stressful dangerous careers and early mortality experiences propped up by an ideology which normalizes this as essentially male is easily conceived.

In a now classic study, Emily Martin (1987) deconstructed the representations of women’s bodies found in Medical Textbooks. She concluded that several powerful metaphors of women’s bodies permeated the textbooks which were cloaked in scientific (supposedly value free, or neutral) terminology. Martin found one metaphor employed throughout the texts was that the female body is geared to “production” (not really reproduction, I would add) and consists of a control hierarchy that falters and breaks down with age. The image is identical with that of our economic system. In menopause, she writes, “what is being described is a breakdown of a system of authority... at every point in this system, functions “fail” and “falter.” Follicles, for example, “fail to muster strength to reach ovulation. As functions fail, so do the members of the system decline” (1987, 42). The key to the metaphor, as Martin sees it, is “functionlessness.” She concludes, “these images frighten us in part because in our stage of advanced capitalism, they are close to a reality we find difficult to see clearly: broken down hierarchy and organisational members who no longer play their designated parts.” I would add that outside the body the hierarchy that is breaking down is also one of male authority, and the members no longer playing their designated parts are (mainly) women. Not only, as Martin forcefully concludes, is the body described in a way which props up a view of women defined solely by their

reproductive function, but this is done in a way which strongly implies that menopause is a negative experience and that post-menopausal women do not have an economic roles to play—being broken parts, as it were, and viewed as emotionally unstable ones at that. Such a negative evaluation of identity and slim prospects for the future can easily lead to anger, which is transformed into a symptom and called pre-menstrual syndrome (PMS).

A considerable literature exists on post-menopausal women's lives outside of the mainstream of industrial capitalism. In Oceanic societies, after women stop having children; they enter the domain of political leadership. A considerable number of Oceanic people appear to have older women and younger men—often their sons—serve as political leaders. Many old men retire to a life socializing with one another, in caring for grandchildren, and in fishing. The change of role from that of a person prohibited via various taboos (centred on menstruation and fertility) from playing political roles is essentially validated for women by menopause and the clarity of mind it is said to bring (Brown and Kern 1985). This reinterpretation of what menstrual taboos mean has also been extended to various Native American groups (Underhill 1965, Powers 1980, Wright 1982 and Buckley 1982). What then, happens to the so-called symptoms of menopause and PMS in such societies? There is a considerable literature that has shown that the experience of menopause is quite variable and, not surprisingly, related to the position of women in particular societies (Lock 1993, Davis 1996). Menopause and PMS are relatively culture bound expressions of so-called symptoms operating in societies where change in fertility has long been construed as a loss of fertility—i.e., as a deficit. Most disturbingly, even though there is little evidence for menopause and PMS as universal experiences of women, negative connotations and readings of the change of life can be introduced by what is essentially medical propaganda and a changing view of women associated with the spread of biomedicine (Davis, 1996: 75).⁵

There is another approach to this issue which complements both the analysis of language afforded by deconstruction, and the cross-cultural research into roles and symptoms. This challenge to medical orthodoxy is particularly ironic because it challenges biomedicine on something like its own territory as essentially an uncritical and culture-bound form of folk biology of the West.

Evolutionary Anthropologists, Zoologists, and Primatologists have long noted that fertility is not directly or invariably related to systemic decline and mortality in animals. At one end of a spectrum, animals essentially spawn and die in such a manner that the two processes

are entwined. For example, the entire digestive tract of some migratory fish (*Salmonids*) is reabsorbed and energy and space directed into reproduction. At the other end of the spectrum, highly social animals can have prolonged post-fertile stages in their lives. Interestingly, in human beings and other highly social Primates, this stage may even exceed in duration the period of socialization of the young of the species. There also consists an abundance of information on child-care and provisioning in many groups of food foragers, which shows that after infants begin to walk with confidence, they often become the charges of the oldest generation. The parental generation is often busy acquiring food—indeed, they may be the only ones allowed to hunt and gather because the activity is considered to be polluting in some fashion. Turnbull's (1983) description of Mbuti society vividly illustrates this and adds yet another ironic element; it is the youth and the elderly among the Mbuti who are allowed to make political commentary and reprimand the middle-aged adults for their anti-social behaviour.

Did natural selection play a role in creating both a long period of socialization and a long post-fertility stage in the lives of women? Are the two not rather directly related, each producing the other? Viewed in this way, the negative construction of post-menopausal life becomes, instead, a species-specific adaptive attribute of human beings. To construe menopause as a "loss" obscures what might be understood far more profoundly as the way our species gained its most defining attribute: culture. The evolutionary development of culture depended on an adaptation that allows for considerable post-reproductive life, particularly among women. Such a view of post-fertile life-span suggests that it is a highly evolved characteristic and part of what has made us into *Homo sapiens*: cultural knowledge shared among three generations rather than simple survival techniques transmitted between two. What kind of an ideology operates in such a way that something as profoundly human as the collective evolutionary gain of culture as a species attribute can be viewed as inevitable individual loss? It must be a powerful ideology asserting a form of truth that it is incontestable and exclusively individuated.

The evolutionary perspective allows us to examine another critically important issue where the weight of the scales of eternal justice have tipped so far towards individual rights over group rights that I fear we may have endangered ourselves as a species.

Example #5: Pharmaceuticals and the Ultimate Iatrogenesis⁶

As almost every student of pathogenesis and infectious disease has come to understand, over time, natural selection tends to favour the less virulent forms of any particular pathogenic organism. This is simply because the most virulent forms wipe themselves out when they kill their hosts. For example, we can see that many pathogenic relationships between organisms that afflict mammals, are now carried rather benignly by reptiles and birds that have had much longer periods of evolutionary time to come to terms with them. The greatest scourge of humankind since the advent of agriculture in central Africa, *Plasmodium* (Malaria), is an example of this. "A corollary of our discussion thus far is that a well-adapted 'healthy' parasite is one which has increased its potential for survival by not killing the host. In evolutionary terms, this means that older parasites are often highly complex in their interaction with their hosts, and while they may kill some, particularly children and older people, they debilitate many. They also will have evoked an adaptive response on the part of humans which is genetic in those areas where the disease is endemic." (Stephenson, 1986: 49-50). What, we should now ask with some urgency, do we accomplish when we indiscriminately apply broad-spectrum antibiotics to mild infections in otherwise healthy individuals? Rather obviously, we create a hot-house environment for the breeding of increasingly virulent forms of the infectious diseases we have targeted. Moreover, we also disrupt many other unintended targets such as our normal intestinal flora (*e. coli*) with pharmaceuticals, causing them to rapidly evolve forms of resistance, which they then transmit laterally to infectious pathogens through the unique ability of bacteria to swap genetic material across species lines. The process of pharmaceutical driven micro-evolution of virtually all bacteria and some viruses we blithely term in common parlance, "medicine." One is given to wonder at the ultimate wisdom of this . . . and the role that individual rights ascendant over collective responsibilities may play in ever trying to remove so-called "modern medicine" from this nasty evolutionary *cul de sac*. Disturbingly virulent forms of old diseases (and perhaps a few entirely new diseases) are increasingly the legacy of the era of the "magic bullet" (Stephenson, 1989, 1991). But most insidiously, the pharmaceutical industry is unlikely to change this situation for the simple reason that a positive feedback loop links their profit motives to epidemiological imperatives when so-called "new" diseases arise or

resistant bacteria evolve. Quite simply, a larger potential market arrives with every resistant strain that appears. The pharmaceutical industry appears to contain a fundamental iatrogenic contradiction, which is obscured by common beliefs surrounding the term "cure." After all, we say that "medicines" (e.g., drugs) "cure"; we do not conventionally say they "cause" disease. A more culturally situated evolutionary and economic understanding of Western antibiotic pharmacopoeia rooted in social costs as opposed to individual gains, suggests something very different. Every new generation of drugs increases pathogenic resistance in a downward spiral spreading death and destruction in its wake—along with a generous bonus of increasing dividends for wealthy individuals and corporations. Moreover, resistant bacterial infections grow fastest in the underdeveloped world because once resistance begins, pharmaceutical companies with overcapacity dump cheap drugs into Third World countries where their use is uncontrolled. Additionally, more than half of the antibiotics used are added to feed in agriculture to promote growth (and profit margins) in agribusiness and so the resistant reservoir of bacteria has become immense (Davies, 1996).

What does this rather dismal scenario entail for either the concept of culture, or medical ethics. I think it means leaving behind the deeply mistaken notion that biology and culture are not linked in some very critical ways. Their linkage is one in which humans have blundered into the biological realm while under the illusion that they were "controlling disease" through the sheer brilliance of their culturally-based superiority (Stephenson, 1997).

In his influential work, *The Predicament of Culture*, James Clifford (1988) concludes that the idea of coherent "cultures" is deeply problematic. According to Clifford, anthropologists (among others) have generally used the culture concept to imagine a world of neatly bounded, internally "coherent," aesthetically "balanced" collective entities. However, such a concept,

. . . contain[s] and domesticate[s] heteroglossia. In a world with too many voices speaking all at once, a world where syncretism and parodic invention are becoming the rule . . . it becomes increasingly difficult to attach human identity and meaning to a coherent "culture" or "language." (Clifford, 1988: 95)

Thus, Clifford rejects essentialist models of culture and identity. Culture is not located within a group, just as identity does not inhere in individual human beings. Rather, culture and identity happen between people: "we should attempt to think of cultures not as organically

united or traditionally continuous but . . . as negotiated, present processes” (1988: 273). He concludes that the “deeply compromised idea” of culture must be “replaced by some set of relations that preserves the concept’s differential and relativist functions and that avoids the positing of cosmopolitan essences and human common denominators” (1988: 274-75). This newer formulation of culture must itself be multivocal and grounded in experience as opposed to being defined in universal terms. Such a conceptualization may allow for intercultural understanding as opposed to cross-cultural studies. Yet we must also caution that Clifford’s argument about culture, as a loose construct containing internal contradictions and incoherence, is also mainly an analytical perspective informed by the chaotic aspects of social life. From a more localized and grounded ethnographic point of view, many newly consolidated identities—sexual, ethnic and cultural—are also continuously being asserted and the symbols used to unite these identities in the political domain are created against a backdrop of alienation and a human need for meaning and consistency. So, there are forces pushing in the other direction too—towards homogeneity and consolidation in a specified place and time. One has only to think of many ethnic nationalist political movements around the world to see that the creation of culture is a process of fusion as well as fission. If the most salient lesson is that culture is a process occurring between people(s), then the transmission and creation of both illnesses and health are also cultural processes occurring between groups of us.

Case #6: Mortality and Death: The Dance of Measurement and Meaning

Consider the recent rather surreal court cases of a physician in the U.S. who has been given the moniker “Dr. Death” by the public and the tabloid media. Dr. Kavorkian has invented a machine that allows his clientele—mainly individuals with mortal illnesses—to push a button, leading to the release of a lethal substance through an I.V. As a researcher who has witnessed the deaths and attended funerals of a number of people in various cultural contexts (Hutterian, Cree, Haida, Dutch), this has always struck me as a particularly absurd medical appropriation of a natural process. What is it about industrial medicine that has made people feel that they require this kind of assistance? In many cultures, people can often die more or less when they want to because they stop eating and taking fluids and their desire to do so is respected. If one is ill and takes in no fluid for a couple of days, one dies. Not only do people in

many cultural groups appear to know when and how to die, all other animals appear to manage this too.

The variation in mortality experiences of Hutterites as these relate to ageing, sex roles and fertility are particularly relevant here, Stephenson (1991, 1985, 1983). The Hutterites do not share a similar life expectancy pattern to that of the rest of North America. They may be the only known group in the industrialized world where men and women die at about the same age—indeed men may even outlive women by an average of about six months. In trying to understand how this comes about I have had most of my notions about death itself challenged. I have concluded (in contrast to the proponents of the doctrine of specific aetiology) that people almost never die of any one underlying cause but of multiple factors. Whenever a specific cause of death has been sought for in epidemiological studies of Hutterite women, we have only succeeded in finding that they have fewer deaths from that cause than would be expected: the Hutterites die earlier from less of just about everything than does much of Canadian society in the prairie region where they dwell. They have lower rates of cancer, in particular. What do they die from? Early researchers concluded that the high numbers of births per woman (a measure called parity) was responsible through some sort of systemic weakening of their bodies. This hypothesis went untested for about 30 years and derives from the same perspective that Martin so successfully deconstructed. I should also point out that large families are often considered to be irresponsible and unhealthy by the social class and society from which the researchers themselves were drawn. Parkinson (1981) finally showed that there was no statistical or clinical data to support the parity hypothesis. Indeed, Hutterian women with the largest number of children appear to live slightly longer on average, although the age difference is not particularly significant. Long-term ethnographic fieldwork suggested instead that many Hutterian women probably die earlier than non-Hutterite counterparts of multiple sub-clinical cardiovascular conditions within a context where death is not feared and where dying is a lingering social process which is drawn out over time, allowing them to be visited by dispersed daughters. In short, death does not mean the same thing to Hutterites as it has meant to medical researchers. For Hutterites dying is a normal, inevitable process which makes one the focus of community attention and love. It concludes a period of relative isolation from ones dead kin and friends and transports one to the realm of eternal perfect communal living (heaven) while ending a life of increasing travail and isolation from daughters as well. To many researchers, how-

ever, death is generally the enemy; it is, if not entirely preventable, then something to be indefinitely postponed. Any conventional demographic or epidemiological use of mortality statistics to try to either evaluate or prolong life in the Hutterite colonies is likely doomed to failure. Hutterites tend to greet death with hope rather than fear and prefer a prolonged deathbed to a sudden departure. Just how does one do comparative epidemiology when the major variables for severity of expression of symptoms and even mortality (and hence life expectancy itself) are imbedded in cultural values which evaluate pain and death very differently from the way the researcher does? Have we made of death such a fearsome “enemy” that we no longer know it as a universal and normal experience?

Conclusion: Industrial Medicine and The “War” on Disease

Recently I have come to view much of industrial medicine as founded to a great extent on culture-specific metaphorical notions of a moral war. The working conditions of almost any emergency ward in a major city in the industrialized world tend strongly to reinforce such a view. People maimed in accidents or assaulted by those around them swamp emergency wards. The caseload of traumatic injury is so heavy in many of these institutions that the same kind of medicine (triage, gallows humour, etc.), which prevails in war, is found in them. Many physicians undertake their basic training in such circumstances, but receive almost no training in public health and know little of the culturally diverse populations they must serve. When this understandable siege mentality is then later extended into the realm of chronic problems, however, disease becomes the enemy instead of poverty, ignorance and neglect. And, although our conditions are “targeted” by drugs, “bombarded” with X-rays, and “operations” performed to remove various “invasions” of our personal landscapes, our experience of this war is deeply problematic. The perceived enemy is, as always, small and escalation breeds guerrilla tactics to which we, in the ranks of industrial medicine, are extremely vulnerable.

In this metaphorical war against disease, the historical significance of our allies—medical technology and “civilized” culture—in the domination of smaller cultures and their experience of disease and suffering has been greatly overestimated and generally misconstrued. As McNeil (1976, 1979) has shown, the disease load harboured by civilization has been its major weapon during colonial expansion. Epidemics of diseases causing herd immunity in adult survivors are maintained in large,

dense populations via the annual infection of large numbers of children. These “childhood” infectious diseases evolved from herd and flock animals along with agriculture and animal husbandry. They were (and are) devastating to smaller societies when both children and adults become simultaneously infected. Not only are adults far more seriously symptomatic, but they cannot care for their infected children, leading to exceedingly high overall mortality. The political advantage won for western medicine early in the colonial encounter between resistant adult Europeans and diseased and dying indigenous peoples around the world is difficult to overestimate. Both parties appear to have attributed notions of superiority (cultural and racial) to immune Europeans. Paradoxically, the greatest initial advantage Europeans had over smaller cultures and their medical practice was not western medicine, it was the diseases they carried with them (Cohen, 1989). Many in the medical fields, however, still live with the illusion that it was a superior culture in the form of technology and medicine, which gained for the West much of the world. This arrogant perspective buttresses notions of superior values and morality in the form of those key assumptions which lie behind our ethics as well.

To summarize, much of western medical ethics is generally framed by a set of cultural themes from which I suggest we must begin to break away.

1. Individual demands are generally valued at the expense of group rights. Put in another way, our notion seems to be that individuals have rights; groups have responsibilities to individuals, and it is rarely the reverse. Since culture is quintessentially a group concept with ramifications for individuals, then an intercultural medical ethics will of necessity have to move beyond the dimension of individual entitlements and rights and towards some way of addressing the rights of groups of people who are disadvantaged.
2. A large population cohort of elderly individuals in a culture obsessed with youth and phobic about death utilizes vast amounts of health care resources in the last months of life. Medicalisation can make old age a nightmare for many seniors and their families while simultaneously diverting limited resources from prevention of problems among marginalized minorities. A generalized extreme fear of death (thanatophobia) also wreaks havoc with the normal ageing process for both women and men and even distorts our understanding of what makes us human; the long post-fertile life stage that allowed culture to evolve in the first place. A critical approach to this means shifting the concerns of medical ethics from the tangle of individual rights at

life-end stages dominated by technology, and towards group processes that promote prevention and acceptance of life and death as normal events.

3. Competition is pervasive and actually believed to be the universal fountainhead of individual creativity in a global economy. This particular ideology creates adversarial relationships between humans and their environmental contexts and human moral dilemmas where solutions must be co-operative. Much discourse in medical ethics takes the narrative form of debate between two sides of an issue with a winning position. That this is culturally situated motif of competition similar to everything from game shows to the awarding of the Nobel prize for literature seems obvious; that it generally reproduces problems rather than finding solutions appears to be almost invisible to the participants.
4. The widespread view of co-operation as a suspect activity that is unnatural, and, at any rate, unattainable in the individual struggle to survive is a corollary of (3). This makes solution-oriented programmes directed at prevention and promotion in intercultural contexts extremely difficult to maintain. Where failure is expected the economic and structural supports required to achieve success are generally minimal. Any consequent failure of co-operative activities is then said to prove the point that it initially presumed. Much inadequate funding for public health initiatives among marginalized groups (the homeless, indigenous groups, etc.) is like this and never moves beyond inadequately funded demonstration projects whose goal appears to be to demonstrate the intractable nature of the problem, not to find a solution.
5. The conquest of much of the world by Europeans tends to be viewed as the inevitable result of cultural and technical superiority (including medicine) rather than the result of diseases transmitted to non-immune populations that killed millions of people between 1500 and 1900. This illusory interpretation of history tends to breed an arrogant and ignorant self-confidence about cultural hegemony and a supremely overconfident science. An intercultural ethics of medicine will have to be vigilant in adopting a more self-critical stance and be able to hear other points of view through a very dense and rather self-congratulatory cultural screen. Otherwise, the crisis in antibiotic resistant bacteria will ramify into an overwhelming array of iatrogenic problems threatening our collective existence.

All of these points appear to be related to an extraordinary need to exert personal control over events that accentuate individual powerlessness in those kinds of

societies which, paradoxically, thrive on individual powerlessness. As such, an ascendant form of individualism threatens the actual existence of the collectivities to which we belong—families, cultures, and species. This, in my view, leads to the neglect of vulnerable minority groups and to a view of public health measures that are not seen or understood in ethical terms. A cover of *LIFE* Magazine recently viewed at the newsstand reveals this well: “Can We Stop Ageing?” the headline demands. Ironically, one wonders if notions of individual immortality will make us collectively extinct. The deeply imbedded Christian notion of life after death understood as “life everlasting” has represented a long-term (perhaps fatal) blind spot in understanding cancer in particular. Only in the last two years has the fact that cancer cells are immortal begun to be recognized as the principal factor making them so dangerous. Understanding what makes cancer cells immortal is a fundamental step towards alleviating the uncontrolled growth of tumours. Quite simply, in social species or groups individual immortality is essentially a malignancy. Yet many in medical science have interpreted this cautionary lesson instead as a way to begin pushing forward life expectancy into the range of centuries through gene therapies to prevent normal cell apoptosis.

Our place in both the world and among other peoples appears to be deeply flawed by the notion that we are incontestably superior beings, with an arsenal at our disposal. Left unchanged, I fear such hubris may actually hasten our species' departure from the scene. Dreams of immortality are antithetical rather than fundamental to the love and care of others which should be intrinsic to health care and to an intercultural ethics that supports it. Milan Kundera, in *Immortality*, summarized this very precisely:

The gesture of longing for immortality knows only two points in space: the self here, the horizon far in the distance; only two concepts: the absolute that is the self, and the absolute that is the world. That gesture has nothing in common with love, because the other, the fellow creature, the person between these two poles (the self and the world) is excluded in advance, ruled out of the game, invisible. (Kundera, 1990: 211)

Notes

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- 3 To read the results of this endeavor, please see Coward and Ratanakul (1998).
- 4 See Foster, et al (1995) for a detailed discussion of these graphs.
- 5 Diet is also a largely unexamined factor in the experience of PMS in particular, although its implications for menopause are somewhat better understood. There are many naturally occurring estrogens in plants and there are also numerous human-made products (plastics, herbicides) which mimic estradiol. These forces may influence population specific physiological experiences around reproduction in ways we are only beginning to understand.
- 6 See Stephenson, 1986, 48-50, 1989, 1991, 1997, and Davies, 1996.

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