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# 台灣醫學人文學刊

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# Understanding Criticisms of Clinical Ethics and Ethics Consultation<sup>1</sup>

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Controversies over clinical ethics have continued since the earliest days of applied ethics and the beginnings of bioethics and clinical ethics. Beneath the well-known debate between defenders of a principle or theory-based method, and those who would urge a casuistic or narrative approach, lay deep disagreements and uncertainties about the nature of clinical ethics itself, which has often been the field where these disagreements are set. In this paper, I offer a historical sketch of the background for criticisms of clinical ethics showing that the criticisms reflect concerns from the perspective of the critic about what clinical ethics might be rather than a critical assessment of the field itself. Many criticisms of clinical ethics and ethics consultation fail to appreciate the nature of clinical ethics as a practice and, instead, express theoretically based concerns that may not accurately reflect the field.

Beginning in the 1960s, the literature on applied ethics confronted the question of whether ethics can or should be applied. These questions were raised at a time when the dominant view of ethics featured analytical approaches concentrating on descriptive ethics, metaethics, and normative ethics. Except for descriptive ethics, which most philosophers marginalized as a subject of study, metaethics and normative ethics had little or no connection with the everyday world and its concrete ethical problems. In reaction, some philosophers began thinking about problems that

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<sup>1</sup> An early version of this paper entitled, "Controversies over Method in Clinical Ethics" was read at the *Symposium on Moral Theory and Health Care Practice*, Center for Bioethical Research and Analysis and Department of Philosophy, National University of Ireland, Galway, Ireland, March 8, 2006.

occurred in the actual world utilizing the term applied ethics as a way to capture their concerns. A full historical account of the development of clinical ethics is beyond the scope of this paper. However, some points can be highlighted to show that its emergence served as a lightning rod for a set of critical concerns embedded in the philosophical and ethical interest in medicine and the life sciences that inchoately emerged in the 1960s and 1970s.

The term bioethics was introduced in English for a discipline envisioned as an environmental rather than a specifically medical ethic by Van Rensselaer Potter in 1971<sup>1</sup>. An earlier, but largely unknown paper, "Bio-Ethics: A Review of the Ethical Relationships of Humans to Animals and Plants" by Fritz Jahr was published in 1927.<sup>2</sup> In this paper, Jahr redefined moral obligations towards human and nonhuman forms of life and he set out the concept of bioethics as an academic discipline in a broad way. Within philosophy, the applied turn engendered a lively debate. By 1976, Stephen Toulmin, in a provocatively entitled article, "How Medicine Saved the Life of Ethics," came to argue that the engagement with medicine had restored a relevance to ethics, which was "lifesaving" for the discipline.<sup>3</sup> This view, however, while important for the bioethics and clinical ethics, did not quell concerns about philosophers who ventured in the world of medicine. Two developments outside academics, however, forced what might otherwise have remained an academic set of concerns about the application of ethical theory or normative analysis to concrete problems, and the related question of the expertise or qualifications of those individuals so involved into a public discussion. Three developments promoted the emergence of the social role of the ethics consultant at the bedside: First, public ethics bodies, like the President's Commission for the Study of Problems in the Biomedical and Behavioral Sciences, showed that one can achieve broad consensus on controversial ethical issues. Second, a consensus emerged that most conflicts over withholding or withdrawing life-sustaining treatment are best addressed within hospitals rather than the courts. Third, the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) accreditation standards revised in 1992 required that hospitals have an "ethics mechanism" to address ethical questions and problems arising within the health care organization.<sup>4</sup> These developments provided a framework of incentives that spurred the development of ethics committees and ethics consultation.

This development was not without its skeptics and critics. Whereas the earlier criticism of applied ethics and philosophy primarily involved academic concerns, the emergence of ethics into the public space engendered a political criticism. The locus classicus of this critique is Cheryl Noble's broadside against ethics experts, whom, she alleged, claim to have ethical expertise. She argued that deferral to the judgment of these so-called ethics experts, especially in the public sphere, is inconsistent with the values of a democratic society; furthermore, the existence of such putative experts threaten democratic processes and undermine liberal principles. Similar and parallel claims have been made with respect to the involvement of ethics consultants and ethics committees in the resolution of conflicts in medicine. Thus, the criticisms of clinical ethics consultants and ethics committees should be seen against a larger debate over expertise in ethics and the debate over the legitimacy of ethics experts in society.

A number of specific complaints have been leveled against clinical ethics and/or the "experts" that this field cultivates. These criticisms can be summarized in the following points:

First, the functions performed by the clinical ethicists are unnecessary.

Second, even if needed, the tasks could be better performed by others.

Third, the problems addressed are typically not ethical, but rather communication or psychosocial problems associated with facing and making hard decisions.

Fourth, clinical ethics consultants, who are "strangers at the bedside,"<sup>5</sup> override the rights and/or judgment of autonomous patients, their surrogates, and health care professionals.

The underlying worry is that the clinical ethicists and ethics consultants encourage a deferral of judgment and an objectionable abrogation of responsibility for making important decisions by patients, families, and health professionals. At the worst, clinical ethicists usurp the rightful authority of patients and health care professionals. The implicit belief seems to be that, if there are genuine and irresolvable conflicts or disagreements in patient care, then the law is the best place for their resolution, because only the law can provide the legitimate normative guidance that is

needed. Thus, in ethical issues arising in patient care, law is given—without argument, I might add—the authoritative voice on this view. This belief seems to persist despite the fact that the law in the United States has, for decades, sought to return conflicts over medical decision making back to their original clinical settings, and social policy seems to strongly support the use of ethics committees and consultants to resolve these matters. Rather than preferring that these difficulties be resolved in courts of law, which are not equipped to deal with emergent issues, the consensus in the United States is that ethical problems are best resolved as close as possible to the “bedside.”

The question is, “Why have these controversies and concerns about ethics consultation persisted?” First, many commentators seem to implicitly view the ethical questions and conflicts that arise in patient care as matters primarily, if not exclusively, of decision making. The paradigm situation is that the doctor or health professionals want a procedure done, or do not want to provide a procedure, whereas the patient and/or patient's family take the opposite view. On this interpretation of the nature of ethical questions and problems in patient care, clinical ethics consultation is understood to involve the rendering of expert judgment on disputes much like a judge (or jury) renders an authoritative decision to decide a case for or against the parties involved in litigation.

It is remarkable that many commentators and critics from different perspectives and disciplines share this rather simplistic view of ethics consultation. For example, some philosophers have claimed that because true “expertise” is impossible in ethics generally, since ethics is not a science open to conclusions based on evidence, then clinical ethics, in principle, cannot render anything approximating an “expert” judgment. Hence, any resolution of ethics problems or conflicts in patient care must involve an imposition of an authoritative decision making by a person or committee who is vested with unjustified power. This is seen as particularly problematic given the prominence of patient autonomy in medical ethics. In light of this principle, why should patients or their surrogates, who are not expected to defer to physicians, should nonetheless defer to ethics consultants?<sup>6</sup> Others have taken up the line first articulated by Noble, namely, that the exercise of expert judgment is inconsistent with individual autonomy and liberty in democratic society. Hence, the fundamental arbiter in ethical matters must be the individuals involved themselves and

not some philosopher wearing a white coat, or a health professional masquerading as someone qualified in ethics to render definitive judgments. When patients and their surrogates are in conflict with their health care providers about important medical decisions, then courts of law are the most neutral location for settling these disputes. But is this view of clinical ethics accurate?

The notion that clinical ethics renders a definitive and authoritative ethical judgment not only elevates the clinical ethicist to a position of privilege, a view which, however, is not corroborated by the empirical research on ethics consultation, but also presupposes that the paradigm ethical issues in health care involve conflicts over medical decision making. In fact, a careful review of the literature on clinical ethics and ethics consultation will show that ethics consultants actually make modest rather than grandiose claims regarding ethical authority. It is widely accepted that the process of ethics consultation is primarily a process of facilitation, one that uses ethical analysis, argument, and communication to identify options, recommend courses of action in ways that utilize a range of techniques such as conflict resolution or mediation, but infrequently engages in proffering binding recommendations or decisions.<sup>7</sup> There is, therefore, a striking discordance between the critics of clinical ethics and ethics consultation and the circumscribed statements about ethics consultation and clinical ethics. The presupposed paradigm of conflicts between patients and their surrogates on the one hand, and healthcare professionals and/or healthcare organizations on the other, vastly oversimplifies the complexity of clinical ethics. This view overlooks the ethical questions, quandaries, concerns, and problems that arise when healthcare professionals, operating from different and sometimes divergent individual ethical and professional ethical perspectives, confront confusions about their responsibilities and how to best meet them in complex patient care situations. It also oversimplifies the conflict as one between patients and their families on the one hand, and health professionals on the other, when not only are there disagreements and confusions on the side of health professionals, but families and patients, too, can struggle with conflicting expectations and beliefs about what is appropriate in particular clinical situations. Thus, the ethical questions and difficulties that make up the field of clinical ethics involve much more than straightforward conflicts of decision making. More frequently, the complex emotional relationships among family members and the patient as well as the uncertainties and anxieties that arise when patients and family

members must deal with serious or critical health issues engender ethical questions and concerns as well as conflicts. Why these complex value questions are addressed within health care are addressed by ethics consultation rather than other existing mechanisms and services, such as pastoral care, social work, or ombudsman services, has not been sufficiently examined, but it is a fact that this has occurred.

Thus, while critics may bemoan this development, their criticism misses its mark if it assumes that ethics consultation is simply or primarily a matter of decision-making that has thrust itself into health care with the audacity to presume ethical expertise in making decisions rather than having emerged in response to a rather diffuse set of unmet needs. Such critics need to confront the reality that so much of the empirical literature, including formal studies and reports of ethics consultation, note that ethics consultation is dominated by the task of dealing with communication confusions and occlusions. Addressing these concerns, more than resolving the standard ethical issues as defined in bioethics textbooks, makes up the bulk of ethics consultation. This is an important point that critics overlook. Aside from the fact that there is ignorance or misunderstanding of ethics consultation by some of its critics, we need to ask the question, "What promotes this misunderstanding of the field?"

One reasonable hypothesis is that critics of clinical ethics or ethics consultation conceive ethics consultation primarily in terms of an idealized paradigm of ethical decision making. This model is based more on theoretical concerns than on a sound understanding of ethics consultation as a practical field, which involve a wide range of communicative, deliberative, and interpretive interactions designed primarily to facilitate the resolution of an equally wide range of ethical problems within patient care. On this hypothesis, clarification in ethical and practical problem solving is more characteristic of ethics consultation than is a process of using formal methods for reaching normatively strong decisions.<sup>8</sup> Under the decision making paradigm, clinical ethics is criticized for not being able to provide sound ethical justification for its recommendations, or for usurping role of decision making from patients or health professionals. Some of the criticism would be understandable if the practice of patient care lacked broadly accepted normative standards to guide decision making. If there were no such standards, then one could only rely on patient or physician authority for

making decisions. But if such standards exist and health care is structured by their ethical norms—and I assume without arguing the point here—then ethics consultants or committees who provide services to elucidate and apply these standards would not imply their usurping the authority of patients or health professionals that critics allege.

To be sure, some standards deriving from law and professional guidelines, and expressed often in health care organization ethics policies, are clear, but others are open to interpretation and dispute not only theoretically, but also as they are applied in complex or difficult circumstances. Involving persons skilled at negotiating the communication conflicts and occlusions, as well as in interpreting and applying ethical standards in complex situations, is legitimate so long as these individuals operate within appropriate boundaries. Given that there is broad consensus about the general ethical principles of ethical health care, ethics consultation is wrongly characterized as a process in which ethics consultants make and impose decisions on patients, families, or health professionals. Instead, the process of ethics consultation is better understood as an activity primarily concerned with clarifying confusions and developing consensus about how to proceed in light of practical problems that obstruct the achievement of the accepted norms. If critics argued that the boundaries for ethics consultants are not well defined or publicly available, then there would be no dispute. Unfortunately, critics confuse their concerns about potential abuse, which are legitimate, with actual abuse for which there is no evidence.

Of course, this point does not address the skepticism about the existence of accepted that may underlie some of the criticism of ethics consultation. Such skepticism, however, seems to be more a theoretical concern about the adequacy of the justification of norms than a practical concern about the existence of norms as socially accepted. It seems undeniable that fundamental patient rights such as informed consent, refusal of life-sustaining treatment, confidentiality, privacy, and the acceptance of patient decision-making and the reliance on surrogates or advance directives when patients cannot make decisions for themselves are widely accepted. Within this framework, nonetheless, many ethical questions and concerns arise, which contribute to confusion about what course of action is ethically justified. Furthermore, policies for applying what are often broad principles have a degree of vagueness that requires interpretation and reflection. Thus, it is not surprising that health

professionals as well as patients and families have found ethics consultation services useful, and have increasingly relied upon them to help clarify their understanding of the ethical dimensions of their decision making and provide moral reassurance and support. In this regard, ethics consultation has successfully created a space within which ethics can be safely addressed within the institution.<sup>9</sup>

Despite the prominence of worries about the abuse of authority or power of the clinical ethicists, the concerns are often overstated. The fact is that many statements of ethics consultation offer a weak view of the authority of the ethics consultant; for example, the Core Competencies for Healthcare Ethics Consultation of the American Society for Bioethics and Humanities views ethics consultation as a process of facilitation.<sup>10</sup>

Many of the criticisms surrounding clinical ethics are premised on a deep confusion about clinical ethics that underlies these concerns, a confusion based on a misunderstanding of the clinical or practical nature of the ethics consultation. In a paper entitled, "The Question of Method in Clinical Ethics,"<sup>11</sup> I undertook the task of staking out the conceptual terrain of what the question of methodology involves, namely, the various elements and features that conceptually make up method. I concentrated on the notion of a rule defined in a rather Wittgensteinian fashion. Rules clearly have normative force. The rules involved in ethics consultation, however, also have the important and peculiar feature that they function, as Wittgenstein points out in his concept of a language game, in defining a practice. The rules of a practice exist in their use rather than as stated in a grammar, and they have to be understood in terms of their use. This means that the rules are embedded in or are part of the very actions making up the practice.

In contrast to the normative function of rules in a practice, the normative function of ethical principles and theories, which gets the most attention in the bioethics literature, typically ABSTRACTs from the concrete details of the case, much less the actual communication, psychosocial, and institutional processes and circumstances that make up actual clinical ethics cases. Hence, the usual treatment of the rules is done ABSTRACTly without engaging the concrete, ongoing circumstances or the actual reality of the case.<sup>12</sup> For example, the normative principle of respecting

patient rights, or the legal surrogate's right of decision making, is frequently next to useless in actual cases, because the question is not what principle the physician should follow, but how, namely, what actions should the physician engage in to comply with the principle in this case. The case and fact circumstances require the ethics consultant to engage in a process of inquiry and communication that itself involves rules, which when followed (or not) characterize a good practice of consultation. These process rules, which I call rules of enactment, are far more important for clinical ethics as a practical discipline than the usually understood normative ethical principles. Saying this is not to deny the relevance of ethical theory, concepts, and principles, but to make the claim that these usually require interpretation and application in ethics consultation cases. To the extent that there is settled agreement about the high-level ethical principles, what is required is less knowledge of these matters, than the ability to reason about them and to apply them in the clinical circumstances.

Beyond these considerations, however, there are other rules for ethics consultation that are important. This can be illustrated by reflecting on the process of learning to work with wood. The master woodworker can point out that the book or manual says to use one tool rather than another in cutting and shaping the wood, but to the apprentice or learner, knowing which tool to use does not yet specify how to use the tool. Further specification in a manual about how firmly the tool is held cannot, of course, provide a direct guide to the amount of pressure or tension in the novice's hands and shoulders as one works the wood. That "rule" is learned as one acquires the skill and it is experience-based. The rule, as it were, is one with the experience, and its achievement makes up the skill or the competence that differentiates the accomplished craftsman from the novice.

Clearly, in a communicative field laced with significant intellectual and cognitive content, the rules involved in ethics consultation as practical enactments will be complex. The care of patients, particularly in hospitalized settings where most ethics consultation occurs, is a highly complex system of social structures involving cooperating hierarchies of specialized practitioners. When ethical problems arise in the course of patient care, the ethics consultant must engage the complex social setting within which the ethical questions or issues arise. Dealing with these ethical questions or issues is not a matter of theory, but a complex communicative interaction

with all of the individuals involved in the issue. The skills that need clarification and the rules that need analysis with respect to ethics consultation turn out to be fundamentally different from what critics of ethics consultation usually have in mind.

The critics assume that ethics consultation involves authoritative decision making, but they operate within an inflexible notion of authority that associates it more with power than guidance.<sup>13</sup> Thus, to understand why a cutting tool that was improperly sharpened, a teacher could tell the novice that it is so pointing to normative standards, but that would be less than helpful. Instead, a good teacher would demonstrate the right "feel" that is achieved with a finely honed tool by comparing the cutting of both tools on various types of wood. In that way, the novice would learn the lesson of the necessity and practical utility of having a properly sharpened tool.

What implications does this line of argument have for the controversies over clinical ethics and ethics consultation? If clinical ethics is a dynamic practical pursuit, then the question of method in clinical ethics is less about decision making using normative concepts or principles authoritatively imposed on patient care, but rather a more complex set of activities. Thus, understanding the nature of ethics consultation is a prerequisite for addressing the controversies surrounding this field of activity and for assessing the adequacy of the various criticisms that have been leveled against clinical ethics.

#### **Note**

1. Potter, Van Rensellar, *Bioethics: Bridge to the Future*. New York: Prentice-Hall, 1971.
2. Sass Hans-Martin. "Fritz Jahr's 1927 concept of bioethics." *Kennedy Inst Ethics J* 2007; 17(4):279-295.
3. Toulmin, Stephen E. "How Medicine Saved The Life of Ethics." *Perspectives in Biology and Medicine* 25, no. 4 (1982): 736–749.
4. Kuczewski, Mark G., "Ethics Committees and Case Consultation: Theory and Practice." G. Khushf, ed. *Handbook of Bioethics*. Dordrecht: Kluwer Academic Publishers, Inc., 2004, pp. 315-334.

5. Rothman, David J., *Strangers at the bedside: a history of how law and bioethics transformed medical decision making*, New York, Basic Books, 1991
6. I have argued that this is the wrong way to frame the question, because it begs the question by presupposing that the involvement of the ethics consultant potentially overrides patient autonomy. See, Agich, George J. "Why Should Anyone Listen to Ethics Consultants?" In H. Tristram Engelhardt, Jr., ed. *The Philosophy of Medicine*. Dordrecht, Holland and Boston: Kluwer Academic Publishers, 2000, pp. 117-137.
7. American Society for Bioethics and Humanities. *Core competencies for healthcare ethics consultation*. Report of the American Society for Bioethics and Humanities 1998;1-48.
8. A paper by Stella Reiter-Theil ["Dealing with the Normative Dimension in Clinical Ethics Consultation." *Cambridge Quarterly of Healthcare Ethics* 2009, in press] is helpful in understanding this point. She argues that the normative element in ethics consultation has been misunderstood. She offers view of normativity as a pervasive dimension of ethics consultation and shows how the normative element in ethics consultation is actually quite complex. Rather than entering "all at once," she shows that the normative element functions in a graded fashion according to a hierarchical typology and argues that escalation up the scale of normative of the towards the authoritative imposition of outcome is actually quite rare.
9. Walker, Margaret Urban, "Keeping Moral Space Open: New Images of Ethics Consulting." *Hastings Center Report* 1993;23(2):33-40.
10. American Society for Bioethics and Humanities. *Core competencies for healthcare ethics consultation*. The Report of the American Society for Bioethics and Humanities 1998;1-48. Paradoxically, this characterization has itself come under criticism by those who insist that a stronger decision-making or advice-giving model of ethics consultation better captures the exercise of ethical expertise that the well-trained—read in here your favorite discipline—consultant brings. Ironically, such claims seem intended to elevate one discipline over another in what is essentially a multidisciplinary field. In my judgment, they do not offer much evidence about what ethics consultation actually involves and, correlatively, what skills and knowledge well-trained ethics consultant should possess. Instead, they seem to support what critics see both as unjustified claims to professional power and status, which creates the potential for abuse. This

paradoxical situation is a bit beyond the scope for my exploration in this paper, even if it is not beyond explanation. I leave it to sociologists and social psychologists to attempt to explain what drives the continued promotion of professional status by some individuals and disciplines. The relevant point for this paper is that the controversy does raise an important question about the underlying assumptions about the nature of clinical ethics and the activities that legitimately comprise ethics consultation.

11. Agich George J. The question of method in ethics consultation. *American Journal of Bioethics* 2001;1(4):31-41.
12. Some thinkers have advocated casuistry as a remedy to this approach that is often associated with a theoretical or principle oriented approach. Surprising to some, casuistry, at least in its most common forms, does not usually address the ongoing or concrete circumstances of a case. It takes the case as presented or given considers the case over and against other paradigm cases and renders a judgment regarding the ethical probity or appropriateness of a course of action based on the consideration of this case, against others. The case, as I have argued elsewhere, is treated primarily as a given and the casuist is typically not an agent involved practically in the case as such, but rather functions as an adviser or coach outside the field of action or play. To use developed the sports metaphor, one could say that the function that I am trying to describe would be satisfied by one who not only in gauges in the game on the field, but does so as a coach, and, at the same time, is a commentator and analyst addressing the play-by-play and action as it proceeds. This analogy helps us to realize the difficult and complex nature of the phenomena that I am describing.
13. Agich George J. "Authority in ethics consultation." *J Law Med Ethics* 1995;23(3):273-283; Casarett DJ, Daskal F, Lantos J. The authority of the clinical ethicist. *Hastings Cent Rep* 1998;28(6):6-11.

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# **Interactive Health Care Principles in the Clinical Setting : Competence, Compassion, Communication, Cooperation, Cultivation**

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## **ABSTRACT**

Health is not just a status, rather a balanced result of health-literate and risk-competent care of one's own physical, emotional, and social well-being and well-feeling with the support of health care professional. To care for my health primarily is my own responsibility and benefit. Principles in health care ethics are the five C's - COMPETENCE, COMPASSION, COMMUNICATION, COOPERATION, CULTIVATION - for all partners involved. Principles of respect for autonomy and justice are civil rights; the no-harm and do-good principles always had been essential in expert ethics, in medicine and elsewhere; these are common sense principles already integrated in the four C's. The interactive model of the five C's will be exemplified by presenting interactive principles and virtues, eight each for the expert and for the lay person, based on traditional interactive rules by 15<sup>th</sup> century Confucian doctor Gong Tingxian.

## **BALANCING HEALTH IN CULTIVATING HEALTH CARE**

**Caring for health is a balancing act.** As far as we all want to live a happy life, it is primarily our own responsibility to care for health by means of lifestyle modification, sometimes making hard choices between fun in life and length of life. As far as individual health is concerned, health is the essential basis for a good, happy and long life. WHO wrongly defines health as 'a state of complete physical, mental and social

wellbeing and not merely the absence of disease and infirmity' [cf 10:280]. Such a definition is too small, too static, quite misleading as a maxim for medical intervention, health care policy and health care ethics. Health is not a status, health is a challenge, a gift to take care of; health is balance, health care is a balancing act. We better define **'Health is not just a status, rather a balanced result of health-literate and risk-competent care of one's own physical, emotional, and social well-being and well-feeling, achieved in competent understanding, modification and enhancement of individual genetic, social and environmental properties, with the support of health care professionals and through equal access to health care services, including information, prediction and prevention'**. The prime responsibility in caring for health lies with the individual person and her or his competence to understand the foundations of health and to care for health, - only indirectly with others as competent and compassionate experts in diagnosis, treatment and advise and therefore all health care service models need to be modified in order to set priorities and support in the care for health right and correct; the health care system should not be a repair shop, rather a well defined expert complex to serve health, individual health and public health; both are human and civil rights of highest priority. Such a modern understanding of health actually comes close to the traditional Asian understanding of health and health care; I quote Tai and Lin: 'Confucius said that our body is a gift from our parents; therefore we must take good care of it rather than abuse it. Whoever fails in this duty is unrighteous because he does not comply with the mandate of heaven' [cf. 5:280]. Mencius in the 'Doctrine of the Mean' defines: 'a person with great virtue will surely have longevity' [cf. 10:362]. Thus, health competence is essential for a good life, for quality of life, for happy and healthy social interaction. I also can quote Fritz Jahr, a German protestant pastor who recognized three levels of protecting and promoting life in his interpretation of the biblical 5<sup>th</sup> commandment 'Thou shall not kill': [a] the Golden Rule of not hurting, i.e. of helping and supporting, [b] the obligation to self-preservation 'by not taking one's life, by not shortening it, hurting or endangering in weakening it with unchastity, extremes in eating and drinking, rage, foolhardiness etc.', and [c] the 'bio-ethics imperative 'Respect each living being as an end in itself and treat it if possible as such' [7:appendix]. The arguments of Confucius, Mencius, Jahr and others make sense to many cultural traditions and moral attitudes in the modern world of caring for health. Basic health care competence by the lay person and professional competence in

compassionate communication, cooperation, and care by the experts are the two basic elements of successfully caring for, protecting, and restoring health. Thus health care ethics is partnership ethics.

## **HEALTH CARE ETHICS IS PARTNERSHIP ETHICS**

**Partnership ethics are interactive.** Mencius once said: 'Between father and son, there should be affection, between ruler and minister, there should be righteousness, between husband and wife, there should be attention to their separate functions, between young and old, there should be a proper order, and between friends, there should be faithfulness' [cf 10:201]. I add to Mencius: '**Between experts, lay persons, and corporate persons there should be competence and compassion, fairness and trust, communication and cooperation**'. A view at a 500 years old interactive list of virtues of physicians and lay people demonstrates such a superiority over more simple modern sets of principles very clearly. Confucian doctor Gong Tingxian in the 15<sup>th</sup> century was the first who presented an interactive list of health care ethics for both, doctor and patient, the expert and the lay: 'First Rule for Physicians: In the first place they should adopt a disposition of humaneness: this is a justified demand. They should make a very special effort to assist the people and to perform far reaching good deeds. – First Rule for Patients: In the first place they are to choose 'enlightened physicians [ming-i]' and thereby receive help in their ailment. They have to be careful, because life and death follow each other closely'. [cf 10:234]. Doctor Gong Tingxian made it mandatory that medical students study humanities first, i.e. what we would call 'philosophicum', and only thereafter physical and medical sciences, i.e. the 'physicum'. For the patient, he requires strict adherence to the regimen advised by the expert including changes in lifestyle. It is also interesting, that Gong Tingxian does not mention the traditionally strong cultural influence of the family; rather, he holds the quite modern view, that the lay individual is directly responsible for good and successful communication and cooperation with the expert. In the modern world, we have to include corporate persons such as hospitals, nursing homes, health insurers, politicians, and regulators into the partnership model; if the institutional framework for providing and financing health care is not competent and compassionate as well; physicians and patients will not be able to successfully

interact in the care for health. Codes of conduct and virtues and principles have to be obeyed by lay persons, experts, and corporate persons in partnership of communication and cooperation.

**Compassion and competence belong together.** Without compassion, competence is blind and dangerous; without competence, compassion is helpless and fruitless. For specialized tasks and complex issues throughout history we always were depending on professional and expert services. This is even more true in the modern worlds everywhere. Thus, trust-based communication and cooperation with the expert is important for the lay person. What would be the type of medical expert, I should trust? The answer comes from famous Confucian doctor Yang Chuan, who 1700 years ago advised **'to trust and rely only on such physicians who have the heart of humanness and compassion, are clever and wise, sincere and honest'** [cf 10: 200]. This is a much more detailed and wider list of virtues and principles requested from the expert than modern models of clinical ethics based on the four principles –autonomy, nonmaleficence, beneficence, justice – would suggest. But as we know so much more about risks to health and causes for diseases in modern health care, we also can have and must have more health competence in citizens as lay persons. According to Aristotle, a competent master in his craft knows how to do things and does things right, knows why it is done the way it is done, and knows how to talk about it and teach and train disciples. There are and will be different and highly specialized professional competencies in health care such as family medicine, oncology, neurology, nursing, hospice care, but we also can have and must have basic lay health competency in health care matters, competency by mothers and couples, children, seniors, the sick and the healthy. Without a certain level of health literacy and health care competency, there cannot be a successful communication and cooperation between the expert and the lay, no so-called 'autonomy' of patients in decision making or consenting.

**Deficiencies of the 'autonomy, nonmaleficence, beneficence, justice' model.** It is remarkable that neither 'competence' nor 'compassion' are mentioned in modern lists of virtues and principles for health care professionals based on the Belmont Report and the four principles of 'autonomy, nonmaleficence, beneficence, justice' which since have had a global influence on shaping medical and clinical ethics

and clinical ethics teaching and consulting [1]. Those four principles were originally developed in 1978 as a basic and common moral principles which could be agreed upon in a pluralistic society with diverse religious and cultural views to guide human experimentation and only later introduced into the treatment setting of family and clinical medicine. The bottom line of the Belmont Report requires 'informed consent' from probands and patients; but such a maxim was already introduced 1900 in Prussian regulations and again 1934 in German regulations together with the principle that the highest officer in the research or treatment institution be personally responsible for research and treatment [10:355]. Given the strong reference to competence and compassion in physician's ethics in all cultures, it is significant, that the requirements for professional competence and personal and professional compassion unfortunately are missing in the Belmont Report and subsequently in all other modern sets of medical ethics principles.

Also, the Belmont Report and its subsequent modifications only contain a list of professional ethics principles with no reference to interactive principles with health care partners and to virtues and principles on the side of the probands and patients. The principle 'informed consent' as a subsequent soft-paternalistic requirement for allowing medical research to start and to continue actually is a principle essential for all interactions among free people in free societies everywhere and not only in medical research and clinical care. Similarly, the principle 'justice' as the right to equal treatment and equal opportunity is a basic element of human and civil rights and should be self-understanding in the hospital setting. Whenever societies, cultures, or political systems are not strong enough to 'respect persons' and to guide 'just and equal treatment', then those principles will fail in the subsystems of caring for health in a competent and compassionate manner. Thus, the lack of detailed reference to - actually not even mentioning - the principles of competence and compassion is an essential deficiency in modern medical ethics; so is the lack of understanding that principles of respect for individual self-determination and justice are primarily social and political principles in general and not just for the health care setting. Lack of medical and nursing competence is widespread everywhere; unfortunately non-compassion actually is taught in many teaching settings of Western medicine arguing that compassion should not interfere with 'scientific' diagnosis and therapy.

Whenever respect for persons and justice are trampled and missing in a society or culture, the health care field will have a hard time to implement those within unfriendly and inhospitable cultural, legal, and political environments. Respect for persons, nonmaleficence, beneficence, and justice, however, are important principles for situationally defining and fine-tuning the principles of competence and compassion, of communication and cooperation in the health care setting, not at least in the clinic. Principles of 'non harm' and 'doing good' have to be implemented in balance with each other, depending on the medical and ethical situation of each and every case. Consulting and treating medically rarely is without risk, potential harm or harmful side-effects; they cannot be treated separately as is suggested by separating the two principles and taught in modern biomedical ethics.

**Networking partners.** Ethics is an interactive enterprise among partners and rarely a one-sided activity towards objects; thus presenting and teaching physician's ethics only is not enough. Acting virtuously or viciously is acting based on moral and cultural principles, traditions, and attitudes of different parties involved, i.e. experts of various kind and different services, customers, consumers, patients, their families and friends and neighborhoods and institutions. Institutions belong as acting corporate persons directly into the **network of acting partners** morally or immorally, of being selfish, arrogant, non-caring, or supportive, person-oriented, compassionate, competent. Even though attitudes and principles are different in different cultures and times, the most common principle and virtue is the so-called golden rule 'do not do to others what you want not be done to you' or 'respect human dignity in all of your fellow humans as you want to be treated by others'.

Thus, ethics is reciprocal and all interactions among humans are based on interacting principles and virtues. For the expert-lay interaction I could formulate as an advice for experts in the field of health care as a counterpart to the advice given by Dr. Yang Chuan, **to be fair and compassionate with such patients who are compliant, clever and wise, sincere and honest in caring for health and being aware of limitations in medical services for health, life and the quality of life**'. Michael Tai has presented a list of Confucian principles for bioethics in general which can very well be integrated into clinical ethics: **'compassion, righteousness, respect, responsibility, ahimsa'** [11:122-127]. **I have suggested balancing principles and**

**virtues: for the patient self-determination versus compliance, for the expert professional responsibility versus respect for the patient's visions and wishes, balancing the good of the intervention with potential harm, - both partners interacting with competence and compassion and in communication-in-trust and cooperation-in-trust within a competent and compassionate institutional and organizational framework [10:204f].** Depending on cultural and professional traditions and expectations, also depending on situational challenges, the balance of responsibility between partners is different.

One of the central questions in international medical ethics is the balance of decision making between the expert and the lay person, the physician and the patient, or the physician, nurse, patient, family. It has been argued that Asian medical ethics is more paternalistic and US-American medical ethics is more oriented towards autonomy of the patient, while European models are in-between. Veatch correctly has observed that contemporary European models seem to be between traditional Asian models supporting the authority and responsibility of the doctor, while US-American medical ethics puts emphasis on the authority and competence of the patient to make decisions, - 'more paternalistic and authoritarian than the American, but less willing to hide reality from the patient than the Japanese' [12:38]. He calls it a 'dilemma that is becoming critical in international comparative medical ethics. Humans simultaneously affirm a belief in a universal foundation for morality – that there is a single moral standard for all people – and that there are obvious cultural differences on matters such as what to tell a dying patient'. These cultural differences will be more prevalent in some countries than in others, but they inform and form individual differences among expert providers and lay receivers of medical and nursing care. So, what roughly can be described as cultural different cultures, in each and any case is a different individual attitude, expectation, vision and wish in regard to health care treatment.

Fan [6] and Nie and Campbell [8] have correctly argued that modern medical ethics and clinical attitudes are quite different even within Asian institutions and among Asian providers and recipients of health care. Thus, to confront Asian and European and US clinical ethics is misleading. We find Buddhists and Moslems in German hospitals and nursing homes, but we also find Christians, Non-believers and

all sort of different world views in Asian hospitals as well, expressing not just a standard Christian or Taoist or Jewish attitude towards health, quality of life and end of life, but the very personal interpretation of a specific cultural or religious tradition or a mix thereof. Also, we find patients who do not 'want to be told' and leave decisions to the physician or the team in Europe and the Americas, and we find Asian patients who want to take part or even direct and control clinical decision making. Then, there are patients who were used to be independent and used to make decisions on their own for all of their life, but due to senility or pain or other factors are not willing or capable to be involved in clinical decision making whatsoever. So, the prime emphasis of US-American biomedical ethics on 'patient's autonomy' is a valuable philosophical and human-right concept, but not working well in the clinical setting in Europe, Asia, or North America. Better would be to use the 'respect for persons' as an overarching principle to remind the network of partners in caring for health and patients of the principles of 'compassion' and 'communication'. We rarely find a clinical situation where the full authority of the 'autonomy' of the patient as the prime principle can be implemented given the influence of pain, drugs, dependency, extraordinary environment on the hospital patient or nursing home occupant.

There is the twofold challenge of intercultural medical ethics: to recognize the differences between cultures and the differences of interpretation within any given culture. Thus, **all ethics, including medical and clinical ethics, has to be 'intercultural' given [a] differences between cultures, [b] personal interpretation within one culture, [c] balancing decision making among and between partners. COMPETENCE, COMPASSION, COMMUNICATION, COOPERATION, CULTIVATION**

Competence, compassion, communication, cooperation are not separate principles, but they are intertwined and they and their implementation have in any given case be put to work to form the framework for best possible individualized treatment and review in clinical care.

**Competence** has been a requirement in most classical schools of physicians and well protected against quackery, charlatans and professionally inferior people; competence is the backbone of professional modern health care; it is required to

practice medicine and to be kept up-to-date in continuing education. Basic forms of health care competence for lay people as well have been part of most cultures. Modern medicine and lifestyle research knows much more about the influence of genetic heritage, workplace and private social environments, eating and physical exercise habits than previous generations; this richness of knowledge has not yet been made available broadly enough to citizens in general or specialized education to promote health literacy, health care competence and health responsibility. Only lay health care competence and literacy will allow citizens to be self-determined and 'autonomous' decision makers as good partners to their doctors. Competence is also required by institutions of health care as corporate persons, presenting to the public and to their employees and customers a professional attitude of reliability, responsibility, and trustworthiness, which integrates organizational, financial and leadership competence with competence that there needs to be free space for competent and compassionate communication and cooperation between experts and their patients, also the competence to recognize that institutions of caring for health have to be solid in organization and financing but the patient and the mission has to come first.

**Compassion** has been an integral part of health care professional's ethos, reputation, recognition, and authority; today it is not widely taught in biomedical and clinical teaching, not even in specialized training courses in clinical ethics consultation. Compassion goes beyond the scientific capabilities of modern medicine and the technical training of doctors, nurses, and other health care professionals; it is the golden rule for respecting life and caring for life in a human, i.e. compassionate way. The compassion principle must inform regulations and guidelines for each and every treatment situation; it is an indispensable tool for educating clinical ethics committee members and for guiding their consulting and decision. Compassion as a virtue of corporate persons in the health care field includes the understanding that strict treatment schemes and financial success need to be measured along the overreaching goal of serving in the care for health. Fritz Jahr, the father of bioethics, once defined compassion as 'universal moral law' (universales Sittengesetz [7]).

Communication is the most important principle for both, patient and health care expert, also among health care experts and with corporate health care persons. Only

communication can evaluate the health status and health care needs of a patient, integrating the value-and-wish status with the medical status into a complete health care and health care need status and associated diagnosis, prognosis and therapy. Communication among different groups of health care experts and individuals needs to be learned and trained in the development of a common language and the development of trust into arguments independently whether they come from a nurse or chief doctor. Communicating with patients and their families is even more complicated; the health care expert has an obligation to initiate and to lead the communication, to choose in individual cases the most appropriate method of communication from narratives to the inclusion of family or friends. Communication is time consuming, therefore costly, but indispensable for good professional and compassionate health care. Training courses in particular for those who are members of clinical ethics committees are essential, but institution leaders and leading physicians and nurses also need to have excellent communication training and competence.

Cooperation is a two-way street, and there are often crossroads where three or more partners meet and exchange expertise and responsibility. Cooperation among health care providers quite often is deficient; patients sometimes do not comply. Cooperation in the clinic is important, but even more so in the every-day life setting when lay persons have to stay in close contact with experts in prevention and prediction, to protect and to improve their health. Modern medicine allows lay persons to become health literate and health responsible; our modern understanding of human dignity and civil right, i.e. the 'respect for person' requires more than informed consent; it requires 'informed contracts' between experts as advisers and lay persons as advise seekers. Much needs to be done to develop a truly cooperative framework in the care for health. Not at least are government and educational institutions responsible for developing such a comprehensive system of health care cooperation far beyond the clinical setting.

Cultivation is a principle of highest goals and aspiration in many cultures, in particular in Asian cultures primarily for the self-development and the higher autonomy of the individual, but secondly as well for building cultivated communities of persons of culture, compassion and competence in life matters and health matters. Tai [11] and

others in the attempt to present a truly Asian perspective in bioethics have made cultivation a prime principle. Cultivation primarily is self-cultivation with indirect influence on the cultivation of neighbors and others as a role model and in encouraging reciprocal ethics, thus creating harmonious and cultivated communities and societies. For experts and lay persons in health care facilities and for those facilities themselves, cultivation as self-cultivation needs to be an overreaching goal in pursuing and implementing competence with compassion, compassionate and competent communication and cooperation. When leaders and their associates of clinics and other health care institutions just look at the basics of medical science, financial survival, and organizational flows, then the goal of cultivation together with better and sustained competence, compassion, communication and cooperation will not succeed. Thus, cultivation, even though a goal primarily for cultivating individual persons, nevertheless becomes a goal in corporate development and life, - an impulse for continuously improving and cultivating institutional structures and developments; clinical ethics committees can and need to play an essential role in the overall cultivation of their facility. Cultivation as a personal, professional and corporate goal cannot be achieved without competence in professional and personal life, not without compassion, and definitely not without communication and cooperation among compassionate and competent partners. Thus, cultivation is the final goal in all civilized forms of working together, personally, professionally, institutionally, socially, - it is the way of cultivation, rarely ever a final end and complete achievement.

### **INTERACTIVE VIRTUES FOR HEALTH CARE EXPERTS, LAY PEOPLE, AND CORPORATE HEALTH CARE PERSONS**

There are at least three reasons that health care ethics in the future should follow Gong Tingxian's interactive model of partnership: progress (a) in predictive and preventive medicine, (b) in intensive care and in methods of prolonging life as well as suffering, and (c) the emotional, ethical, and economic limits in providing all and every possible medical intervention, they all make the development and the support of an ethos of individualized health care a prime challenge in global bioethics. Patient ethics and lay risk competence in health care matters and the development of virtues and principles for taking care of one's own health should be given priority over secondary

issues in physician's ethics. **Physician's ethics** will have to change from paternalism to partnership. Also, most interactive models of applied ethics have to include Institutional ethics as particularly in the clinical setting experts of various kind and patients and their families and communities have to work in an institutional setting with its own principles in corporate structure, goal, and ethics. A recent Code of Conduct for German Physicians names five core obligations: 'respect the right of patient's self-determination, save life, protect health and restitute it, alleviate suffering, accompany the dying' [cf.4:19]; only the second one, 'safe life', seems to be in the forefront of clinical daily routine with not enough emphasis on the other four obligations. Situational expertise and ethics based on compassion, communication and cooperation with the patient will tell the expert the most adequate mix of the five obligations following a rule given by famous doctor Galen, private physician of Roman Emperor Marc Aurel ,**Non homo universalis curatur, set unus, quique, nostrum, - we do not treat a universal person, but a unique one, a special one, one of us**'. In the institutional setting of universal norms for WHO and professional organization recommended quality norm insurance company set universal norms for reimbursement, such individualized treatment of each and every patient in the clinical setting is the greatest challenge to the experts, the consulting bodies and the institution.

The global richness in individual, familial, and communal cultures calls for differentiated health care services according to the values and wishes of the individual client or patient, not those of the 'doctor' nor those of the 'system' which provides health care. Following is a set of interactive maxims, virtues and principles in expert-lay partnership care for health: Eight for the lay person and eight for the health care expert, built on the interactive format of Dr. Gong Tingxian. Lay risk competence in health care matters and the development of virtues and principles for taking care of one's own health should be given priority over secondary issues in physician's ethics. Physician's ethics will have to change from paternalism to partnership. The global richness in individual, familial, and communal cultures calls for differentiated health care services according to values and wishes of the individual client or patient, not those of the 'doctor' nor those of the 'system' which provides health care. Future bioethics research and teaching has to shift emphasis from physician's ethics to lay ethics and patient's ethics and the ethics of cooperation-in-trust. [10: 12-13;212-213]

**1. Building Cooperation and Trust:** The First Rules stress the lay person's obligation to actively search for and to find the right expert and the expert's obligation to serve her or his patient as a fellow human and not just as a technician of medicine.

*1. Find truly educated and trustworthy health experts .- 1. Treat your patient as a person, not just his or her symptoms. - No educated person will leave important issues such as health care solely to the discretion of an expert. From the true health care professional we rightly request not just best technical service but personal attention, compassion, patience, helpfulness and even sacrifice. At times difficult balances between patient autonomy and expert responsibility, between beneficence (bonum facere, do good) and non-maleficence (primum nil nocere, do no harm) need to be established; this will not be possible without trust as the underlying virtue and principle of all parties involved. In the clinical setting, the first rule for the institution would be 'Provide and improve efficient health care settings for providers and customers'.*

**2. Develop Health Risk Competence:** The Second Rules call on the educated lay person to educate herself or himself in matters of health and to develop individual competence in the care of health, while the health care expert is called to teach and to educate the lay person and to assist her or him in accepting health care responsibility.

*2. Develop competence and responsibility in health risk management. - 2. Assist you patient in developing health risk competence. - Health care primarily has to be understood as a human and civil obligation, rather than a right which can be claimed from others. Professionals should be partners rather than elitists and not withhold information necessary to the educated citizen for her or his self-determination in health care matters. In the clinical setting we require the institution: '2. Protect and support competent and compassionate professional health care'.*

**3. Total Health Care:** The Third Rules emphasize the particular importance of mutual responsibility and interaction of the lay and the expert in predictive and preventive health care. The simple principle of informed consent to medical treatment does not meet the challenges of preventive and acute health care. *3. Make extended use of predictive and preventive medicine. - 3. Integrate the 'clinical status' and the 'value status' of your patient into differential ethics, diagnosis and prognosis. Patient oriented treatment will also depend on cultural traditions and the critique of modern cultures treating medicine as a repair system and tool, rather than the science and art of*

balancing health risk and challenges. In the clinical setting we have to ask: '3. *Set institutional frameworks for the whole range of health care services*'.

**4. Risks and Results of Intervention:** The Fourth Rules remind both groups that acute medicine has its limits and risks and calls for trust-based cooperation and risk partnership. *4. Expect healing or relief from acute medicine, but be aware of the limits and risks of any medical intervention. - 4. Be aware of the benefits, limits and risks of acute intervention and discuss those with your patient.* Expert-lay partnership ethics has to communicate risks and benefits in an adequate way and also look into alternatives to purely medical and clinical interventions. Trust-based communication and cooperation will go beyond 'informed consent' and best be transformed into a model of 'informed contract' determining rights and responsibilities for both sides. The clinic as a corporate person has to allow for and to protect free space for complex individualized decision making among and between providers and customers; so we just need to require: '3. *Support and protect providers and customers of health care service.*'

**5. Expert-Lay Partnership:** The Fifth Rules underline that it is the lay person first who carries prime responsibility in preventive care for health, while the expert's role is reduced to understanding and compassionate information, advice and support. *5. Expect information and advice from medical experts and be a fair partner with them. - 5. Be an expert partner with your patient and respect her or his wishes and values. -* The obligation to care for one's own health is the precondition for rights one might claim that others should care for one's health. Expert advice as well as treatment has to be individualized; individual risk parameters, values, goals and wishes, and the difference between well-being and well-feeling mark the limits of 'objective' health care as defined by WHO and executed by modern repair type medical and clinical systems and disease description and payment schemes. The health care institution needs to establish itself as an active and creative facilitator of a variety of health care services.

**6. Great Health Care Learning:** The Sixth Rules stress, that qualities of life can only be defined individually, never objectively and not easily by others. *6. Define and implement your sense of qualities of life, from childhood to old age, in sickness and in health; seek information from experts, the media and internet .- 6. Continuously educate yourself and provide the best possible clinical and personal service.*

Health care professionals have to strive to continuously educate themselves in best possible technical service. Educated citizens have to recognize that qualities of life do transform and modify themselves – they do not reduce - over the years and that they have to redefine or adjust goals and preferences accordingly. Professional health care advice therefore must respect individual preferences and choices in the delivery of technically best but individualized service. Patient-oriented support and compassion is of particular importance in the care for the incompetent, the terminally ill and the dying. The clinic, thus, has the obligation to request highest possible professional standards in medicine, nursing, and management: *'6. Provide for support of continuing professional education'*.

**7. Health and Care Communication:** Therefore Rule Seven calls on the professional to help the patient to develop health literacy and to discuss health and care related issues within the family and with friends and to assist the lay person in understanding suffering, weakness, and dying, also to help her or him to recognize those values and wishes and to establish those directives in advance which should govern trusted surrogates and health care experts to make adequate decisions in circumstances of incompetence. *7. Discuss health and care issues and goals with family and friends; prepare advance directives and name proxy decision makers for circumstances of incompetence. - 7. Help your patient to become health literate and to discuss health and care with family and friend; assist your patient in preparing advance directives and in working with proxies for the benefit of your patient.* Advanced Directives are just one tool to protect patient's personal values and visions and the cultural environment of her or his particular family and value community. It is here, where personal and cultural differences have to be recognized in the clinical setting probably more than in primary health care and advice. Thus, health care communication is a prime principle for the clinic as well, for leadership internally and for outreach into the neighborhood as a good and trusted neighbor: *'7. Offer outreach programs and be a good corporate neighbor'*.

**8. Responsible Organization and Financing:** Rule Eight remind both, lay citizens and health care experts, that it is matter of justice and solidarity to be responsible in the allocation of health care funds. *8. Act responsibly in the use of*

*communal health care funds.* - Modern health care depends on a complex system of prevention and intervention, basic and supplementary care, distribution of labor, cooperation and specialization, also on effective and just administration and allocation of funds. Therefore it is mandatory that all players in the field of caring for health, for the suffering and the dying, are responsible for the protection and improvement of existing health care delivery and follow the same Rule: '8. *Act responsibly in the use of communal and other health care funds and resources*'.

## **CLINICAL ETHICS DECISION MAKING**

Tai and Tsai once described three models of clinical decision making in Asia 'physician making paternal decisions, physician given the power to make decision, physician consulting with family to make decision' [cf 10:235]. We find these three models not only in Asia; we find them as well in the praxis of clinical ethics in Europe and the Americas.

**1. The paternalistic decision making** model as a general rule does fit into the partnership model and also not into the civilized understanding of human dignity and civil rights and responsibilities. It may however be the model of last resort in cases of emergency when the patient cannot give an input into health care or treatment decisions. If patient's wishes and values or those of the family or community cannot be evaluated and if time permits, a special consultation body would be helpful to serve as a sounding board and/or partner-in-communication.

**2. Allowing the expert to make decisions** in a trust-based expert-lay relationship seems to be a special form of cultivated communication and cooperation to leave decisions to the expert. This is in particular true for all detailed technical issues. But also if there is a stark difference between health care competence of the patient and the family on one side and technical or even life-and-death decisions to be made by the expert. For centuries, this was the model preferred by in most cultures. It is a model which sets particular trust into the individual expert, not necessarily into the institution or the system; it needs to be seen and be taken care of that the trust given to the individual expert is honored by the system and the institution as well, eventually

opening new avenues of communication and cooperation via ethics consultation bodies or experts.

**3. Experts making decisions based on communication with family** or friends might be in the best interest of the patient is a model which suits the clinical setting much more than expert-lay interaction in primary care. Many patients might be too sick or too ill or too incompetent to make reasonable contributions to decision making based on their values and wishes; therefore others –primarily and traditionally the family – has to be a partner in making decisions in the ‘best interest’ of the patient. But there is a professional obligation of the expert to find out about potential unethical motives of family decision makers or about the family’s competence to evaluate the situation and the issues at stake in the patient’s ‘best interest’.

4. Therefore, we need to add as a golden standard a fourth decision making model: **competent and compassionate expert-lay partnership in communication and cooperation**, assisted or supported by family, friends, institutions, and society. Such a communication-and-cooperation model of partnership is particularly difficult to work in the clinical setting as patients and experts regularly have no long-term established history and experience of building trust and mutual understanding. The expert-patient partnership model is superior to the other model for two reasons: (1) patient oriented medicine treats the entire person, not just this or that disease or illness and different people have different visions and wishes in regard to medical treatment and its options, (2) in a more and more intercultural world even the hospital setting, it cannot be assumed that the patient shares similar visions and values to those of the medical system, the hospital, the doctor, the teams, and the family and neighborhood.

Complicated as it is for the integration into clinical decision making, this golden-standard model for most clinical cases can and should be supported by a number of supportive tools: advance directives, health care proxies, communication with family (who speaks for the family? with friends?), good professional training in medical ethics and nursing ethics to better evaluate patient’s visions and wishes even in compromising situations, finally by the support of consultation services.

Consultation groups or individuals serve a multiple purpose of supporting communication-and-cooperation between different individuals and groups of health care experts, with patients and their families and with the wider community. Of particular importance therefore is the research in and the development of development of communication-consultation-cooperation education.

## **TRAINING IN CLINICAL ETHICS CONSULTATION**

To demonstrate how expert-patient partnership needs to work, I briefly introduce a checklist, which I have developed and tested over the last 30 years at the Bochum Center of Medical Ethics in Germany [4;9;10:45-45;248-254]. It is a tool for clinical-ethics decision making and consultation services, which is time-efficient, poor in deep philosophical and moral argumentation and rich in narratives and other material which allows to put actual cases into the perspective of similar scenarios and professional and cultural values and standards.

Methodically we follow in ethics the checklist model which is well known and the golden standard in technical clinical status evaluation, prognosis and therapy review. We assume that the few issues we address – values and wishes of the patient, her or his intention or competence to be involved in specific clinical decisions, the good balance of professional obligations with patient's wishes – are existing in most cultures and traditions, including cultures and traditions in health care. For special cultures and situations, however, we use a small number of additional questions to be answered. The checklist has three parts: part 1 evaluates medical, information, facts, uncertainties and risks, part 2 evaluates ethical and cultural information, facts, uncertainties and risk associated with this particular patient, part 3 combines information and judgment from parts 1 and 2.

In part 3 we ask: 'What options are available in the face of potential conflicts between medical-scientific and medical-ethical aspects? Which options are the most appropriate given the value-and-wish profile of the patient? Who, if anyone should be consulted as an advisor? Is referral necessary for medical or ethical reasons? What are the moral (in contrast to scientific or legal) obligations of the physician/team to the

patient? What are the obligations to of the patient, the family, the society and state, health care institution and financing authorities? – What, if any, are the arguments against the treatment decision? Does the treatment decision need consensus? How does the physician in charge respond to these questions? Was the treatment decision adequately discussed with the patient and/or family? Does he / do they agree? Summarize in writing the decision and medical and ethical reasons!

In part 2 we ask: What is known about the patient's values, wishes, fears and expectations? What is the patient's understanding of intensive or palliative treatment as well as resuscitation criteria? Is the patient well informed about diagnosis, prognosis, and the various treatment options available for him/her? How is it possible to satisfy the patient's preferences in formulating the treatment plan? To what degree should the physician permit this patient to determine the treatment plan? Who else, if anyone, could or should make decisions on behalf of a patient and his/her best interests? Must the patient agree with the chosen therapy? Here are 2 cases which we use in clinical ethics training using the checklist approach. The first case is a case of paternalistic decision making without 'trust and good communication' with the patient and no concern for patient-oriented treatment. The other case is of cross-cultural relevance and addresses as well individual understandings of 'trust and good medicine'.

**Case in Hospital Care:** Mrs. M, 38 years-old, had her left breast removed 5 years ago because she had breast cancer. Now she has increasing pain in her lower back, and her physicians have determined that the cancer has metastasized to her bones. They recommend chemotherapy to reduce pain and to prevent or slow down the spread of cancer. Mrs. M. undergoes chemotherapy with uncomfortable side effects. Her pain increases and is not treated adequately. The physicians to not tell the 'full truth', that chemotherapy will not kill the cancer, but might prolong her life. Mrs. M. dies in the hospital 8 months later, not as she had wishes at home. Without chemotherapy she might have died a few months earlier. - And here are the questions which we pose in the training course, if they are not voiced by the participants themselves: What did the physicians know about Mrs. M.'s wishes and values when making treatment decisions? How would you have incorporated your medical-ethical diagnosis in treatment decisions? Does the doctor have to treat the disease or the

patient as a person? Is full and professional palliative care a basic right of each and every patient? Would you follow patients' Advance Directives or wishes based on their value-and-wish profile, even so when that differs from your own?- Describe and discuss some cases which demonstrate that careful information on the patient's medical status and history is essential for good treatment! Review the second section of the Bochum Checklist based on your experience! Do you have recommendations for improvement or modification to this list; do you have your own list already? [9]

**Case in Multicultural Care Setting:** Mr. T., a 28 years-old married Turkish patient of a German Doctor in Germany suffers from low sperm count. The couple wants to have children. The doctor prescribes a mild prescription drug based on pig pancreas and explains to the patient stronger medicines would be available if this one does not work. A week later the young Turk storms into the doctor's office, throwing the pills at the doctor and shouting 'You are a pig. Who does give a man pills from pig to make son. Doctor, you are a pig!' – And here are questions we pose, some of them relate to potential cultural conflicts, others to a patient's individual understanding of 'good medicine' others to the physician's understanding of 'good therapy': Is it always responsible to start with the least invasive therapy even when non-medical factors such as culture or religion or even unacceptable and crazy ideas would suggest otherwise? Would you have explained to the patient that eating pork and using medicine based on pig tissue by many Moslem scholars has been defined as to be different and that in Muslim ethics and medical ethics the protection of life supersedes other religious laws such as fasting? In which cases would you compromise on the principle of full truth-telling and full and informed consent; in which rare situations would you use one of the supplementary lists of the Bochum checklist? Would you follow patient's wishes and values, which you might not share, such as prescribing contraceptives or antinidatives? When would you do not follow patient's wishes? Would you in such a situation direct her/him to see another doctor or not? - Give a few cases which demonstrate that careful information on the patient's medical status and history is essential for good treatment! Review the second section of the Bochum Checklist based on your experience! Do you have recommendations for improvement or modification to this list; do you have your own list already?

The **short list of questions** in the checklist allows to concentrate on essential issues, but for special situations we have **additional sub-lists**, such as a sub-list to evaluate a patient's willingness or competence to take part in clinical decision making and to implement the principle of 'informed consent' into clinical reality: 1. Does the patient wants treatment based on paternalistic or autonomous decision making or on partnership? - 2. Does the patient want to include the spouse or family members or someone else in making decisions or consenting? - 3. What are the special challenges for physician's practice and ethics to include others in decision making? - 4. What can/should be done to guarantee that each and every patient is treated according to her/his system of belief, independently whether Christian or secular humanist, Jewish or Muslim, and according to her/his value-and-wish profile? We have other supplementary lists for special situations such as long-term treatment, cases of considerable social impact, therapeutic research with even more detailed –sub-sub-lists such as one for cytostatica research, intervention in psychiatry, dementia, paediatrics with sub-sub-list in neonatology, and for hospice care. When introducing these lists in workshops, we do so with cases and associated questions if those are not raised by the participants. Also, we ask participants to add one or two questions of their own and not treat our own small list as inflexible and modify it as necessary.

## **FINAL REMARK**

I have discussed only one side of the ethics of health partnership in communication and cooperation between the experts and the lay. And I have tried to exemplify my approach by limiting details of methods and principles to the clinical treatment, which is only one field – unfortunately the one which is primarily in focus of health care politics and health care financing. It is the obligation of the community of health care experts to help the lay people individually and as a community, and to help experts in health policy and insurance to modify the system **towards a more healthy model of health care partnership in competence, compassion, communication, and cooperation, finally in the cultivation of all persons involved, experts, lay persons and their families, institutions and their partners, by a cultivating society and cultivating global cultures of care, competence and compassion.**

Famous doctor Sun Si Miao put it this way: 'Superior doctors treat the state, better doctors treat a patient as a person, common doctors treat the illness' [cf 10:356]. Cultivation can be understood as the highest goal for the treatment of the overall culture of the state and society, which will guide and improve competence, compassion, communication and cooperation the clinical setting as well. Classical concepts of good health care in public and professional cultures of the East and the West will help to modernize medicine, which has deteriorated towards an intervention based system of disease management. In this regard, **there is no basic difference between Eastern and Western bioethics, medical ethics, and clinical ethics, just different characteristics and emphases based on cultural traditions, attitudes and expectations.**

Thus, clinical medicine and care and clinical medical ethics need to be seen in the wider context of individual and collective health care as a partnership enterprise requiring **competence, compassion, communication, cooperation** from all partners. These C-principles –competence, compassion, communication, cooperation, and cultivation – are formal principles which translate into personal and professional virtues independent of different worldviews and cultures, including cultures in health care ethics and clinical ethics. Competence, compassion, communication, and cooperation need to form the base in clinical ethics teaching and consulting, also in defining special situation strategies and in devising clinical ethics checklists. The four C's express a common morality, not commonly shared moral beliefs, but as such they qualify for a clinical culture which follows the old maxim 'aegroti salus suprema lex - **the good of the patient is the highest order**'. The 'salus' - the good, the sake, the interest, the goal, the vision and wish of those who are in our care - will need to be found out competently and compassionately, in communication and cooperation with the patient, within the team, with consultants and with family and friends. Such an approach to and practice of clinical service and clinical ethics will lead to professional and personal cultivation of all involved; clinical ethics committees have to play an essential role in this never-ending cultivation processes of individuals, families, institutions, societies and global humankind.

## **APPENDIX**

### **EIGHT HEALTH CARE RULES FOR THE LAY PERSON**

1. Find truly competent and compassionate health experts.
2. Develop competence and responsibility in your health risk management.
3. Make extended use of predictive and preventive medicine.
4. Expect healing or relief from acute medicine, but be aware of the limits and risks of any medical intervention.
5. Expect information and advice from medical experts and be a fair partner with them.
6. Define and implement your sense of qualities of life, from childhood to old age, in sickness and in health.
7. Prepare a health plan, also advance directives and name proxy decision makers for circumstances of incompetence.
8. Act responsibly in the use of communal health care funds.

### **EIGHT HEALTH CARE RULES FOR THE HEALTH PROFESSIONAL**

1. Treat your patient as a person competently and compassionately,, not just his or her symptoms.
2. Assist you patient in developing health risk competence.
3. Integrate the 'clinical status' and the 'value status' of your patient into differential ethics, diagnosis and prognosis.
4. Be aware of benefits, limits, and risks of acute intervention and discuss those with your patient.
5. Be an expert partner with your patient and respect her or his wishes and values.
6. Continuously educate yourself and provide the best possible clinical and personal service.
7. Assist your patient in preparing a health plan including advance directive; work with proxies for the benefit of your patient.
8. Act responsibly in the use of communal health care funds.

### **EIGHT HEALTH CARE RULES FOR THE CORPORATE HEALTH CARE PERSON**

1. Provide and improve efficient health care settings for providers and customers
2. Protect and support competent and compassionate professional health care.

3. Set institutional frameworks for the whole range of health care services.
4. Support providers and customers of health care service.
5. Establish yourself as a health care center for prevention, education and treatment
6. Provide for support of continuing professional education.
7. Offer outreach programs and be a good corporate neighbor.
8. Act responsibly in the use of all health care funds and resources.

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# **Current View on Ethics and Genetics: The Importance of Progressive Evolution of Medical Genetics and Genetic Counselling**

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## **ABSTRACT**

The unprecedented rate of discovery and application of medical genetics requires us to pause and ask if humanity as a species is well served or compromised by this development. Newborn screening tests practiced in developed countries, though beneficial, raise questions of ownership, identity, confidentiality and disclosure or results. Prenatal genetic testing, widely available, but not mandatory, creates pressure on physicians to offer and for patients to undergo them. A new, bizarre notion of 'responsible parenthood' means to give birth only to children who are without genetic abnormalities and to abort all others. Most disturbingly, medical genetics' goal of eliminating severe disorders has silently morphed into a collective evolutionary "imperative" driven by an ideology of creating the perfect human specimen, and by default appropriating exclusive rights to the production and control of human life. Yet, history provides us with numerous examples to remind us that a prerequisite "to being human, and to be worthy of life" is not synonymous with a state of biological perfection. In addition, human diversity may be the secret of humankind's success. Without diversity, there would be no effective selection. We must have a balanced ethical debate. This can happen only after scientists, physicians and all people become educated about the realities of genetics and willfully work at setting limits on these pursuits. Unfortunately, current normative bioethics does not provide a satisfactory solution for a unique, global approach. For the new 'genethics', we need to be mindful of bioethical, legal, psychological and social implications of genetic research and its applications. This must inform genetic counselling, which is critical for beneficial interventions, and it requires informed geneticists with imagination and intuition. The

power of human genetics over the future of humankind is unprecedented. Imperceptibly, the range of genetic interventions is increasing without full consideration to benefits, harms, future consequences or responsibility. It is imperative to embrace genetic responsibility for maintenance of diversity and richness of human life.

**Key words:** bioethics, eugenics, genetic information, genetic counselling, medical genetics, genethics

## **Introduction**

The science of genetics as it is applied in medicine is advancing under its own energetic momentum to such an extent that it is virtually outstripping all existing checks and bounds previously imposed by various scientific, and political controlling bodies. In light of this unprecedented rate of discovery and application, one must pause and ask if humanity as a species is well served or compromised by this development.

Let there be no doubt, that medical genetics has had and will continue to have its positive effects and outcomes, however, its overall positive attributes will continue to flourish if, and only if, there exists the attentiveness and the will among all concerned – scientists, politicians, lay people in general – to pursue a goal which is defined by its service to human life, and not its converse.

This paper will briefly review some of the advances of genetics with their medical interventions and consequences and its power over the future of humankind. It also looks at the phenomenal shift in medical goals, which shifted from an attempt to 'decrease the number of physical and psychological human disorders' to a quest for achieving 'biological human perfection'. In view of these extraordinary developments and challenges, we draw attention to the urgency of timely and accurate professional education, and the necessity of an all encompassing form of genetic counselling. Finally, this paper proposes the development and implementation of appropriate meaningful tools for the enhancement of genetic ethical inquiry, which is so essential for the evaluation, examination and application of the fruits of the new genetics.

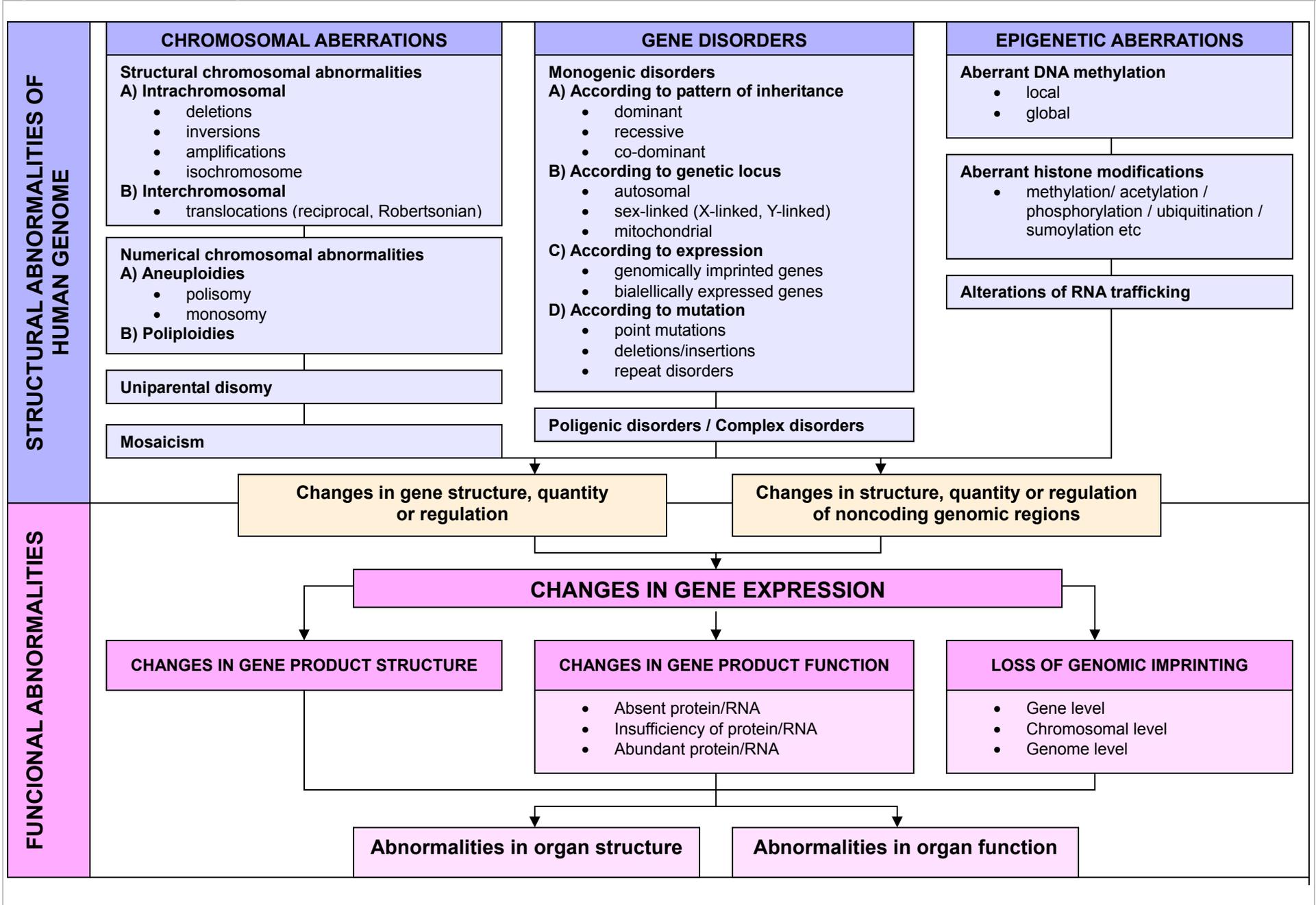
### **I. Recent technological and clinical advances in medical genetics**

For most of the 20th century, many medical practitioners viewed genetics as an esoteric academic specialty; that view is now dangerously outdated<sup>1</sup>. Unquestionably, the completion of the draft sequence of the human genome (2003) was a milestone in the history of biology and medicine<sup>2</sup>. The explosion of information continues as we write. Every day, researchers are discovering the functions of new genes, and over

6000 known single-gene disorders have been identified<sup>3</sup>. The outcome of this is translated into uncovering the connection between genes and hereditary diseases, which in turn is then utilized in advancing medical clinical practice.

Genetic disorders occur in 1:200 live-births but it is believed that all diseases are affected by genetic factors, either inherited or influenced by environmental factors<sup>4</sup>. For example, congenital anomalies are present in 3-5% of all newborn children, thus representing a significant part of prenatal and infant mortality and morbidity<sup>5</sup>. We now know that a significant number of congenital anomalies have a genetic etiology (15-25%) (Figure 1), while only a smaller fraction is caused by environmental factors, such as teratogens (8-12%)<sup>6</sup>. Many more congenital anomalies are the consequence of the interaction between genes and environment (20-25%). At this time, the etiology in the majority of cases still remains unknown (40-60%), but it is supposed that they are somehow genetically influenced.

Figure 1. Genetic causes of genetic disorders<sup>6</sup>



The new genetic knowledge has brought immense progress in the promotion of human health. **Newborn screening** programs may screen for up to 50 diseases, including phenylketonuria, cystic fibrosis and hypothyroidism. About 3,000 newborns tested in the United States of America are positive each year for one of these severe disorders<sup>7</sup>. Newborn screening currently represents the largest single application of genetic testing in medicine and the first and largest public population-wide health program for genetic conditions<sup>8</sup>.

Genetics has united us and made us equal as every live born infant shall have an adequate blood test for all disorders. Newborn screening programs, often initiated within 48 hours after birth, are mandatory in most developed countries. Although they have brought many positive changes in the promotion of human health, their further expansion will lead to grave ethical concerns. Today, newborn screening tests are developed for a more comprehensive genomic screening at birth<sup>9</sup>. In some parts of the United States of America, the government is now retaining indefinitely, each baby's test results and DNA for research without parents' approval<sup>10</sup>. This practice raises the question of ownership, identity, confidentiality and disclosure<sup>11</sup>.

Highly developed **prenatal genetic testing** is widely available and although it is not mandatory, that is, nobody is literally forced to have a genetic analysis, the pressure exists for physicians to offer and for patients to take them<sup>12</sup>. Today, although it is never really said out loud, responsible parenthood is defined by giving birth to children that are not marred by genetic abnormalities that soon after birth or in the future, may require medical interventions or treatments and will have in the opinion of some people, low quality of life!. The expectation is that parents will wish to prevent the birth of a child affected by a genetic disorder<sup>13-15</sup>. No one is literally forced to undergo an abortion, but the subtle pressure is ever present to terminate a pregnancy (genetic abortion) when a genetic problem has been identified. This principle of "procreative beneficence" assumes that parents or single reproducers are at least prima facie obligated to select the child, out of a range of possible children they might have, who will be likely to lead the best life<sup>16</sup>.

"What does it mean to be human?" the great philosophers asked! "Which humans have a right to be born, or, to continue their existence?" is the new question that modern genetic medicine is forcing us to ask. If not controlled, this unreflected attitude is likely to

evolve into a most pernicious form of a new eugenics. Perhaps, the best way to prevent genetic information from being used to restrict reproductive freedom, by this type of societal pressure, is to educate the public about the scope and limitations of our understanding of genetics and genetic tests<sup>17</sup>.

In addition, contemporary genetic technology also allows **genetic enhancement** which refers to the transfer of genetic material intended to modify non-pathological human traits<sup>18</sup>. The term genetic enhancement is commonly used to describe efforts to make someone not just well, but better than well, by optimizing attributes or capabilities - perhaps by raising an individual from standard to peak levels of performance.

## II. More genetic intervention, more problematic consequences

It is necessary to consider how these advances in the biomedical sciences will affect the willingness of all humans to continue their existence as nature formed them, and in particular with the will of mothers and fathers to maintain a pregnancy or even to desire future conceptions. It is also crucial to ponder the paradigm shifts that have taken place, which affect the value we place on all the stages which define human life. For example, **pregnancy**, the natural, normal, female physiological process has shifted from a “natural condition” which may have required, at times, some medical intervention, to a “medical condition”, which is always in need of medical interventions. Is the fetus a symptom necessitating medical attention for the mother, or is it a normal stage defining a life in process? Or, take **genetic prenatal tests**, which were previously offered as matter of personal choice, but are now becoming the norm, as a seemingly medical and social necessity. Besides instilling anxiety, this process of medicalizing pregnancy has encouraged a mindset that a child is not a “child” until prenatal tests have been carried out and the results have confirmed that all is well<sup>12</sup>.

A genetic predisposition to diseases, when established by testing a child or an adult, represents a life-long risk factor which often affects family relations and quality of life, and can lead to the development of depression, tension, anxiety, potential loss of a family member, the possibility of social stigmatization and great financial burden<sup>19</sup>. Prenatal genetic analysis, whether in the form of genetic testing or screening, according to the

European Commission's recommendations, should be voluntary and performed only in order to gain knowledge about fetal health status (as described by medical indications)<sup>20,21</sup>. Following this, prenatal genetic analysis can be requested or recommended based on two different intentions. One intention is to seek and apply, if available, a cure or treatment for the abnormality detected, or else gain information to help one cope and be psychologically, spiritually, materially prepared for the situation<sup>20,22</sup>. The other, by default, is the intention to terminate the pregnancy and remove the embryo or fetus which has a probability to be diseased<sup>22</sup>. Both create personal challenges, but the latter is the most morally problematic because the intent is to destroy a yet unborn human life for the simple reason that it could be less than perfect<sup>23</sup>. In light of such serious outcomes, all those involved must continually ask what the role is of genetic science and medicine, ought it to be at the service of life, or to rule over life?

We must be continually vigilant so that genomic medicine is not reduced to only its technical aspect. Many questions need to be asked. Can we really be certain that this increased power to detect and predict genetic diseases will allow their eradication by "genetic hygiene"? Certainly not! No genetic test can detect all forms of birth defects and abnormalities, and probably never will because genes can have hundreds of disease-causing mutations, and mutations in different genes can cause same disorders (genetic heterogeneity)<sup>24</sup>. While it is well known that a good part of our phenotype is strongly influenced by genes, it is now clear that environment plays an important role in the modification of our genome through epigenetic mechanisms. Not only do the non-gene mechanisms of inheritance exist, but these epigenetic modifications also determine most of the human phenotypic variability<sup>25</sup>. Epigenetic factors govern the interpretation of DNA within each living cell just as the conductor of an orchestra controls the dynamics of a symphonic performance. Epigenetic effects in human populations have been more difficult to identify, but the potential is immense. Do they have a major impact on human health? Probably yes, but only a large-scale Human Epigenome Project can address this question<sup>6</sup>.

Genetic determinism, that is, the idea that genes determine all human phenotypes should be seriously re-examined, although not necessarily rejected. Although the environment is greatly implicated in the functioning of our genome, it must not be forgotten that these changes happen inside the genome structure itself, and thus the resulting

phenotype should not be considered as a straight line but more as a circle of interaction between the environment and genetic information<sup>27</sup>. These interactions are known as epigenetic modifications and comprise a great part of genetic research today. The discovery of epigenetic modifications has finally begun to unravel many mysteries of human physiological and pathophysiological variability. For example, although monozygotic twins share identical DNA sequences, they show numerous epigenetic differences. Even if both twins have a genetic predisposition of the same hereditary disease, there is a minimal chance that the epimutation will progress in the same manner in both of them, which points to the fact that these epigenetic differences in the critical DNA region could result in differences in the expression of specific features<sup>28</sup>.

Human genetics is often fueled by sensationalist media reporting and developments are often exaggerated and create unrealistic expectations for the "new genetics"<sup>29</sup>. But this is to be expected, given the desire to control illnesses, eradicate disease as well as all unfavourable traits from the human condition.

Do we need to keep an open mind? Yes! Genetics is a broad field of unexplored treasures which could answer many questions on human existence; it cannot be considered just a technical and scientific discipline, but foremost it is a calling which demands from geneticists immense imagination and above all, good intuition, as we will discuss later<sup>6</sup>.

### **III. Elimination of disorders to a quest for human perfection**

The development of sophisticated genetic technologies leads to an increase in the availability of genetic tests and screening programs that are more accurate as well as commercially viable. These, in turn, make possible, not only, the detection of hereditary diseases and congenital anomalies, but also, the selection of specific human qualities, which quietly leads to an unavoidable genetic revolution.

Medical genetics moves rapidly from its goal to eliminate severe disorders to its goal to attempt to produce the perfect human specimen. So, it appears that mankind's noble dream to eradicate diseases has transformed itself into a silent, collective

evolutionary “imperative” for constant improvement of the human species. And the present day perception is that this worthy cause can be achieved only by the utilization of the newest discoveries from within the discipline of genetics.

History provides us with numerous examples to remind us that a prerequisite “to being human, and to be worthy of life” is not synonymous with a state of biological perfection, or, however medical science defines such perfection. History abounds with individuals, who excelled and contributed to the world in remarkable ways in spite of, or even because of their handicaps. Take for instance, Einstein, who was born in the 7th month of gestation; Van Gogh, whose 30 different diagnoses suggested for his insanity; Toulouse Lautrec, who was only 140 cm tall; Beethoven, who was deaf since age 28; Baudelaire, who had aphasia (the loss of ability to produce and/or understand language); Tesla, credited with inventing the 20th century, who had obsessive-compulsive disorder; and our present day Stephen Hawking, who has Amyotrophic Lateral Sclerosis, motor neuron disease, is considered by many, the greatest physicist of our time. And, who does not recognize the name, Elephant Man, popularized by numerous plays, television productions and David Lynch’s award winning 1980 film by the same name. The life of Joseph (John) Carrey Merrick, 1862-1890, otherwise known as Elephant Man was wrought with physical, emotional and psychological suffering caused by a congenital disorder which manifested itself in macrocephaly, gigantism, and numerous tumors<sup>30</sup>. Today’s witness, to the extraordinary short life of this remarkable man, will understand that behind Merrick’s deformed body lived a man who was imaginative, emotional and intelligent enough to understand his misery. It was his practice to end his letters with the following poem by Isaac Watts<sup>31,32</sup>:

Tis true my form is something odd,  
But blaming me is blaming God.  
Could I create myself anew,  
I would not fail in pleasing you.  
If I could reach from pole to pole,  
Or grasp the ocean with a span,  
I would be measured by the soul,  
The mind's the standard of the man.

Although we are all members of the same species, we are significantly different in the ways we perceive our existence, background and lifestyle as well as our genome and genetic knowledge. Even though as human beings we share a common 'book' – the genetic code, its interpretation around the world is not the same. As we are unable to standardize the approach to our genome, we behave like children who first want a new toy, but as soon as they get it, they disintegrate it into nonfunctional parts. What we need above all is a discussion which accepts, but also sets out our cultural, social and religious differences, and tries to bring about the view which unites all human knowledge in its essence.

Do we need norms at all? Most certainly yes, but what we need more is a changed global attitude toward the misguided quest for the eliminations of all imperfections that is aiming for a "perfect" human. Let us not forget that the important determinant of natural processes and evolution is the survival of the most adapted and by no means of the best. Take for example the mutation in the hemoglobin gene which leads to sickle cell disease, but creates a natural defense from malaria. Recently, it was discovered that people with Down syndrome appear to have genetic protection against some forms of cancer, atherosclerosis and possibly multiple sclerosis<sup>33,34</sup>.

It is possible that there are people who are resistant to all currently known diseases. Sometimes the evident imperfection brings an unknown evolutionary advantage for survival. But when we admit such a fact, we are opening the way to a global (r)evolution and new order, which is not based on the unsparing battle for the best, but on the cooperation of the imperfect. Domination as an imperative for existence should grow into the toleration of biological, social, political, economical and bioethical differences.

If the imperative of existence is to be the best, and to subsequently transfer these traits to the next generation, then, we should ask what kind of qualities are inherited from "the best" after several millions of years of perfection and natural selection on Earth?

Technological civilization has come to a crossroads. We are heading for self-destruction unless we change the course. The anthropocentric view of the world where the human dominates over everything around it including members of its own species is turning our life into a meaningless race in which we are being alienated from our

altruistic self. Is it really true that competition is the major drive of survival? Experience would demonstrate that humans are a rare species ready to engage in acts of altruism regardless of reward or recognition and in spite of danger or threat of death to themselves. The truth tells us that we urgently need a new view on the achievements of medical genetics.

#### **IV. Power which human genetics has over future of mankind**

Silently almost invisibly, the range of genetic interventions is increasing without full consideration to the consequences. This development needs to be corrected as we need to enter the age of *genetic responsibility*<sup>35</sup>. Developments of new molecular tests have already begun to herald a revolution in the practice of genomic medicine<sup>36</sup> and genetic testing is becoming part of the everyday healthcare systems<sup>21</sup>.

However you look at it, genetic testing has the potential to revolutionize medicine. But revolutions can have casualties. The metamorphosis of mankind's dream of "eradicating disease" to "improving the human species" is perhaps in its final stages of completion.

There is a popular belief in our society about genetic determinism which says that our genome represents a "coded future diary". But the real truth is that the genetic knowledge gained through the HUGO project is not sufficient and genes are not destiny<sup>26</sup>. Most diseases are an interplay of (epi)genotype, environment, behaviour and... bad luck. This is why society cannot choose its own prototype. Take for example breast and ovarian cancer – all breast/ovarian cancers are genetic disorders but only 5% of them are heritable due to the inheritance of high risk cancer susceptibility genes (BRCA1 and 2)<sup>37</sup>. As quantitative somatic mutations are more important than hereditary mutations, the risk of cancer development associated with mutations is different for every person<sup>38</sup>. Genetics is just one piece of the "puzzle" that is recently being upgraded with epigenetics. Genetic analysis tells nothing about these epigenetic modifications and environmental influence. The recently acquired knowledge is not yet matched with a full understanding of the implications for us.

Understanding the function of each and every human gene is a huge undertaking. However, the undertaking to use this information to understand and treat diseases is of even a larger magnitude. The objective to understand the function of the human genome has forced a redirection of research processes to study hundreds or thousands of (if not all) genes in terms of their expression patterns, pathway interactions and so on<sup>39</sup>.

Could new genetics provide the final answers? We will never control everything! The ability to read our “gene horoscope” will take away the true experience of freedom. We can be free only if we don’t know the part of our destiny influenced by our heredity. We should be happy people, not just healthy people. John Merrick died in sleep as his head fell back under the weight, dislocating his neck. He had often spoken of wanting to sleep like normal people, and perhaps he was trying to do so<sup>30</sup>.

Let us not forget – when you are dealing with humans, be human. Medical clinical genetics is the one branch of biomedical sciences where intuition is a key feature<sup>40</sup>. By definition, human genetics pertains to relatedness, rather than separateness<sup>41</sup>.

Although the human race has always longed for perfection in every aspect of life, today this collective evolutionary “imperative” for constant improvement of human species is becoming even more dangerous because it is happening silently. Today, all that is negative in the idea of human perfection is hidden behind a shield of supposed positive genetic progress, which alleges to give us knowledge of the genetic code and possibly treat genetic disorders, and at the same time it facilitates our rejection and eradication of all that we perceive to be a set-back for our illusory progress. It is quite probable that in trying to ascertain human values and validity from present day developments in hereditary genetic strengths and weaknesses, one can succumb to the old eugenics through a new approach. In this way, we are alienating any progress from the basic bioethical concept of respecting the dignity of every human being regardless of its genetic qualities.

The truth is that we are all carriers of abnormal genes that can cause certain disorders. Discrimination on the basis of genetic tests could make everyone a target. We are all in the same risk pool, and it is very pretentious and erroneous to qualify people as genetically healthy or deficient. Consider the situation faced by Einstein, Van Gogh, Hawking, Toulouse Lautrec, Beethoven, Baudelaire and Tesla; **if their parents had the**

**chance of prenatal genetic selection, would they have chosen them?** Modern science brings a growing wealth of knowledge and techniques to the diagnosis, treatment and prevention of genetic disorders. So, what can be considered as acceptable genetic diversity?

To face honestly the consequences of arriving at the edge of the “sustainability” of our civilization - which includes the possibility to change one’s genome, gene therapy, cloning, preimplantation genetic diagnosis and various types of genetic testing - is much more important than all the rules we could set on a piece of paper, because they would not bring a new approach to the understandings of the “Pandora’s box” – our genome.

In the discussion of defective genes, the word “defect” supposes that we have a perfect prototype, negating human diversity. The right of every person to life and dignity includes the right to inherit a genetic code which hasn’t been artificially modified<sup>42</sup>. Genetic freedom should be the freedom to bring about the conception of a child with any characteristics, whether they are good or bad, desired or undesired<sup>43</sup>.

## **V. Need for new gen-ethics**

It is obvious from what has been discussed above that no branch of science has ever created more acute or more subtle and interesting ethical dilemmas than genetics<sup>44</sup>. Given its complex nature, it is not always clear to the patient, what ought to be the right decision following specific genetic consultations. Although there are a number of ethical frameworks that can be employed to assist those concerned in resolving ethical dilemmas within a clinical setting, such as the four principles of biomedical ethics<sup>45</sup> and the structured approach to case consultation (Ethox approach), one must always keep in mind that ethics is not a static set of theories or principles that can be easily ‘applied’ to new situations<sup>46</sup>. Although genethics is defined as the study of ethical issues that arise out of the science of genetics and the uses of genetic technologies, the new challenges or conflicts that emerge from the evolving field of genetics may not be resolved using the established ethical frameworks, which can be compared to Willie Stark’s comment about the law, “The law is like pants you bought last year for a growing boy; it is always too short and too tight for growing mankind”<sup>47,48</sup>. It is therefore incumbent on every scientist and

clinician active in a genetic field to assume personal responsibility in the development and expansion in this field of ethics and in his/her area of expertise. Science cannot resolve moral conflicts, but it can help frame the debates about those conflicts.

Medical ethicists have traditionally referred to beneficence, nonmaleficence, respect for autonomy, and justice as fundamental principles of medical ethics. Normative bioethics, including these four principles, and even their expansion with the virtue ethics, doesn't provide a satisfactory solution for a unique, global approach to the human being. In the case of genetic counselling, when applied in the context of genetics, beneficence and non-maleficence sit easily, but, autonomy and justice can be problematic<sup>49</sup>. Counselling and ethical challenges related to genetic diseases require new approaches to ethical analysis, as well as more resources.

Individual autonomy has been the most valued principle in clinical ethics, but if patients possess no knowledge on genetics, how can they make decisions regarding their entire family and progeny? Should autonomy be the most valuable principle of bioethics in new genetics? probably not, because autonomy is not synonymous with unconditional freedom, and part of the concept of autonomy must be the recognition of other people's autonomy, or values<sup>50</sup>. There are tensions between the rights of individuals and the rights of the family, for whom this information may have relevance to health<sup>49</sup>.

The familial nature of genetic information demands some modification of the usual principles of privacy and non-disclosure, in both directions. The information should be able to be shared with family members whose health may benefit from their access to this information because it alerts them to the risk of a genetic disease and enables them to institute preventive or therapeutic strategies, but the information must be protected more carefully from outsiders<sup>49</sup>.

Although uniquely personal, the information from gene analyses impacts not only the human being whose genetic material was analysed but also parents, siblings, children and sometimes entire ethnic groups. When parents are faced with a birth defect of their child or when a patient is faced with an inherited genetic disorder, it still creates a heavy emotional, social and financial burden<sup>51</sup>. Physicians need to carefully balance the right of a patient to privacy against the wider family and society interests, consistent with ethical

standards and their legal obligations.

While medical genetics is developing faster than law regulations or public opinion, the human species hasn't precisely determined whether its priority is to "shape" new generations according to the will of the parents, or to create a society which is prepared for "less perfect" individuals. Today, human medical genetics needs to include biomedical, ethical, philosophical, social and theological considerations of genetic disorders which are specific by the fact that they can only be prevented and most of them never completely cured. In addition, gene therapy and genetic drugs (especially orphan drugs) as they are emerging for practical use, are very expensive and it is unclear who should carry the cost.

These developments suggest that instead of "ABSTRACT" bioethics, we need the real, life bioethics, the one that tries to understand the human genome, and not control it. After all, genethics is an exploration of the clash between modern genetics and human values<sup>48</sup>. It is a recombinant word that splices the words genetics and ethics together to capture their conceptual inseparability. Genethics represents a search for broad, lasting moral guidelines gleaned from complex, real-life ethical issues in genetics that are at once more imaginative, humane and scientifically sound. And so, the kind of bioethical "l'art-pour-l'art"-ism should once again try to turn to the understanding of human essence and the right interpretation of the human genome.

Society needs to be involved in setting limits about the individual choices that can be made<sup>52</sup>. Although there is some disquiet about genetic interventions, as a society, we need to ensure that we have a balanced ethical debate on issues of concern and that we distill the real ethical issues. The challenge ahead is to ensure that the newness of genetics does not unreasonably impede its implementation<sup>49</sup>.

## **VI. Education and Counselling as keys to a desirable genetic future**

Widespread genetic education is needed across the globe. All discussions of genetic progress and its implications in ethics can be done only when people are highly educated about genetics<sup>53</sup>.

Despite the exciting advances in medical genetics, many practicing clinicians perceive that the role of molecular genetics, especially that of genomics, is confined primarily to the research arena with little current clinical applicability<sup>2</sup>. The importance of education in medical genetics for the primary physicians and others who are involved in its practice cannot be exaggerated.

Francis S. Collins once said that most physicians in practice today have had not a single hour of education in genetics and are going to be severely challenged to pick up this new technology and run with it. Primary care physicians and other health care providers who are not specialists of medical genetics are not well prepared to handle patient inquiries about these new genetic tests and capabilities<sup>54</sup>. They are caught between the popular media and patient curiosity on the one hand, and on the other hand, the lack of research about the clinical utility of these tests, and the outcome of interventions based on these tests. It is important that the central resource of information about human medical genetics and genetic disorders for other health care professionals, patients and the general public must be exclusively medical geneticists.

Genetic counselling as the main form of communication between specialists and patients is under constant pressure to evolve and progress as it is a unique medical specialty that provides clinical health care for patients across the lifespan facing genetic and inherited diseases<sup>19</sup>. Thus counsellors should possess extraordinary teaching skills, whereas the professionals and patients would have to learn to make decisions and understand their consequences<sup>21</sup>. It is also important to emphasize the importance of sub-specialization and diversification of genetic counsellors' roles due to the constant growth of knowledge in medical genetics.

The new knowledge has to be disseminated quickly. It is imperative that opportunities for education are organized for both the public and the media. It is important to increase public awareness, education and understanding of genetic concepts<sup>21</sup>.

Genetic counselling is complex, not just because of the complex system of genetics, epigenetics and environmental influences, but also because of the numerous ethical dilemmas. The massive amount of genomic information now available allows for new insights into these processes. The problem of complexity becomes even greater when we

consider the fact that hereditary diseases do not follow only the classical monogenic traits, but also include complex mechanisms of genomic imprinting, trinucleotide repeat disorders, multifactorial diseases, mitochondrial inheritance, Y-lined inheritance, incomplete penetrance, variable expressivity, environmental factors, work, lifestyle, health care and many others. And these complex traits are present in the most common diseases of today such as cardiovascular diseases, and they are just small, almost imperceptible, changes in lots of genes.

The fundamental component of genetic counselling is education, attempting to present a large amount of complex information in comprehensible ways that allows a patient to make an informed decision<sup>54</sup>. Therefore, genetic counselling might be considered more as patient-education than actual advice. The biggest challenge for proper education of patients represents prenatal and presymptomatic diagnostics. Education of parents about the condition of their unborn child can give them the chance to "prepare" for a baby with a health problem and/or enable timely medical or surgical treatment of a condition before or after birth. Proper education of people, who take presymptomatic diagnostics, helps them to cope with discovered mutations before symptoms appear, so they can be monitored for early signs of the disease and treated promptly to reduce morbidity and mortality. With the proper lifelong medical and psychological support the quality of life can be improved<sup>55</sup>!

When we look at the increasing number of identified genetic disorders - currently, there are tests available for over 1400 disorders - and the huge interest in the role of new genetics, we can more greatly appreciate the importance of genetic counselling and the role that it can play, especially in the lives of those individuals that are directly affected: those with identified genetic disorder, those whose ancestry points to probable genetic disorder and pregnant women.

When patients at risk are identified, the counsellors must quantify, qualify and contextualize the risk, then provide to the patient pre-test counselling - professional information and education of the patient about his/her condition; receive an informed consent; select and offer testing, disclose results, provide post-test counselling and follow-up. Counsellors must leave clients emotionally and psychologically stronger, and more competent to deal with their own lives<sup>55</sup>. They protect the individual from making a

precipitous decision which might be regretted, and can help evaluate the client's understanding of cause and its relation to scientific explanation, clarify alternatives and anticipated consequences<sup>56</sup>.

Many would attest that in countries that remain deficient in medical resources, selecting and offering genetic or any other form of screening for genetic disorders is definitely the most sensitive aspect of genetic counselling. Our experience tells us that, as people who seek genetic counselling are usually of deficient genetic knowledge, the process of informing about the complex and mostly expensive genetic analyses turns genetic counselling into the highest skill of communication. Not only must the counsellor provide full information about the purpose of the test and testing options but he/she must also explore the patient's motives for testing<sup>57</sup>. Once the result of genetic analysis is disclosed the counsellor must discuss the predictive value and meaning of a positive or negative test and explore the potential impact on relatives and the risk to offspring<sup>57</sup>. Another especially important task is to discuss the future reproductive options: the counsellor must inform individuals that it is their ethical duty to tell blood relatives that they may be at genetic risk<sup>57</sup>. Because of the sensitivity and potential harmfulness, the person concerned also has the right to decide not to be informed about the results.

Certainly, with the importance placed upon the emerging discipline of genetic counselling, one would infer that the emphasis of genetic science is on service, and that its greatest promise lies in its potential to enhance human life. If we are convinced by the statement that the main goal of genetic counselling is to help individuals or families cope with complex decisions, required because of medical, psychological, emotional, social and economic consequences of genetic disorders<sup>56</sup>, then, there is hope that a genet(h)ical environment will prevail. Let's stop divorcing ethics from genetics – we must consider them equally and not forget that genetics as the science of life cannot be complete without ethics as the study of what constitutes right and wrong, and that these are two sides of the same coin... it is the human mind that sets them apart.

The goal of genetic counselling should resemble that of other health education programs: understanding personalized disease risk; enhancement of health-promoting behaviours including the client's self-determination in exercising choices; and facilitation of client understanding and acceptance, both aspects of adaptation<sup>55</sup>. Not only is genetic

counselling an important tool for education of patient but it is also a useful tool in preventive medicine as it usually presumes a lifelong dynamic communication process of providing genetic information on the course and prognosis of a specific genetic disorder.

Language can also be a powerful manipulator, body language, even more so. Patients are always influenced by the kind of information provided and the manner in which it is given. Whatever way you present genetic information, it always reflects the message being sent. And whatever way you present your information, it is wittingly or unwittingly directive, but providers should try to be aware of their own views and not project his/her values on the patient<sup>58</sup>. A counsellor must know that it would be unwise to answer such a posed question, "What would you do if placed in my position?" Rather, consideration ought to be given to the consequences of each possible course of action that is initiated from a patient's or society's interests.

There are two major concepts in providing genetic information – the teaching and the counselling model<sup>59</sup>. The teaching model is based on the conjecture that clients come to seek information. It assumes that clients should be able to make their own decisions. The counselling model is based on the conjecture that clients come for complex reasons.

Perhaps here it would be important to emphasize that both models have positive and negative sides. Providing genetic information is sensitive because of its lifelong implications and thus patients expect and need supportive counselling. Genetic counselling is by all means a multi-step process<sup>60</sup>. It can be imagined as a series of spirals, where each circle is built on previous efforts. All of these circles represent different implications of genetic counselling - social, psychological and legal<sup>55</sup> and the steps which must be passed are: diagnosis, disorder management, mode of inheritance, risk/benefits of possible testing, screening and diagnostic tests, risks assessment and prognosis possibilities.

In both models of genetic counselling, the counsellor's main role is to provide lifelong medical and psychological support<sup>55</sup>, to assist people to obtain access to medical services and follow-up care. The counsellors also have another very important task as they must learn to minimize distress in their patients because genetic disorders might evoke complex emotions in the individual or his/her family, such as helplessness, guilt and

fear.

Until everyone, who is involved in the process of genetic counselling, understands the sense and achievements of "new genetics", they will hardly understand and won't be able to contribute with a meaningful discussion about it, even if it is based on strong medical professionalism. We must all understand how difficult it is to face our own "genetic horoscope" and that it becomes more difficult when it concerns members of our family. Conversations on modern medical genetics becomes more complex when we understand that the genetic code is only one of the three main carriers which determine our life, health and disease – genetics, epigenetics and the environment.

## **VII. Conclusion**

Medical genetics, the science of human biological variations related to health and disease is an inevitable part of modern medical practice. The specificity of hereditary diseases comes from the fact that for now, they cannot be cured, but some can be prevented, and with the proper medical and psychological support the quality of life can be improved.

Medicine has a great capacity to test and screen for gene mutations and chromosomal aberrations, but currently little ability to cure the clinical consequences of these mutations. Because of the newness of this information, and the deterministic way in which many interpret the data, there is a risk that predictive genetic information will be misunderstood and too much weight will be placed on it<sup>29</sup>.

Considering that we will never be able to control everything around us and especially not our genome, it is important for modern society not be deceived by pseudo-excellence and sophisticated gene selection. We must attempt to create a society which is aware, and set to include those less competent individuals<sup>61</sup>.

Discrimination, which can hurt people with disabilities, is an issue. The challenge we face is a society which claims to recognize disabled people's human and civil rights, while at the same time it embraces a social discourse and clinical structures that promote

genetic cleansing<sup>62</sup>. The key to survival on Earth is in the global setting of moral standards and accepting the limits which cannot be crossed, even though technology can make it possible or available.

Now, more than ever, we need to quest for the real truth behind the purpose of the available knowledge concerning our genome, and an intellectual escape from the nonsensical excellence and manipulation to which we are all exposed. The truth about our genome is the greatest test for the survival of our civilization.

Genetic variation is what makes each human being a unique individual. It also can determine our unique susceptibility to disease. Human diversity may be the secret of humankind's success. Without diversity, there is no effective selection! Variety is not the spice of life, it is life itself. Instead of promoting genetic 'search and destroy' strategies, we should extend our sense of the richness of human life<sup>62</sup>.

No matter how great our contrasts are, they are still something immaterial. The things we share are far more valuable than those which divide us.

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# The Role of Religion and Culture in Clinical Ethics Consultation

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## **ABSTRACT**

This paper discusses the role a patient's religion and culture should play in analysing and discussing ethical issues in clinical ethics consultation in a multi-cultural environment. The first part of the paper presents a case of a family requesting a specific, normally very minor non-clinical procedure to be performed on an elderly patient with severe dementia as part of the preparation for a very significant religious festival. This had been done the two preceding years but staff was now unwilling to perform the procedure because the patient had become agitated when it was performed a year ago. The case was therefore brought to the clinical ethics committee (CEC) which had to consider two issues:

1. Should the procedure be performed by the staff?
2. If not, should staff allow relatives to perform the procedure?

Based on this case the paper will then discuss:

1. Does it matter whether the procedure is required by religion or culture?
  - a. Can a clear distinction be drawn between religion and culture?
2. Does it matter what view the majority culture has on this procedure?
3. Does the patient's own previously held views matter and why?

I will argue that the distinction between religion and culture or between what is required by religion and what is "merely" cultural is in most cases spurious and drawn primarily to either valorise or devalue a certain practice.

What matters is whether a given value is deeply held and whether giving it up will require major transformations in a persons system of beliefs (in the non-religious sense of beliefs). I will further argue that an attempt to determine the patient's objective "best interest" is also futile and unlikely to further the resolution of the problem since that concept is culturally determined.

## **Introduction**

It is generally accepted that when a proxy decision maker makes a decision for an incompetent person that decision has to be made in the best interest of the incompetent person (1). This holds both for family and for professional proxies. From this it follows that when a clinical ethics committee (CEC) is asked to advise in cases involving incompetent patients the CEC should advise the clinicians to follow the course of action that is in the patient's best interest. But deciding whether something is in the best interest of the patient is not always a straightforward matter and it may in some cases be extraordinarily difficult and contentious. In this paper I will discuss a case that illustrates these problems.

Mr. A was an elderly Muslim gentleman with slowly progressing, but now fairly severe dementia. He had been a resident of a nursing home for several years. He could sometimes recognise his family but it was clear to everyone that he no longer had decision making capacity, even in relation to very simple matters. Before he became demented he had always maintained a high degree of adherence to the standards of propriety common in his ethnic and religious community. He was a first generation immigrant but had lived in the country for many years. His religion required that all body hair was removed once a year before one of the most important festivals in the religious calendar. When his body hair had been shaved the previous year he had become agitated and was nicked once by the shaver. His family had asked that this religious preparation could be performed again this year, but the case was brought to the CEC by the staff who wanted support for the decision not to perform the shaving.

What advice should the CEC give?

### **Substituted judgement as best interest**

There is no doubt in this case that if Mr. A had been competent he would have performed the hair removal himself, as he had done every year of his adult life, and that if he had become merely physically unable to do it he would have got someone else, probably one of his sons to do it for him. What role should this fact play in our analysis? If

we think that the appropriate standard for proxy decision making is substituted judgement instead of best interest we might initially be lead to the conclusion that Mr. A's strong and undoubted commitment to this particular course of action should be dispositive of the decision making. Because Mr. A would have pursued this course of action, had he been competent we should now, as his proxies pursue this course of action.

But this is too hasty, because even under a substituted judgement standard the question we have to ask is something like "what would a competent Mr. A decide to do, if he knew that there was a great likelihood that he would not understand what was happening to him and that he would become agitated?" To answer that question we need to know much more about Mr. A and the reasons why he, throughout his life had consistently chosen to adhere to this and other standards of propriety. We also need to know how Mr. A had viewed the various exemptions from religious observance allowed by Islam. Such information might be difficult to come by. It is common that those who are truly devout are also those who feel least compelled to give reasons for their devotion. And if Mr A had never had reason to think about exemptions he might not even have formed a view about them.

### **Best interest and personal values**

Let us now assume that we have decided that the right approach to proxy decision making is not to try to divine what Mr. A would have decided if he could decide, but that the right approach is to try to find out what is in Mr. A's best interest now.

In this context it is first important to note that best interest is not the same as medical best interest, but that best interest properly conceived encompasses a much wider range of considerations. Health is undoubtedly important, but it is not the only thing that is important. Competent people often trade off health against other goods and there are no good arguments why similar trade offs cannot be made by proxy decision makers for the incompetent.

It is also important to keep in mind that there is no good reason to believe that there will always, or even often be only one course of action that is in a person's best interest.

There may be several, or we may be in a situation where we cannot determine what is in the person's best interest. I have argued this point in a previous paper written with Andrew Edgar and will not repeat the argument here (2).

And finally we have to remember that our intuitive response to this case may be influenced by the fact that the request is alien to our culture. Would we have the same intuitions about someone wishing their husbands beard shaved in time for the Christmas dinner? Given these caveats, how should we go about deciding what is in Mr. A's best interest? In the current case the agitation and risk of physical harm counts against the procedure and Mr. A's previous commitment to religion and propriety counts for it.

One way of resolving the problem is to find a way of showing that shaving is not, and has never been in Mr. A's best interest. It is perfectly possible that a competent person is mistaken with regard to what is in his best interest and thus possible that Mr. A and his family have been and are mistaken. Should we not therefore investigate whether there really is a religious obligation to shave before this particular festival?

In Islam there is, at least in principle a clear hierarchy of authority of sources. The Quran is most important, followed by the Hadith (i.e. the accounts of the custom and sayings of the Prophet and his first followers), followed by the consensus of scholars and custom. There is no Quranic authority for shaving of body hair, but there are a few reliable hadith with a good isnad (i.e. provenance or line of transmission) that locate shaving of the pubic hair as part of the Fitra (the good deeds that are not obligatory but highly commended and that are known to all through their conscience). A representative hadith from Bukhari, one of the major hadith collections for instance state that:

*"Volume 7, Book 72, Number 778:*

Narrated Ibn 'Umar:

Allah's Apostle said, "To shave the pubic hair, to clip the nails and to cut the moustaches short, are characteristics of the Fitra." (3)

We could therefore argue that Mr. A had been mistaken in his belief that a religious obligation existed and/or in his belief concerning the strength of such an obligation. If it is only a "highly commended" action it cannot be obligatory.

But this would, again be too hasty. Religious requirements are not only or perhaps even primarily ABSTRACT obligations derived through correct textual exegesis of holy texts. Religious requirements are embodied in a faith community and most often inextricably intertwined with a much larger cultural tradition. If everyone in the community with which Mr. A identified believes that a specific religious obligation exists, then that obligation exists for them. There may be other Muslims, belonging to other communities for whom this obligation does not exist, but it is a general fallacy, interestingly often shared by fundamentalists and secularists that there is an ABSTRACT and pure Islam we can refer to in order to decide whether Mr. A is really obligated.

And even if we had after careful analysis of Islamic sources decided that there was no Islamic basis for Mr. A's prior practices, that they were purely culturally determined it still would not determine whether we should take into account these practices in deciding what would be in Mr. A's best interest. The fact that I wear clothes that cover most of the body and that certain tribesmen on Papua New Guinea wear nothing apart from penis sheaths is mainly decided by culture. It could, if we discount differences in weather between the UK and Papua New Guinea have been the other way around. But the fact that style of clothing is culturally determined and could have been otherwise says nothing about whether or not it is in someone's best interest to wear a particular style of clothing. If I live in a culture that have strong views concerning proper clothes and I have internalised those views and made them mine, then it is and continues to be in my interest to be dressed in a proper way if I become unable to dress myself.

What matters is not whether a view on a particular set of interest is religious or cultural or purely self-chosen, but whether it is strong, sincerely held and integrated with other parts of the person's personality.

Another question to explore is whether Mr. A's interest in fulfilling his religious / cultural obligations has disappeared because he now has severe dementia? It is tempting to pursue an analysis along the following lines: 1. When Mr. A was competent it was in his interest to fulfill his obligations because of either the psychological or the reputational effects of not following them, but 2. In his present situation Mr. A will not experience any negative psychological effects if he does not discharge his obligations and it is unlikely that there will be any reputational effects (he is in a nursing home and if there is any blame it

may well be apportioned to the nursing home staff and not Mr A), therefore 3. It was previously in Mr. A's interest to discharge his obligations, but it is no longer so.

But this analysis is surely wrong, because it obscures important features of the case. Although not certain it is very likely that if we had asked Mr. A why it was important to discharge this, and similar obligations he would have said that 1. That acting in this way was the right thing to do and 2. That not discharging ones religious obligations had religious consequences. A central tenet in Islam is after all absolute submission to the will of Allah. Mr. A's interests in doing the right thing and submitting to the will of Allah are very plausibly not affected by whether he will experience any negative psychological effects and therefore persist. To use a distinction made by Ronald Dworkin (4), sincerely held religious interests are not experiential but critical and persist even in those with severe dementia. To claim otherwise is tantamount to claiming that Mr. A was, and had always been wrong in believing that he had religious interests.

### **Other options**

In considering this case it is important not to limit the possible courses of action prematurely. In the analysis so far it has been an implicit assumption that the CEC only has two courses of action it can advise; Either the staff shaves Mr. A's body hair or they refuse to do so. But this does not really exhaust the space of possible actions. Hair can be removed in many ways and since it is the end state and not the specific means that were important to Mr. A and are important to his family it might be worth exploring whether there is a form of hair removal that can be used without Mr. A becoming agitated and potentially physically harmed. Could the staff, for instance use an electric shaver or hair removal cream?

Another option would be to allow Mr. A's sons to shave their father. They may be able to get a better rapport with their father and they may conceivably have much more time to spend calming him and convincing him that he will not be hurt.

A third option would be to ask for advice from a respected religious or other leader in Mr. A's community. Most religions and cultures provide explicit or implicit ways of

exempting the incompetent and the infirm from their obligations, or of making it possible to discharge the obligation in a purely symbolic way. Prominent examples in Islam are exemptions from the Ramadan fast for those who are ill and from the prohibition against using pork products for those who need medical products derived from pigs. It may be the first time this specific problem has arisen in the context of a community member in a nursing home, but it is surely not the first time this problem or very similar problems have been encountered by Mr. A's community. Dementia occurs in all cultures. The family may, quite rightly regard the nursing home staff and the CEC as culturally incompetent outsiders but may listen to the advice of a respected insider.

## **Conclusion**

Two related conclusions follow from the analysis above: 1) we are not in a position to say with certainty whether shaving Mr. A is in his best interest and 2) we cannot say with certainty that shaving him is not in his best interest. If Mr. A had not become agitated on a previous occasion it would have been much easier to claim that shaving was in his best interest, because there would have been no countervailing considerations.

From these conclusions it seems to follow that if his family after consultation with community leaders still want the procedure to go ahead we should explore less traumatic ways of removing Mr. A's body hair and that we should at least try to fulfill the requirements of the family and only refuse if Mr. A becomes agitated again.

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

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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.<sup>1</sup>

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.<sup>2</sup> 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.<sup>3</sup> 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.”<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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,<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup>

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.<sup>11</sup>

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.<sup>12</sup> 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”<sup>13</sup> 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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# **BIOETHICS IN LATIN-AMERICA: SOME CHALLENGING QUESTIONS FOR THE PRESENT AND FUTURE**

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## **ABSTRACT**

This article aims to present some challenging questions that bioethics has to face in Latin America Region nowadays. In its beginning in USA (1970) bioethics dealt basically with new ethical dilemmas created by the fantastic progress of science and technology that generated new discoveries related with human life. We have new concept of death, the beginning of the era of transplantation (kidney, heart and liver), and scandals with research with human beings, that fostered the emergency of the principlism paradigm. Bioethics in Latin America, in its beginning is a transplantation of the bioethics of principles of United States. It started to build its own identity, only in the mid 90', when began to take into account and address some key ethical issues related with the socio-political and Cultural reality of Latin America. We identified five points: 1) Broadening the ethical reflection from the "micro" to the "macro" level; 2) Taking into account the cultural differences between Anglo- Saxon and Latin cultures; 3) The challenge to develop a horizon of meaning for bioethics; 4) Going beyond principles; 5) Consider justice and equity in the health care area as one of its key ethical referentials; and finally 6) to establish a respectful dialogue between bioethics and religious values.

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## **Introduction**

When we reflect about the historical process that marked the development of bioethics in Latin America, that differs in some aspects from the one from Iberian Peninsula (Spain and Portugal), we can see a continuity, not without obstacles, that encompasses three important phases in Latin American countries: the 1970's, when North-American bioethics was transplanted and accepted; the 1980's, of assimilation and evolution with a specific Latin American identity; and, from the 1990's on, the recreation phase, that is, the proposition of an original Latin American bioethical thinking and practice that, without refusing the contributions from other parts of the world, not only interprets them in its own way but also contributes for challenging them, in a enriching dialogical process. This creates a deeper understanding of the epistemological bases of the perspective of Latin American bioethics, (cf. Garrafa, Kottow & Saada, 2006), something that brings to light some topics that are, more than axis for reflection, real challenges to be faced in the region. Among these issues we can point out, ecology and the environment, research with human beings, public policies, legislation and laws regarding issues on human life and, in a ever more pluralist context, the dialogue between values in the secular and religious world.

In its beginnings in the United States, bioethics was faced with the ethical dilemmas created by the extraordinary techno-scientific developments in life and health sciences. Research on human beings, the humane use on technology, issues about death and dying were some of these sensitive areas in the 70's. The original issues in bioethics expanded to problems relating to values in the different health professions, such as nursing, public health, mental health, etc. A large number of social issues were introduced in the broad theme of bioethics, such as public health, the allocation of resources in health, women's health, the issues of health populations and ecology, merely to mention a few.

It is said that medical technology gives force to the development of clinical bioethics, and this happens both in Latin America and the United States. In the beginning, the questions most frequently asked were about research with human beings and about of a new technology: the use or the non-use of medical equipment, the acceptance or not of informed consent.

In some countries in Latin America, the simple existence of state-of-the-art technology and advanced medical care centers with high technology raises issues about discrimination, injustice and exclusion in the health care field. The most difficult issues to respond to in the region focus not on how medical technology is used, but else on who has access to it. A strong social thinking permeates Latin American bioethics. Culturally strong concepts and values such as justice, equity and solidarity should have a place in Latin American bioethics similar to that of autonomy in the United States.

According to James Drane, Latin Americans are not as individualistic and are certainly less inclined to consumerism in their personal relationships with their physicians than North Americans. It would, however, be a mistake to think that informed consent and everything that it entails would not be important for Latin Americans. The challenge is to learn from the USA and the Europeans without naively trying to imitate and import their programs that are certainly adequate to a different reality (Drane, 1996). In this sense, we emphasize now some relevant points.

**Some key issues for the present and future of bioethics in this region:**

**(1) Broadening ethical reflection from the "micro" to the "macro" level**

A bioethics thought from a "macro" level (society as a whole) must be proposed as an alternative perspective to the Anglo-American tradition of a bioethics thought from a "micro" level (the solution of clinical issues). In other words, a bioethics restricted to a high-technology "bios" and an individualist "ethos" (privacy, informed consent) needs to be integrated in Latin America to a humanistic "bios" and a communitarian "ethos" (solidarity, equity, the other).

The great challenge is developing a Latin American bioethics that redress the exaggerations of the outlooks of others and which will redeem and value the Latin culture in its most unique aspects, a truly alternative vision that can offer a multicultural dialogue. We cannot forget that Latin America bioethics necessarily suffers the impact of poverty and social exclusion. To elaborate bioethics only at the "micro" level, in case studies for deontological knowledge among the professions in the health care are, without taking into

account this socio-cultural reality, would not respond to the desires and needs for a more dignified life. We are not contesting the undeniable value that all human lives deserve; all life should be saved, cared for and protected. What we cannot do, however, is lose sight of the global vision of the Latin American reality, which is one marked by poverty and exclusion.

As modern medicine becomes for present cultures what religion used to be in the Middle Age, the issues that impact bioethics become ever more central and generate a growing interest from the public at large. At the threshold of bioethical controversies, basic meanings are changing in all the corners of this planet: the meaning of life and death, family, disease, who is a father or a mother etc. Greater communication and mutual dialogue amongst people with different outlooks are immensely advantageous, in the sense that they bring a deeper understanding of each culture and better solutions to similar critical problems. People of different regions and cultures can work to integrate sociological, historical and philosophical differences, and one day perhaps, who knows, generate a set of bioethical standards that will be respectful and coherent and which can be shared alike by religious and secular people.

According to J. A. Mainetti (1995), Latin America can offer a different bioethical vision from that of other regions of the globe, because of its humanistic traditions and due to its social conditions as a group of peripheral countries. For this Argentine bioethicist, the European discipline of medical philosophy with its three main branches (medical anthropology, epistemology and axiology) could be better equipped to transform scientific and academic medicine into a new humanistic biomedical paradigm. Such an approach would avoid the accusations frequently directed to medicine that bioethical discourse emerges to make medicine more humane but seems to forget or does not focus on the true dehumanization of the system. For example, the bioethical discourse on autonomy may mask the depersonalization of medical care and its risks of iatrogeny, the exploitation of the body and the alienation of health. As a response to the development of biomedicine in a technological era, bioethics should be less complacent and optimistic in terms of progress and be able to carry out a critical role in this context.

The Latin American reality of bioethics in a time of cholera, Aids and measles demands a social viewpoint of ethics, which will be concerned with the common welfare,

justice and equity before individual rights and personal virtues. A "macro-ethics" in public health can be proposed as an alternative for the Anglo-American tradition of "micro-ethics" or clinical ethics. Our greatest need in poor countries is for equity in the allocation of resources and the distribution of health services.

## **(2) Cultural differences between Anglo-Saxon and Latin cultures.**

It is enlightening while reflecting on bioethics from the cultural perspective of Latin America, to reflect on what says Diego Gracia, a famous Spanish physician and bioeticist, who's thought has a great influence in the region.

"Latin Americans feel deeply uncomfortable with rights and principles. They are used to judging things and actions good or bad instead of right or wrong. They prefer benevolence to justice, friendship to mutual respect, excellence to rights. (...) Latinos seek virtue and excellence. I do not believe they reject or think little of principles (...) As the Latin cultures traditionally were oriented by the ethics of virtues, the principlalist approach may be very helpful in avoiding some traditional defects of our moral life, such as paternalism, the lack of respect for laws and tolerance. In the search for virtue and excellence, Latin American countries by tradition have been intolerant. Tolerance has not been included as a virtue in the ancient catalogue of Latino virtues. The true virtue was intolerance, and tolerance was considered a vice. (...) Anglo-Saxons discovered tolerance as a virtue in the XVII Century. Perhaps this is the most significant difference with other cultures. The most important moral issue is not the language we use to express our moral feelings, but the respect for moral diversity, the choice between pluralism and fanaticism. Fanaticism states that values are total and absolute and objective and should be imposed forcefully upon others, whilst tolerance defends moral autonomy and freedom for all human beings and the search for a moral agreement through consensus " (GRACIA, 1995, p. 204-205).

The growing movement of bioethics worldwide lately is tackling ethical issues and concerns of many scholars of Latin America and the Caribbean region. Daniel Wikler, a North American Philosopher (Harvard University) in the closing address at the III World Congress of Bioethics (San Francisco, USA, 1996) entitled "Bioethics and social responsibility", said that when we look at the birth and development of bioethics, we clearly

detect four phases: First phase: we have the codes of conduct of professionals. Bioethics is practically understood as being medical ethics. Second phase: the doctor-patient relationship comes onto the scene. We contest paternalism, rights of patients begin to be debated (autonomy, freedom, truth, etc). Third phase: questions arise about the health systems, including their structure and organization, funding and management. Bioethicists have to study the economy and the politics of health (cf. Callahan, 1980), and Fourth phase: we entered this phase at the end of the 90's. Bioethics will deal prioritarily with the health of populations; and social sciences, humanities, public health, human rights, the issue of equity and the allocation of resources, among other burning issues, will enter the scene. This agenda has a great deal to do with the ethical moment of Latin America (PESSINI, 202b).

### **(3) The challenge of developing a horizon of meaning for bioethics**

Our reflection will be incomplete if we do not mention the challenging necessity of developing a broader horizon of meaning, or a mystic for bioethics. It may seem strange for a line of thinking marked by pragmatism and by the cult of efficiency to suggest that bioethics needs a mystic. Bioethics needs a horizon meaning, regardless of how narrow or broad it may be, to develop its reflections and proposals. Simultaneously, we cannot make bioethics without making the option in a world of human relationships. This in itself is an indication of the need for some type of mystic, or of a set of fundamental meanings which we accept and based on which we will cultivate our idealism, make our options and organize our practices.

It is not easy to define in a few words this broader horizon of meaning for bioethics. It necessarily includes the conviction on the transcendence on life, which rejects the notion of disease, suffering and death as absolutes that cannot be tolerated. It would include the perception of others as partners able to live in solidarity and understand and accept life as a gift. This horizon would doubtlessly be a witness, in the sense of not allowing egoistic individual interests to prevail and silence the voice of the vulnerable ones, the excluded, and mask their needs. This horizon would proclaim before all of the discoveries in life sciences and health care that the technical-scientific imperative, I can do, would have to pass necessarily through the ethical imperative, therefore, must I do? More than this, it

would motivate people and groups from the most diverse socio-political-economic-cultural backgrounds to unite in the enterprise to guarantee a dignified life for all, to build an economic, technical and scientific paradigm which would be guided by the demands of human solidarity with the most vulnerable ones of the society (ANJOS, 1996).

#### **(4) Going beyond principlism**

The principlist model (paradigm) of theoretical analysis, initiated with the Belmont Report and implemented by Beauchamp and Childress, is a language among other ethical languages. It is neither the only nor the exclusive one. The ethical experience can be expressed in different languages, theoretical paradigms or models, such as those of virtues and excellence, the casuistic, the contractual, the liberal autonomist, the model of care, the anthropological humanistic, the model of liberation, to mention only some. Obviously, living with this pluralism of theoretical models demands a dialogue respectful of differences where tolerance is the essential aspect. All these models or languages are intrinsically interrelated, but every one is also intrinsically incomplete and limited. A model can deal well with a definitive aspect of moral life, but not at the same time with all others. We cannot consider them as being exclusive, but complementary. The moral dimensions of human experience can not be captured in an exclusive model. This causes no surprise, for the broadness and the wealth of human experience depths are always beyond the reach of any philosophical or theological system. It is this modesty coming from wisdom that will make us free of the virus of "isms", that are partial truths that take one partial aspect of the reality as being the total reality (ANJOS, 1994).

#### **(5) Justice and equity in the health care area**

The bioethical problems that are of utmost importance in Latin America and the Caribbean are those which relate to justice, equity and the allocation of resources in the health care area as we mentioned earlier in this reflection. In large sectors of the population there is a lack of medical technology and even less of the greatly desired process to emancipate the sick ones. There is still a great deal of paternalism disguised as charity. Over the principle of autonomy, so deeply important in the Anglo-American

perspective, we need to put justice, equity and solidarity.

Bioethics elaborated in the developed world (USA and Europe) most of the time ignored the basic issues afflicting millions of excluded people in this continent and focused upon issues which for them are marginal or simply non-existent. For example, in the developed world there is much talk about dying with dignity. Here we are impelled to proclaim that human dignity should first of all warrant a life with dignity and not simply a degrading survival, instead of being concerned with death with dignity. Among us, what happens is the premature death that is unjust, that cuts short and destroys thousands of lives since childhood, while in the developed world, one dies after having lived and enjoyed life with elegance until old age (PESSINI, 2002a).

Reflecting prospectively with Alastair V. Campbell (1998), a Scottish philosopher, regarding the bioethics of the future, a key issue to be faced is justice in health and health care. A greater research effort seeking to build a "bioethics theory" is a necessary step in order to avoid that bioethics become a kind of "chaplain in the real kingdom of science", losing its critical role before techno-scientific progress.

## **(6) Bioethics and Religion**

A characteristic of the Latin American and Caribbean regions is the deep Christian Catholic heritage, which nowadays is being strongly impacted by the fundamentalist sects through electronic media. The secularization process has reached the educated bourgeoisie, but not people in general. The morals of this society continue to be basically religious and confessional. This society did not know the pluralism that is a strong characteristic of many developed countries of the world. Without a doubt, what arises here is a challenge towards a dialogue, bioethics-theology; between this secular, civil, pluralist, autonomous and rational bioethics and this religious universe so deeply rooted in culture and history of these lands.

Edmund D. Pellegrino (USA), one of the notable pioneers of bioethics, raises three questions that bioethics will have to face in the future. The first question is how to decide among the diversity of opinions on what is bioethics and on which is its field! The second

question is how to relate the various models of ethics and bioethics among themselves. The third question is precisely the place of religion and the theological bioethics in the public debates on abortion, euthanasia managed care etc. So far, religious bioethics was in the penumbra of philosophical bioethics. These authors (Thomasma & Pellegrino, 1997) predict the emergence in public debate of religious values, the more our conscience of cultural diversity increases. They warn us of the need of a methodology able to deal with the increasing polarization brought by authentic convictions and values, and propose that we must be able to live and work together even when our philosophical and religious convictions about what means “right” or “wrong” are most of the times in conflict with others values. In other words, we always lived so far with “moral friends” and now we challenged to learn how to live respectfully with “moral strangers”.

We need to deep our anthropological understanding in bioethics, that is both consistent with the theological vision of Christian personalism and not in opposition to the scientific vision of biomedicine. Elio Sgreccia, termed this approach as ontological personalism because it is based upon the concrete human being and not upon functional qualities or subjective interests. For the adult person herself, an ontological level to be fulfilled exists; her own essence in the wholeness and harmony of her own nature and in harmony with and service towards others” (SGRECCIA 2005, p. 125).

### **A Final Note**

It is necessary to cultivate a wisdom which will challenge prophetically the ethical imperialism of those who use force to impose their own morals upon others, as if it was the only truth, and also the ethical fundamentalism of those who refuse to enter into an open and genuine dialogue with others, in a even more pluralistic and secular context.

Who knows the pioneering intuition of V.R. Potter (1971) when he coined bioethics as being a bridge to the future of humanity needs to be studied again and reworked upon entering the new millennium, also as a bridge towards multi and transcultural dialogue among the different people and cultures. A bridge to a new dialogue that should enable us to recover our humanistic tradition, the meaning of life and our respect for the it's transcendence in its maximum magnitude (cosmic and ecological) and enjoy it both as a gift from high and a human conquest with dignity and solidarity.

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# **Rationality of Refusing Treatment: Clinical Ethics Conference at the Department of Emergency Medicine**

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## **Introduction**

The number of hospitals in which clinical ethics conferences are being held besides medical conferences has been increasing recently in Japan. Either the four-quadrant method by Albert R. Jonsen et al.<sup>1</sup> or the communication process sheet by Tetsuro Shimizu<sup>2</sup>, a Japanese philosopher, is used for decision making or problem solving regarding ethically controversial issues among medical staff, patients, and their family members. The participants include doctors, nurses, ethicists, lawyers, and psychologists. In this paper, I examine the major points to consider and tasks to undertake based on the discussion of the clinical ethics conference held at the Department of Emergency Medicine of Osaka University Hospital. The central topic is how to cope with cases of patients such as suicide attempt survivors who refuse the proposed treatment, in which most medical staff members usually find various difficulties.

## **1. Case presentation**

The following two cases related to attempted suicide are to some extent arranged based on the actual cases that we discussed in line with the Sheet for Case Examination in Clinical Ethics by Shimizu.

### Case 1

A man in his 40s was sent to hospital because of the serious injuries caused when he set fire to himself. He has been in and out of hospital for the treatment of schizophrenia and has taken drugs for several years. After emergency intervention, he recovered from a critical condition and was managed by respirator. He refused such treatment and asked to go home immediately; however, since there was no one to take care of him, the medical staff were concerned about the possibility of suicide attempt recurrence.

### Case 2

A woman in her 20s who repeatedly took overdoses due to panic disorder was taken to hospital and treated immediately. As medical staff members had experienced problems with the woman several times before, e.g., making a noise and shouting, as well as violent conduct and language toward them or other inpatients, they are frustrated both by not giving adequate care and wanting her to leave at the same time. The patient refused a psychiatric examination and left the hospital.

In both cases, medical staff found some difficulties in terms of how to provide adequate care for the patients and felt that care had been insufficient after their discharge. This is why some medical staff members raised these cases as topics of the clinical ethics conference.

## **2. Sheet for Case Examination in Clinical Ethics**

There is a strong necessity for an effective method of discussion among medical staff coping with clinical ethical issues. The sheet proposed by Jonsen et al., a so-called quadrant sheet -- medical indication, patient preferences, quality of life, and contextual features -- has been widely used around the world including among Japanese medical staff. However, this sheet often indicates that the communication process and the general Japanese relationship between the patient and his/her family members are not considered sufficiently. That is why Shimizu and his group have proposed their own sheet.

Basic features of the Sheet for Case Examination in Clinical Ethics by Shimizu are as follows:

- (1) Examination is conducted in line with the communication process for decision making or problem solving.
- (2) Both the patient and his/her family members are regarded as almost equal stakeholders.
- (3) Filling in the sheet is either for ongoing cases or for already-finished cases in order to pass on the knowledge learned from such cases.

The outline of the Sheet is as follows.

0-1 Patient profile

0-2 Summary of the patient's medical history

I. Analysis and sharing of information

A. Medical information:

Possible choices of treatments, their merits and demerits/risks; social issues; explanation by the medical staff to the patient and to the patient's family

B. Life and will of the patient and family:

The patient's understanding and will; the family's understanding and will; the patient's life and values

II. Examination and orientation

A. Finding the problem:

Individualized judgment by the medical staff; consensus among the people involved regarding the best choice

B. Analysis of the problem and how to solve it:

Causes of divergence/impediment and possible ways of solving it; how to promote communication between the patient and the medical staff in order to reach a consensus

III. Process of communication aiming at consensus

- (1) Communication with the patient and his/her family
- (2) Social arrangement
- (3) Conclusion and/or decision
- (4) Follow-up

This sheet can be used for both ongoing and just-finished cases, and is sometimes used for public workshops by persons working in the clinical setting while protecting personal information.

### **3. Discussion: Major Points to Consider**

The decision-making process is based on such factors as "medical indication," "will or preference of the patient and his/her family members," "evaluation of quality of life including risk-benefit analysis," and "familial and social support." By taking these factors into consideration "the best interests of the patient" can be made clear.<sup>3</sup> However, we find some difficulties in the case of suicide attempt survivors.

#### **(1) Rationality of Refusing Treatment**

Conflicts of opinion among persons involved often occur concerning refusal of treatment by patients who are suicide attempt survivors. Some claim the will to refuse should be respected, whereas most Japanese medical staff members tend to regard such will as irrational due to the lack of competence and to deal with the patient in a paternalistic way. We need to assess the decision-making capacity of the patient instead of legal competence.<sup>4,5</sup> In some cases, however, life-saving treatment is withheld because of its medical futility.

#### **(2) Care and Support for Patients after Discharge**

Although hospital medical staff have not formerly been involved in patients' lives after discharge, it is required nowadays for them to connect and cooperate with the local government, health center, and psychiatrists for welfare services or psychiatric care for patients who are suicide attempt survivors. As the patients are likely to be shunned or excluded by those around them, even their family members, as well as being isolated from their community and family, some medical staff provide support for the patients after discharge in order to prevent recurrence.

### **(3) Japanese Cultural Attitude to Suicide**

Japanese cultural tradition has a tendency to condone suicide instead of assigning blame for it. However, suicide attempt survivors are often looked down upon for causing disruption to others. While we can find the norm of valuing one's life and the idea that "suicide is a sin" and "never kill yourself" in Japanese culture, these values seem to be less among the general public, which is shown in such phenomena as the double suicide of a mother who kills her child, the prevailing method of suicide among young people, and the high suicide rates of the population (the highest for advanced countries according to a WHO report).<sup>6</sup> We need to conduct the comprehensive survey to get the basic data concerning attempted suicide and to cope with it in Japan as in the US.<sup>7,8</sup>

### **Conclusion**

The major issues emerging from the clinical ethics conference on patients who are suicide attempt survivors refusing treatment are as follows:

- (1) Is it valid for medical staff to disregard the will of a patient to refuse treatment as rational and conduct life-saving treatment against the patient's will?
- (2) Is it the duty of medical staff to arrange to provide support for the patient after discharge?
- (3) Is it necessary for medical staff to consider the tendency toward condoning suicide and isolation of survivors in Japan?

In my view, the positive involvement of medical staff with suicide survivors is justified from the viewpoints of the social mission of emergency and preventive medicine, public health, and the sociocultural circumstances in Japan.

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# Moral Imperative in the Age of Genetic Medicine

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Modern science demonstrates that if one is not a monozygotic twin, his genome is unique. Today, physicians learn the concept of genetic variability, its interactions with the environment, and its implications for care. Since now we can sequence human genome in the early stage, the practice of medicine enters an era in which the individual genome serves to determine the optimal care, which could be preventive, diagnostic, or therapeutic. Genomics is considered to be a basic science of biomedical research and takes a central place also in clinical medicine. As Guttmacher and Collins show, while genetics is the study of single genes and their effects, “genomics,” a term coined only 15 years ago, studies the functions and interactions of all genes in the genome<sup>1</sup>. Genomics has a broader and more ambitious sphere compared to genetics. The study of genomics is based on direct empirical entrance to the entire genome and applies to common conditions such as breast cancer, colorectal cancer, human immunodeficiency virus (HIV) infection, tuberculosis, Parkinson’s disease, and Alzheimer’s disease. These prevalent conditions are called multifactorial since they are based on the interactions of multiple genes and environmental factors. Genetic variations can have a protective or a pathologic role in the onset of these diseases.

The present-day medical care is influenced also by the occurrence of pharmacogenetics which arised together with the current advances in genomic science, especially by the conception, introduction and ending of the Human Genome Project. In the late 90-s, the interaction of the two areas of biomedical research leads to turn of

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1 Guttmacher, A. et F. Collins. Genomic Medicine -A Primer. N Engl J Med, Vol. 347, No. 19

pharmacogenetics into pharmacogenomics. Despite sometimes the terms “pharmacogenetics” and “pharmacogenomics” are used interchangeably, it has to be considered that pharmacogenomics emerged from the coupling of the advances in pharmacogenetics during the last century and the changes in genomic science such as the completion of the Human Genome Project, the development of expression profiling, and high-throughput DNA sequencing and genotyping<sup>1</sup>. Pharmacogenomics can identify the patients who are likely to receive benefit from some drug which resolves the common practice of broad, random prescribing of a medication to all the patients with the same condition. In this way, pharmacogenomics will lead to fragmentation of the markets for pharmaceuticals. Evans maintains that under the actual balkanized system of health care financing, this situation will burden patients, insurers and pharmaceutical industry with problems that increase in direct proportion to the scientific success<sup>2</sup>. Since insurance plans do not have the complete formularies required to obtain the practical benefits of pharmacogenomics, patients are insured by plans that do not provide reimbursement for a drug that could result in optimal care. As a result, the changes in pharmacogenomics lead to problems which could be solved through new practical and ethical approaches such as the described by Evans broadly pooled insurance risk that is a manifestation of the new ethical principles in the form of solidarity, mutuality and universality.

In regard to ethics, genetic interventions must respect the dignity of the human person and must promote the well being of the patient. This is the most fundamental moral principle related to the genetic intervention and it takes various forms. Science and technology require for their own intrinsic meanings an unconditional respect for this principle (James Walter, Thomas Shannon “The new genetic medicine”). Pythagoras, Plato and Aristotle spoke of suicide and mercy killing. Unlike Judaism, Christianity and Islam, the Stoics allowed killing of terminal cases. In the period of Renaissance killing of these was regarded as a trivial issue. In the 17th century the Church permitted killing of those who were incurable. The time provides the needs to respect the right to life under any conditions and imply that the holy books can provide applicable ideas concerning temporal virtues and vices and to try to solve this problem. Respect must be present even from the very moment of individual conception. Scientific interventions into the human

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1 Weinshilboum, R. et L. Wang. Pharmacogenomics: Bench to Bedside. *Nature Reviews: Drug Discovery*, September 2004; 3:739–748.

2 Evans, J. Health care in the age of genetic medicine. *Genetics In Medicine*, January 2008, Vol. 10, No. 1.

genome must respect the integrity of the person when the focus is put on the benefits for the patient. Experiments that are not strictly directed toward therapy but are aimed at improving the human biological condition can be justified at least partly on the grounds that the experiments respect the human person as one in body and soul. Genetic experiments that are directed toward the creation of different groups of people are morally forbidden because they violate the dignity of the person. The risks and benefits must be calculated in terms of their potential impact upon the patient's well-being and not in terms of their impact on existing others or future humanity.

Since the time when religion was gradually put aside from the social sphere and its presence in culture, politics, management and other fields of social activities was no more tolerated there is more emphasis on secular morals that are free of religion. Development of commerce and industry, social reforms, revolutions in science as well as the birth of secular governments required new principles for individual conduct and social organizations to be enacted. Galileo's naturalism attacked the traditional concepts of the goal of design and value in the corporeal world, which was defended by the Church authorities. The new standards of moral commandments are based instead of the universal design of nature or the Revelation, which suggests God's will on the man himself and it, is founded either on his biological structure or on an agreement between him and his peers or on the socio-political organizations which are founded by him.

When God was replaced by science and religion has been relegated to the background, the question is: was the progress of the sciences and industries of influence in the purification of morals or detrimental to them? The answer which won was the one given by Rousseau in which the second alternative had been emphasized. William Key had no doubt about the contribution of science in solving moral problems. Changes in the political, sexual, economical and environmental texture of human environment introduce new concepts and referents of ethics and anti-ethics to the thought of contemporary man. The attention paid by scientists, physicians to the particular problems with which they are faced can be mentioned as an example. Issues such as the transplantation of organs, the relation between the physician and patient in various cases, awareness or unawareness of patient of his/her disease, euthanasia or saving lives are examples for this.

Concerning moral vices also, taking into account the influence of particular temporal and environmental conditions on human understanding new concepts and referents will originate. The problem of homosexuality which is seriously condemned in the Divine religions can be mentioned as an example. In modern developed societies according to their ways of approach towards issues and in particular based on their special political and governmental system such issues are not so condemned and in these societies all issues are viewed through a social approach; that is what is accepted by society is regarded as good and what is not accepted by society should be ignored. The issue of the temporality of ethics is in turn a function of the temporality of other things, even religion. According to such a view point there are no absolute and eternal things and all of what is related in a way to the context of man's life should be accounted for, because of its temporality in every particular period and society in accordance with that particular temporal, environmental and social condition.

Guttmacher and Collins note that soon it will be possible to sequence anyone's entire genome for a laboratory cost of less than \$1,000<sup>1</sup>. This situation will change dramatically research and clinical care but, at the same time, there will be new ethical, legal and social issues. In the 90-s, ethical debates examined influence of the Human Genome Diversity Project on clinical genetics in the forms of counseling, testing, screening or genetic discrimination. Later, ethical questions included genetic enhancement or essentialism and cloning. In the early 21st century, bioethicists discuss preimplantation genetic diagnosis, commercialization, patenting, DNA banking and pharmacogenetics. Knoppers and Chadwick note that there appeared changes in the way that "ethics" is understood. Public concerns about genetically modified food increase the importance of ethical decisions and the concerns that human genetic research suffer from a loss of trust in science<sup>2</sup>. There are proposed new models of health care due to introduction of predictive medicine and targeted therapies, which are result of pharmacogenetic profiling and genetically informed prescribing. These new models call in question the content of actual ethical guidelines. In this way, ethics takes the central place in public policy.

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1 Guttmacher, A. et F. Collins. Welcome to the Genomic Era. *N Engl J Med*, September 4, 2003; 349:10.

2 Knoppers, B. et R. Chadwick. Human Genetic Research: Emerging Trends in Ethics. *Nature Reviews: Genetics*, January 2005; 6:75–79.

In the 90-s, human genetic research is guided through the moral principles of autonomy, privacy, justice, quality and equity. Current medical ethics has to include the complexity of genetic factors in common diseases and that one of the familial and socio-economic impact of genetic information and genetic tests, together with the concomitant expansion of public participation in policy making. Knoppers and Chadwick identify the new trends in ethics as reciprocity, mutuality, solidarity, citizenry and universality<sup>1</sup>. These moral principle are not completely new – they are well known for moral thinkers but they show possible replacement of the principle of autonomy as the ultimate arbiter in bioethics with the principle of universality which is seen in the so-called participatory approach. We claim that the above-mentioned insurance approach of Evans is an expression of this approach. In this way, genetic research and pharmagogenomics initiate ethical study of personal and social values and their expression in the issues of medical practice.

According to Knoppers and Chadwick, the principle of universality or the claim that the moral point of view has universal coverage, which is very old, receives a new sense in the settings of genomics. In the new ethics, universality is represented by the genome itself as a shared resource. The human genome is shared by all. The conception for the human genome at the degree of the species leads to the specific emergence of the principle of universality in relation to the genome. Universality is expressed also as the common heritage of humanity and grounds obligations to future generations, reinforces the approach of benefit-sharing (also grounded in equity) and of genomic knowledge as beneficial to the public<sup>2</sup>. We think that the principle of universality shows best the main trend of the moral imperative in the age of genetic medicine.

There are many similar features of the principle of universality and the principle of interdependence that is described by Thomas and colleagues<sup>3</sup>. As they show, since the genomics is the study of the functions and interactions of all the genes in the genome, including their interactions with environmental factors, the ethical problems in genomics have their own acronym, ELSI, which represents possible ethical, legal, and social implications. It can be seen that sometimes medicine and public health approach ethical

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1 Ibid.

2 Ibid.

3 Thomas, J. et al. Genomics and the Public Health Code of Ethics. American Journal of Public Health, December 2005, Vol 95, No. 12.

questions in different way. Autonomy is a fundamental principle in medical ethics and public health. Thomas and colleagues underline that because physicians have authority and access to protected resources that may cure or harm, it is important to protect the patient's autonomy. Public health concerns not only the sum of individuals but also the relationships between the individuals in society and the relationship between the people and health agencies. In public settings, individual activity can affect other people and one's infection can be another person's exposure. That is way, occasionally personal autonomy has to be restricted to preserve the social good (in utilitarian sense). In this regard, Thomas and colleagues propose another principle that is fundamental in public health ethics – the principle of interdependence. This principle has important ethical reflections on the usage of genomic tools. We attempt to demonstrate the new trends in ethical studies through the case of the fragile X syndrome (FXS).

The American College of Medical Genetics analyzed the state of newborn screening (NBS) in the USA showing the results of expert ratings of 78 candidate conditions. FXS is the most common hereditary intellectual disability. It is not recommended for screening by the ACMG due to absence of appropriate, cost-effective screening test and data about possible benefits from screening. FXS is more prevalent in males causing moderate-to-severe intellectual disability. X inactivation and cellular mosaicism lead to decreased prevalence in females. Both the males and females suffer from social and behavioral difficulties although the females show more intact neurocognitive functioning. Because of its nature FXS interferes equally the patients and their families. The parents of suffered children prefer screening for newborns because it prevents unnecessary tests and allows timely intervention during the critical brain development, providing information about reproductive risk. Along with the benefits, examination of ethical implications of FXS shows also the existence of additional negative aspects of performing NBS. Bailey described a survey of families with children with FXS where the respondents determined whether learning the diagnosis would change their attachment to the child. Most of the respondents (60.2%) answered that the diagnosis cannot change their attitude since this is still their child and they will love him as any other child<sup>1</sup>. A smaller proportion (9.3%) of the respondents answered that the diagnosis will increase their attachment helping them to understand the child better or making them to

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1 Bailey, D. et al. Ethical, Legal, and Social Concerns About Expanded Newborn Screening: Fragile X Syndrome as a Prototype for Emerging Issues. *Pediatrics*, 2008; 121; e693-e704.

spend more time with the child. Only 10% answered that the attachment will be more difficult since there are difficulties to take care for the child with FXS and the diagnosis leads to negative emotions.

Genes influence all human characteristics and diseases. These influences are identified in patients through examination of the family history, physical investigation and diagnostics. The specific molecular mechanisms of some conditions such as cystic fibrosis and sickle cell disease are clear unlike other chronic diseases as diabetes mellitus and hypertension, which responsible genes are still unknown. In this regard, the term “genetic information” is used in different meanings. In most of the cases, genetic information leads to the apprehension that it could be used for denying access to health insurance, job, education or some privileges. Despite popularisation of the principle of confidentiality common people see that their health information is not completely private. Genetic information is considered more definitive and predictive than other types of data because it seems that we cannot change our genes, which may be foretell our tomorrow. Genetic determinism or the belief in it leads to the sense of inevitability but, in fact, biologic systems develop in different manner. As Clayton notes, the DNA sequence is not the Book of Life <sup>1</sup>. Human characteristics are result of continuous interactions between the individual and exterior genes and the environment.

Most part of the males with the full mutation and slight/borderline degree of intellectual functioning and most part of the females with the full mutation and borderline/normal intellectual function are not diagnosed with FXS. Keeping this in mind, NBS identifies a considerable proportion of the males and females with the full mutation who will not be detected otherwise and some of them may not have the symptoms (with the FXS genotype but without the classic phenotype). Identifying these children can have negative impact on parenting or this can increase parental anxiety or lead to a state of hypervigilance without actual symptoms. When the parents know the diagnosis at an early stage they will be very careful about possible signs of mental retardation or severe behavioral and learning disabilities. However, the child can never show such symptoms. Any genetic testing will identify genetic or chromosomal anomalies that can be different from the condition that was assessed. In general, there are many ethical arguments

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1 Clayton, E. Ethical, Legal, and Social Implications of Genomic Medicine. *N Engl J Med*, 2003; 349:562-9.

against screening for carrier status and late-onset disorders. This information can lead to psychosocial impairment of the child, including anxiety, negative self-concept, and impact on important decisions about his/her future life. Initial identification can provoke stigmatization and legal discrimination of individuals who are asymptomatic but are detected as having the genetic disorder. Bailey maintains that screening leads to the conflict between children's (future) autonomy and parents' right to know information about their child<sup>1</sup>. Genomic medicine brings information about health risks which are faced not only by patients but also by their relatives. We already know that the duty to keep confidentiality is not absolute as in the case of some infectious diseases that have to be reported by the physicians not to allow impairment of bystanders. However, we are not sure that genetic risks are very similar to these existing exceptions from the obligation of confidentiality. Physicians have to be permitted to breach confidentiality to warn third parties of genetic risks only as an ultimate means. Clayton claims that the overall question is whether the public's health is actually improved by the knowledge derived<sup>2</sup>. Not everyone will benefit from this knowledge.

The families whose newborns are diagnosed with diseases such FXS are involved in "genealogical ethics" – the process of taking moral decisions of whom in the extended family to tell, what genetic information to reveal, when to disclose, and who should do the telling<sup>3</sup>. In this way, the disclosure or nondisclosure have ethical consequences for relatives' identities and important decisions. Genetic information has the capacity to influence relationships in the family. In this case, the identified family and not medical professionals have the "duty to inform". The parents are responsible for the information that FXS appears in the family lineage. Disclosure of this information can provoke or increase existing conflicts in the family.

The problem about non-paternity is the primary moral challenge related with genetic research and testing. Later, this question spreads to the sphere in which the patients or their representatives have the right to share genetic information with other family members as in the case with the fragile X syndrome. In 1982, the US President's Commission popularizes the idea about the ethical (not legal) duty to admonish increased-risk family members. This violation of confidentiality is circumscribed by the

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1 Bailey, D. et al., Op. cit.

2 Clayton, E., Op. cit.

3 Bailey, D. et al., Op. cit.

following factors: the family member has to be identified with high risk for a serious condition that is preventable or treatable<sup>1</sup>. Interestingly, the family can be considered a distinct social unit which possibly means that DNA and the information it contains is familial ownership. Some guidelines allow access to family members to the DNA or genetic information of their relative (even deceased) due to some purpose or necessity. Thus, genetic information has a familial character and has to be discussed through the principle of mutuality, to be shared within families, but it is no longer a question of discretionary medical control.

Ethical issues of genetic research are complex since molecular genetics is a new subject, with constant flow of evolving information, and its complete implications are still unclear. As Vahakangas demonstrates, genetic information differs from any other health care information because it is predictive, although the degree of its certainty varies, and it always involves at least family members, but in some genetically very homogeneous populations even a wider group<sup>2</sup>. Not only the populations but also the world itself is culturally xenogenic and the significance and meaning of genetic information varies between the cultures. Knoppers and Chadwick note that solidarity represents an ethical problem in the discussions about the right to know or not to know, the insurance and human genetic databases. In the discussions about the right to know, the issue is whether individuals have the responsibility to learn about their genetic make-up in order to make important decisions (to perform predictive tests, to take reproductive decisions)<sup>3</sup>. Considering the principle of autonomy, the patient has the right to know since he has to decide about his life by himself. On the other side, the principle of solidarity claims that genetic information has to be shared for the benefit of others. As we can see in the case of FXS, it is not so obvious who the relevant others (all the relatives or part of them) are.

FXS shows gendered characteristics of the response through different presentations in males and females. Bailey notes that affected men can feel guilty for transferring the gene in its carrier state to their daughters and consecutive grandchildren<sup>4</sup>.

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1 Knoppers, B. et R. Chadwick. Human Genetic Research: Emerging Trends in Ethics Nature Reviews: Genetics, January 2005; 6:75–79.

2 Vahakangas, K. Ethical aspects of molecular epidemiology of cancer. Carcinogenesis, Vol.25, 2004, No.4 pp.465-471.

3 Knoppers, B. et R. Chadwick., Op. cit.

4 Bailey, D. et al. Ethical, Legal, and Social Concerns About Expanded Newborn Screening: Fragile X Syndrome as a Prototype for Emerging Issues. Pediatrics, 2008; 121; e693-e704.

Since the women deliver the full mutation directly mothers can blame themselves for carrying the gene that resulted in their child's problems. NBS can become a primary reason for these feelings. The women can have more complicated reproductive choices compared to the male carriers since right the women risk having an affected child. The gender difference of the disease influences the children who are carriers and their future vital decisions. However, genomics calls into question the definition of disability since it can be considered a functional limitation as an essential feature or it is rather a question of social justice if the disability depends on the concrete social arrangements. According to the new ethical principle of citizenry, disability includes a complex of functional and social factors<sup>1</sup>. Disability represents only disadvantage when functional limitations or social structures are the main factors producing the disadvantage. There is an expressivist objection to genetic interventions that they express intolerance of disability, facilitating social factors (social model of disability). Other authors propose individual-choice model of disability. The example with disability shows that ethical solutions are not static but they constantly change showing a shift from the principles of individuals' ethics to ethics of interdependence and universality.

## **Conclusion**

Most aspects of the usage of genetic research are different manifestations of the principle of universality proposed by Knoppers and Chadwick. In the case of screening for FXS, the obtained information concerns even the relatives beyond the patient's family provoking moral dilemmas that can be solved through the principles of mutuality and solidarity. Health information is no longer completely private and its implications require moral decisions with increased coverage. Genetic information has to be shared for the benefit of others. We all have genomic risks for some disease, all are genetically impaired, and these risks increase with the capacities of genetic medicine. The future of each individual is strongly associated with the common lot<sup>2</sup> which demonstrates the necessity of accepting the principle of universality as moral imperative in the age of genetic medicine.

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<sup>1</sup> Knoppers, B. et R. Chadwick., Op. cit.

<sup>2</sup> Evans, J. Health care in the age of genetic medicine. *Genetics In Medicine*, January 2008, Vol. 10, No. 1.

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# Aboriginal Health Care in Canada - Bioethics Perspective

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## **ABSTRACT**

Health care for and among the Aboriginal population raises some unique ethical issues. Firstly, the health status of Aboriginal people in Canada, about 4% of the total population, appears to be in most aspects much worse than the health status of the rest of Canadians, leading to a significant difference in their average life span. This is a matter of social justice. The Aboriginal population needs to be recognized as a vulnerable group and Canadian society has to strive to eliminate discrepancy in health status. Secondly, Aboriginal patients living in a traditional community setting may have a set of values that may differ significantly from the values of main stream population of which the health care professional is used to accommodating. Consequently, Aboriginal patients may perceive the health services as alien and not meeting their needs. Furthermore, their values may be very important to other segments of the Canadian population, since it is composed of people of different cultural origins. A health care organization and its professionals, who understand and respect these values, will provide ethically more competent care. With some effort, it may be possible that traditional healers will become respected members of care teams and that traditional healing approaches can become available, along with evidence-based care, in our health care institutions. The attention to the ethical aspect of care for and among the Aboriginal population has a potential, not only to improve the experience of care and the quality of care for this vulnerable minority group, but also, to improve the ethical quality of health care in general.

**Key Words: Aboriginal population, bioethics, culture, health status, social justice, traditional healer, values, vulnerable population**

In this paper<sup>1</sup>, I will discuss some ethical issues of health care involving the Aboriginal population in Canada. Firstly, after providing some background information, I will comment on the ethical implications of the current health status of the Aboriginal population. Secondly, I will discuss some commonalities and differences in values and expectations between the mainstream Canadian and Aboriginal population and suggest how these could be approached in clinical care. Finally, I will comment on the ethical approach to traditional Aboriginal health practices and practitioners. The purpose of this paper is not to claim discoveries or make categorical normative statements, but rather to seek understanding and stimulate discussion of this complex topic.

## **Background**

Some background information about the Canadian health care system and our Aboriginal people will be necessary to make the discussion intelligible. Canada is the second largest country in the world, but the population is only 32 million. The health care system is largely publicly funded and is being delivered in both public and private settings. Most physicians are in private practice, but almost all hospitals are public institutions. Federal law provides guiding principles, and the federal government provides financial support for health care, but the responsibility for health care organization and delivery is in the hands of provincial governments. Residents of Canada receive the services of hospitals, physicians and other recognized professionals for free, as long as the services are medically necessary. The system strives to combine high standards of care with high accessibility. However, crowded hospitals and emergency rooms and long waiting lists for consultations and treatments are disconcerting and periodically produce public outcry for either better services in the public system, or a demand to change the law to allow a parallel private system. However, at the present moment, it seems that most Canadians prefer to continue with a public system, disallowing a formal setup that would allow the private purchase of additional or better medical services or treatments that are not otherwise provided – there is only one standard of service(1).

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<sup>1</sup> An earlier version of this paper was presented at the 5<sup>th</sup> International Conference on Clinical Ethics and Consultation, March 9-13, 2009, Taichung and Taipei, Taiwan.

In Canada, about 4.5 % of the population is Aboriginal, that is, North American Indians (now called First Nations), Inuits, and Métis (people of mixed racial ancestry, one of which is Native American). About 50% of First Nations members live on “reservations”, tracts of land set aside for them by treaties with the Crown, signed mostly in the 18th and 19th centuries. This Aboriginal population of about 1 million is very diverse. There are approximately 50 different languages and cultural groups and 600 First Nations communities. Health care is largely under the jurisdiction of ten provincial and three territorial governments. However, the federal government, to some extent obligated by treaties with First Nations, is providing medical care for those living on the reserves and in remote communities where services by provincial governments would be very limited. In the last two decades, the federal government has been gradually transferring the governance for community programs to First Nations, as they are able and willing to accept this responsibility(2). The other half of the population lives in cities where, as other populations, they have access to medical and hospital care that is organized and funded by one of ten provincial or three territorial governments<sup>2</sup>.

### **Health status of Aboriginal population and its ethical implications**

In theory then, health care for Aboriginal people is well taken care of and access and quality should be at the same level as that for other non Aboriginal residents. However, the health status of the Canadian Aboriginal population is much worse than that of other Canadians. Compared to the general population, heart disease is 1.5 times higher, type 2 diabetes 3 to 5 times higher and tuberculosis 8 to 10 times higher among the Aboriginal population(3). Mortality rate for infants is 1.5 times the rate for non-Aboriginals. Potential years of life lost from injury are 3.5 times of the Canadian rate. Aboriginals require dialysis for end stage renal disease three times as often as others. As a result, the life expectancy for an Aboriginal man is 7.4 years shorter and for Aboriginal women 5.2 years shorter than that of the non-aboriginal population in general. Data are based mostly on the population of the reserves, while the data concerning urban Aboriginal people are difficult to obtain(4). Health Canada, the federal ministry of health, is formally committed to closing this health status gap, but improvements so far have been only modest.

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<sup>2</sup> From this point on, I will use the term, Aboriginal, to largely refer to First Nations.

Recently, some organizations were created to address this issue, such as the National Aboriginal Health Organization and Institute of Aboriginal Peoples Health. This health disparity is not a unique Canadian problem. A recent comparative study of health status of Aboriginal children in Canada, US, Australia and New Zealand showed similarly elevated rates of infant mortality, suicide, accidental death, obesity and infection in all four countries(5).

The question I wish to ask deals with the ethical significance of this disparity. Specifically: Should the disparity between the health status of Aboriginal and non-Aboriginal populations within one state be considered an injustice? I am using the term injustice in the most ordinary sense as denying someone that which is due to him or her.

On first analysis, it may seem that this cannot be the case. After all, health is a complex human good and it cannot be simply provided or guaranteed by society. Health is strongly influenced by the genetic endowment of the individual and the population group, as well as lifestyle choices of people and their communities, thus placing it outside of human control. However, a critical role is played by determinants of health such as drinking water, air, nutrition, housing, education, work and leisure, which are defined by societal policies and actions(6). There is ample evidence that the living conditions of the Canadian Aboriginal population are associated with health determinants uniformly inferior to those of the majority of the population(7).

Health status is also influenced by health care delivery. The quantity and quality of health care provided to the population is largely shaped by society. How is it possible that the health care status of one segment of the population is inferior to that of another? Inadequate access to health care certainly can be a contributing factor. There is evidence that even in Canada - a country that has eliminated individual financial barriers through its universal coverage of health care - the utilization of primary health care(8) and specialist care(9) by the Aboriginal population is much lower than that of the non-Aboriginal population. Utilization may be hindered to a degree by the difficulties in accessing care because of geographical barriers, such as distance and challenging travelling conditions to and from the point of care, or communication barriers created by lack of interpreters, or residual financial barriers due to out of pocket expenses. However, a role played by less

tangible disincentives can also affect a population's access to health care. Non-tangible disincentives can emerge for a variety of reasons, among which are: the sensitivity of Aboriginal people toward their encounter with an overwhelming power-imbalance as they interact with professionals and institutions; anticipated expectation of communication challenges when presenting for care; experiences of receiving care that is not in keeping with a respect for their personal dignity, their values or their needs(10). In addition, we have to consider the lingering affect of past colonization practices that had aimed at enforcing assimilation and which resulted in multigenerational trauma.

We do not have data to show the exact contribution of various factors to these health inequalities. It was suggested that further research is needed "for greater clarity in how we conceptualize barriers, their defining characteristics and their causes"(11). Nevertheless, given this scenario, the unavoidable conclusion is that the disparity between the health status of the Aboriginal and non-Aboriginal population within one state is a social injustice. Consequently, the Aboriginal population is clearly a vulnerable group and as such it deserves the assistance necessary to put in place special measures that will help diminish the burden of disease and reduce preventable early deaths. The role of bioethics is to advocate for serious attention to this matter and make the case that the maintenance of the status quo is not morally defensible. A typical Aboriginal patient is disadvantaged by differences in language, social status, education, knowledge, social support and geography. In such a situation, the barriers to effective care and the moral aspects of patient-professional relationships necessitate careful attention. This will be the subject of the next section of this paper.

### **Values, needs and expectations of Aboriginal Population**

One group of disincentives and non-physical barriers that cause Aboriginal populations to use health care services less than they ought to, and receive less benefit from them when they do receive care, is a cultural gap between the Aboriginal men, women and children in need of care and the largely non-Aboriginal professional care-givers, administrators, public health workers and policy-makers(12). This cultural gap between individuals, in turn, is producing institutional structures and processes which are not meeting the needs of the Aboriginal population. The cultural gap is not bottomless and

it should not be exaggerated. "We are all relatives. If you accept that we are all cut from the same genetic cloth, then all human populations share the same potential, the same raw intellectual genius"(13) and, I may add, the same moral instinct. The Aboriginal population as a minority group shares many basic values with the majority of Canadians steeped in European moral tradition. If you refer to Table #1, you will see compared some traditional First Nations values(14) to some traditional European moral virtues, of which the first five have been called focal virtues for health care professionals(15). This illustrates a remarkable degree of congruence, suggesting that the character traits of a good person, traits that an Aboriginal patient would appreciate to find in an Aboriginal traditional healer, are very much those that the European philosophical tradition considers as important to cultivate in physicians and other health professionals.

However, in the last 100 years, European medical ethics deemphasized moral virtues and instead stressed that one should act according to ethical principles, rules, rights and obligations. This trend continued with the development of contemporary bioethics during the greater part of the last 30 years. There is now a renewed interest among scholars and teachers of bioethics to see virtues as a part of a desirable, comprehensive, moral framework. This trend needs to be encouraged. Teaching and cultivating virtues among health care professionals will help to bridge the gap between Aboriginal and non-Aboriginal populations and caregivers in health care, while at the same time it has the potential to enhance the ethical quality of care for every patient or client, regardless of his or her cultural tradition.

The cultural gap we are speaking about is most apparent if we compare some elements of the worldview of an Aboriginal person immersed in traditional teaching and parallel elements in the worldview which may be commonly found among contemporary non-Aboriginal populations. At the risk of generalizing, I will list in Table 2 some values and attitudes of both population groups which will be reflected in behavior and expectations(16). This difference will have practical implications for clinical practice, whether it is in obstetrics(17) or in end of life care(18). For example, because interdependence, rather than independence, is in the Aboriginal culture understood as a reality and strength, an Aboriginal patient may prefer that decision-making about his/her health care be made by the family, even if he/she is technically capable of making decisions. On the other hand, Aboriginal families may have similar expectations about

receiving medical information and participating in decision-making as non-Aboriginal individuals, who have been brought up with the notion of personal independence and autonomy.

In addition, health, illness and care for the sick have in many Aboriginal cultures a special connection to spirituality. Picture 1 represents what 'health' means in the teaching of First Nations. Spiritual, emotional, mental and physical components of health are each occupying one quadrant of the wheel and are considered to be all equally important(19). One can hazard to guess that if non-Aboriginal persons would be asked to assign a segment to each element of health, the "physical" (including biological) section would likely occupy much more than a quadrant and may compromise greatly the other elements. The importance of spirituality is stressed even in many contemporary official documents. When Nishnawbe-Aski Nation in Ontario formulated their basic health policy, it stated that its goal is "to improve the mental, spiritual, emotional, physical and environmental well being of the membership", placing spiritual well being ahead of the physical one(20).

If these differences are indeed present, does this mean that health care professionals desiring to provide ethically appropriate care need to approach Aboriginal and non-Aboriginal patients quite differently? I will argue that this is neither necessary, nor desirable. There are three reasons for that. Firstly, Aboriginal patients and clients as a group are not homogenous. Some of them, perhaps most, will subscribe fully to the values that are on the left side of Table 2, others will choose some values from both sides, and some will even prefer all values on the right side of the table. Similarly, some non-Aboriginal patients and clients may actually prefer some values and positions which are on the left side of the table that are attributed to the Aboriginal worldview. Canada is a nation comprised of immigrants from many nations and cultures of the world. Canadians, who were brought up in an indigenous culture of Africa or Asia may actually share important understandings and preferences with Canadian Aboriginal people, such as approaching an illness from a spiritual perspective and involving the family(21). In addition, personal traits, life experiences, social and economical position, and spiritual commitments will affect how people govern their life and how they would like to be treated when seeking health care.

Finally, there is a factor of illness. A serious or life threatening illness often leads to re-evaluation and re-assignment of a person's commitment, priorities, understanding of oneself and one's needs. This may be particularly so if the person did not have an inclination, opportunity or need to question the values dominant in the society. The nature of such a shift, as influenced by illness, may be explained by a brief reference to ethical theories. The right side of Table 2 contains several values and positions which are linked to liberal individualism, whereas the left side is compatible with collectivism or communitarianism. A person, whose health is of no concern to him or her, may think and behave in a way that expresses extreme individualism and total independence. But, when an illness deprives the person of physical and emotional strength, the same person may seek shelter in the family or community, accepting restrictions on his/her personal autonomy. Affected by illnesses, an individual may be moved to trust his immediate or extended family to make health care decisions for him, and he may even have to accept a total dependence on others in order to survive. Similarly, a patient interested initially only in the cutting edge, high technology medicine, may find that this medicine utterly failed to rescue her and she may turn to an alternative therapy grounded in tradition rather than science. A wise and ethically competent physician will therefore be aware that both an Aboriginal and non-Aboriginal patient may have similar moral values and human needs and be prepared to meet the patient on his/her cultural, emotional and spiritual turf.

### **Traditional Aboriginal healing practice and practitioners**

The existence of an Aboriginal minority in Canada (as in other countries) cannot be seen only as a challenge and a responsibility. It also can be viewed as an opportunity. The development of an ethical response to the health needs of Aboriginal people will give our health care system a chance to enrich the care provided to everyone, as well as make this care more holistic. This is because the Aboriginal population is the keeper of an ancient tradition of healing and caring that is responsive to genuine human needs and grounded in the knowledge of nature(22). Aboriginal healers and elders are sought by many Aboriginal people in their time of need. Traditional ceremonies and practices, such as sweat lodge, smudging, and herbal remedies are embraced by even those who live outside of reservations and are receiving conventional medical care. This can be seen as a parallel to many non-Aboriginal patients, who seek alternative medicine, with its many

variations. They find that if their illness is prolonged or life threatening, the evidence based, scientifically delivered medical care, however desirable and good, often does not meet all their needs. This will be true even about persons who are not ill but who are very anxious about a possible illness. Often, what they find lacking is the human touch, a caring attitude, compassion, encouragement to engage in self-help and reflection, encouragement to strive for healing of personal relationships and the clarifying of spiritual needs and commitments. University trained physicians and nurses often endeavour to provide these sorely needed elements, but the demands of their technology driven practices and the large number of patients they are expected to see, make this goal difficult to obtain. They have difficulties to combine the curative effort, based on evidence based medicine with support for healing, which is a relationship based medical art(23). A healer or elder in tune with the richness of indigenous culture may be able to provide that missing element of healing and caring.

A contemporary physician, practicing both conventional medicine and traditional indigenous healing methods observed: "In a seeming rush to separate itself from culture and tradition, conventional medicine has eliminated much of the art of healing - those elements of doctoring that may be more important than the specific medicine provided...Many of these arts can only be found now in the practices of the world indigenous cultures. Recovering these lost arts could infuse medicine with renewed vitality and effectiveness"(24). It is true that even in Europe, just a few generations ago, traditional healers without formal medical credentials were greatly relied upon, and European academic medicine, before it was re-casted as a largely practical application of the natural sciences, was esteemed because of its "art of healing". Even contemporary patients, regardless of their culture, are pining for the lost art of healing.

On the other hand, if it becomes a reality, that contemporary health practitioners will share the care of their patients with traditional practitioners, then, conventionally trained health care professionals, besides overcoming prejudices(25), will have to have some concerns addressed. Firstly, they will want to know the ethics of traditional practitioners and especially, whether their art incorporates the commitment to the best interest of patients. Evidence for this cannot be readily provided, given that traditional healing wisdom is a part of the Aboriginal oral cultural tradition, it has not been written down, and has always been transmitted only to selected disciples. It was stated that "(a)lthough

philosophies and practices analogous to bioethics exist in Aboriginal cultures, the terms and categorical distinctions of “ethics” and “bioethics” do not generally exist”(26). Secondly, health care professionals will be concerned about how various healer’s interventions, particularly herbal remedies, can affect the patients, because of possible interactions with diagnostic tests and prescribed drugs. Traditional practitioners, healers and elders will have to decide if it is yet time to share some elements of the indigenous knowledge with conventional institutions in the interest of making traditional care available to more patients.

In my own area of Northwestern Ontario, steps to incorporate traditional healing approaches have already been made. For example, Sioux Lookout First Nations Health Authority incorporated into their Anishnawbe Health Plan of 2006, the goal to involve traditional specialists into the primary health care system. The Sioux Lookout Meno Ya Win Health Centre has appointed an Aboriginal healer to the Board of Directors, one of two “Physician Representatives”(27).

### **Looking ahead.**

All the levels of most educational programs for health professionals already pay some attention to the problem of culture and the special needs of Aboriginal people of the country. At minimum, some of these programs aim to provide certain cultural information in order to avoid blatant social misunderstandings. Considerable attention was recently given to the teaching of cultural competence or cultural safety(28, 29). A more radical approach is to merge the best elements of traditional healing practices, Aboriginal and others, with evidence based scientific medicine, as is being attempted by those who promote narrative medicine(30) and integrative medicine(31, 32). It will be helpful to increase the number of Aboriginal health care professionals, who will be familiar with traditional healing practices, but also trained in science- based medicine (33).

It would seem useful to pursue all of these approaches on a scholarly and research level, to see where they will lead us, and how useful they could become. Individual health care practitioners may decide to become familiar with at least one of those approaches, and cautiously test if they can be used for the benefit of their patients. Biomedical

researchers are predicting the rise of personalized medicine as it becomes possible to apply tests and treatments that are tailored to each person's genetic make-up. If we expand our horizon a bit, we can conceive of personalized medicine in another sense, such as a practice that can be tailored closely to person's psychological, social and spiritual make up, recognizing that while the genetic endowment may be fixed for a lifetime, the elements of what constitute the human spirit are constantly in the state of development and growth.

On a more general level, there are some actions which could be incorporated throughout the health care system, with the aim of providing Aboriginal patients and communities with ethically appropriate care, while at the same time expanding the horizon of health care in general:

1. Recognize that culturally competent care for Aboriginal patients is an ethical concern, and it is important to regularly engage institutional health ethics committees and professional groups in any discussions of health care that involves specific Aboriginal groups in the region that is being serviced.
2. Listen respectfully and record and consider the experiences of Aboriginal patients and their families. We need to hear these stories in order to "allow us to buy into and share our communal imaginative experience"(34). On a practical level, these activities may give us a better idea of how the professional and institutional attitudes and practices may need to be adjusted in order to provide better experiences and better outcomes for Aboriginal patients and clients.
3. Learn from Aboriginal healers, elders, and chiefs who actively care for, or accompany patients and their families, and who are willing to talk about the traditional teachings they have received, and who are prepared to share their personal experiences. These dialogues will require absolutely equal playing fields. The non-Aboriginal party has to accept the internal logic and validity of the traditional approach and appreciate that it is not inferior to the logic and validity of science-driven medicine. These stories and conversations will help to provide a better understanding of the ethos of care found in the Aboriginal tradition, as well as some appreciation of the benefits and burdens that traditional healing practices may carry.

4. Convert what has been learned into imaginative educational programs for health professionals, administrators and support staff of all institutions where Aboriginal people receive health care, in order that Aboriginal values and needs are respected, and that Aboriginal traditional practitioners may be involved in the routine care of those patients who need it or desire it.

The hope that can guide this effort of becoming fully open to the Aboriginal healing culture was best expressed by a Canadian anthropologist, Wade Davis, who states: "If you encounter another people on their terms, open to the reality that their knowledge is as deep as your own, their insights as precise, their hopes and prayers as profound, then magic happens"(35).

## **Conclusion**

There may be those who will say that in order to be socially and economically justified, the attention which the health care system can give to a minority group, like the Aboriginal population, may have to be proportional to the percentage of these people in the population served. There are at least two reasons why this position seems indefensible. Firstly, Aboriginal people represent a vulnerable population, and this recognition creates an ethical obligation to pay special attention to this group. While society at large has to address the determinants of health, it is incumbent on health care institutions and professionals to strive to deliver more fitting health services, overcome the cultural gap, contribute to the improvement of health status, as well as appreciate the subjective experiences of Aboriginal people when they are in need of the health care system. This is a matter of fundamental justice. Secondly, I would suggest that striving for care of the highest achievable ethical standard for the Aboriginal population will have an overall positive effect on health care for all patients and all communities. Our health care will have the potential to become more culturally sensitive to all minorities and to their cultural needs; it can be more holistic, more mindful of human dignity, more realistic about the interdependence and importance of communities and families. It will more successfully meet everyone's essential human needs and become more supportive of human flourishing.

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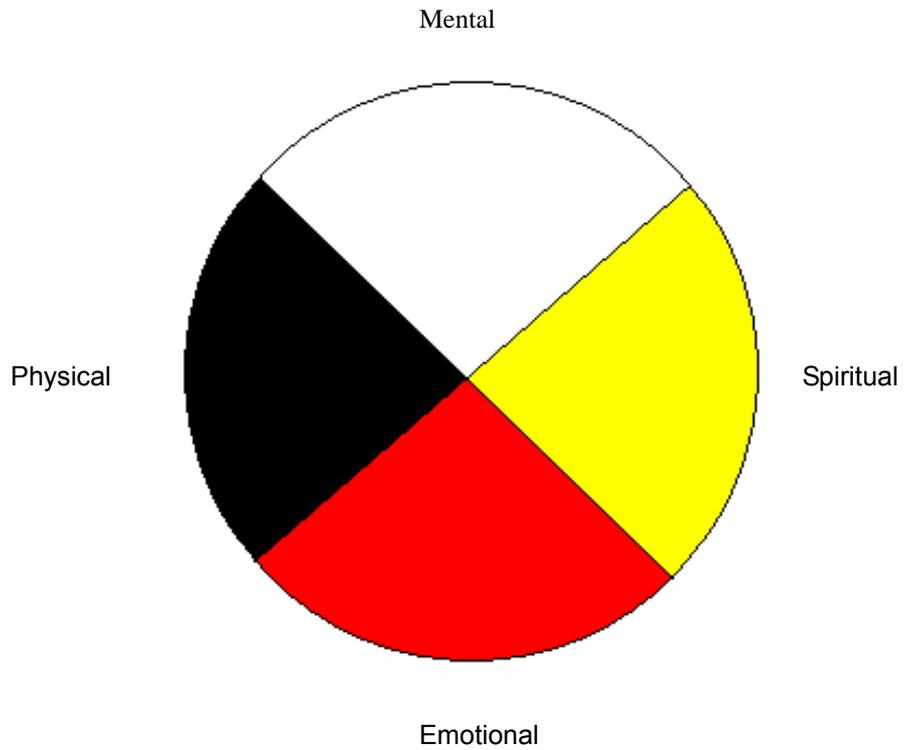
Table 1

The Seven Sacred Teachings in Canadian Aboriginal Tradition	Moral Virtues in European Tradition
Wisdom	Discernment
Love	Compassion
Respect	Respect for privacy and confidentiality
Courage	Integrity
Honesty	Trustworthiness
Humility	Consciousnesses
Truth	Veracity

Table 2

Traditional Aboriginal Values	Common Mainstream Values
Unity of all creation	Individualism is expected and promoted
Interdependence of all	Independence is treasured
Sharing with all	Distribution according to what each one deserves
Non interference	Interventionism, like promotion & persuasion, is accepted and expected
Acceptance of the creator's plan	Fight with disease or fate is admired
Seeking a balance	Celebrating excesses is common
Traditional Medicine is appreciated because it is inherited from ancestors	Medicine at the cutting edge is appreciated because it is "new & improved"
Respect for integrity of human body after death	Human body after death can be taken apart as needed

**Picture 1. Health in First Nations' teachings**



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# 論醫患信託關係與醫學的專業精神

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在5月12日四川汶川抗震救災過程中, 醫務人員所表現出來的大勇無畏, 大愛無私, 讓人們看到了醫生專業精神最光輝燦爛的一面。在廢墟中, 在生命的召喚下, 醫務人員的人道精神與科學精神完美結合, 他們高超的醫術與超越了醫學專業的信念、情操、勇氣和愛心高度契合, 實踐了「健康所系、生命相托」的神聖醫學誓言, 對世界範圍內呼喚「醫學專業精神」回歸做出了最好的詮釋。在危難中, 透過醫生在生死抉擇中義無反顧與患者生死相依, 不惜犧牲自己的生命來實現救死扶傷的專業使命的情景, 最為和諧的醫患關係畫面呈現在世人面前。大災過後, 人們不約而同會更多思考這樣一個問題: 如何將這樣的醫患關係持續下去?

## 醫患關係的本質

醫學存在最根本的理由是一個人人在沮喪和危機中呼籲幫助, 另一個人懷著關切的心情想來幫助他。這種求助的願望和提供幫助的願望促成了最初的醫患關係。直至今日, 醫學的實踐遠不止把醫學科學的知識運用于患者的異常情況。醫學實踐注意中心是病人, 為病人謀福利是它不變的宗旨。治療病人並不是只把病人的痛苦當做我們對抗的敵人而已, 更重要的是在舒解他們的痛苦時, 也能幫病人感受到有人關懷他們, 使他們更能承擔這個痛苦。正如北京協和醫院著名內科專家方圻教授所說, 對病人的同情心和責任感是每一個醫生的靈魂。對患者的同情心源自醫生對人類遭受疾病痛苦的敏感性, 對患者的責任感源自醫學的專業精神。從本質上看, 醫患關係強調醫患雙方都是主體, 都是戰勝疾病和痛苦的主體。在國外醫學院校的課堂上, 學生們常常會聽到老師們這樣的告誡:「對醫患間親密關係重要性的強調永遠不會過分」。

## 醫患關係模型

醫患關係模型是一種概念模型，醫務人員在這個模型下指導和組織自己的醫療實踐。不同的模型反映不同的衛生保健原則和什麼好醫生和好患者的不同評價標準，凝聚著對醫學的看法，對醫務人員的作用以及對醫學倫理學原則的看法。

在已經提出帶來醫患關係模型中，醫學家長主義模型在醫療中有很長的歷史。醫學中的家長主義視醫患關係為家長與子女式的關係。為了子女的利益可不考慮子女的決定或者代子女作決定，由醫生決定患者的醫療問題。家長主義模型的基礎是“有益”的倫理原則。醫患關係的重點在於醫務人員的知識和權威。患者的生命和健康靠醫務人員的醫學知識、技能和良知來保證。家長主義模型的決策過程集中于醫務人員的權力和控制。醫務人員的經驗和價值不受質疑，醫患之間的討論非常有限。決策最終是醫務人員的責任，病人是被動從屬的。

二十世紀中期，我們的社會和醫學都已經改變，醫學家長主義在應用於這個瞬息萬變的時代時不斷受到挑戰。人們認識到，我們生活在多元的價值觀時代，不同的文化、民族、種族、信仰與精神、社會經濟地位以及個人和集體認同的其他方面形成了病人以及醫生在個人層面上的不同的價值觀。價值和優先權的多樣性使得自我決定權幾乎成為社會的一項普遍信念，因此對醫學家長主義的批評也越來越多。認為家長主義破壞了對患者自主權的尊重和對患者的價值觀的考慮，忽視了患者“境遇”在倫理決策中的作用，要麼把患者所有的價值特別是生活價值取向全都包含在醫療價值之內，要麼就是以醫生的價值觀取代了患者的價值觀。結果可能是：治癒了患者，但患者最珍視的價值、生活計畫/生活種類以及與別人的關係等可能都會遭到破壞。(不過需要指出的是，在搶救危重病人的生命時 (life-saving)，醫學家長主義仍然是有效的，有時甚至是唯一有效的模式)

針對家長主義的弊端，人們提出了契約模型。契約模型認為：醫患是平等的合夥人，患者是自主的，能夠對自己的想法和行動做出獨立判斷，並將其付諸實施。契約模型是用契約形式把交易雙方的要求明確起來。醫務人員是具有權威力量的人，這種力量培植了醫療中的家長主義作風。為克服它，要把病人看作一個自主的實體，即，以契約模型來縮小擁有力量的醫務人員與脆弱的病人之間的差距。契約模型強調醫患關係以病人為中心和病人的自

主性。患者的優先考慮和目標是醫療決策時首先要考慮的；患者的經驗和價值是主要的。契約模型承認病人的獨立和控制權，因此有時又被稱為「患者獨立選擇模型」。

不過，契約模型有兩個重大缺陷。第一個缺陷是它忽視了一個事實：需要幫助的、處於擔憂焦慮的病人實際上不可能與擁有知識和技能的醫生處於平等地位，醫患之間確實存在知識擁有上的不平等。這種不平等使得一個病人實際上不可能完全通過協商談判與醫生達成一個契約。患病，疼痛，痛苦，藥物治療和患者的情緒狀態更增加了病人的脆弱性和醫患之間事實上的不平等。這種模型的第二個缺陷是它忽視了「信任」在醫患關係中的作用，縮小了醫患雙方的倫理學要求，只陷於用法律來規定雙方義務，甚至陷入了法律的「條文主義」。單純強調法律的程式，甚至使得程式正義超越了實體正義，而忽視了程式正義恰恰是為了維護實體正義。結果就有可能出現這樣的悖論：為了實現保護患者最佳利益（實質正義）而堅持某種程式（程式正義），其結果恰恰是極大損害了患者的利益。

根據醫患關係的特點：患者處於脆弱和依賴的特殊地位，醫患關係是一種比較親密或親近的關係，患者的求醫行為不言而喻地隱含著對醫生的信任。因此，醫患關係被視為一種「信託關係」——信任和託付。信託關係有兩個基本性質：一個是醫患關係的「行仁性」，行仁性是強調「醫本仁術」；另一個是醫患關係的「契約性」，契約實行強調醫患雙方平等。這裏的契約性是指醫患關係帶有契約的性質，只是類似一種契約關係，醫患關係與一般的契約關係有所不同。醫患關係一般不是從明確地協商訂立某種契約開始，也不是一種在契約生效期間的「短期行為」，而是一種應該努力培養的長期穩定的對患者全面負責的關係。契約是一個法律概念，不是倫理概念，而醫患關係中的契約概念包含深刻的倫理學含義，雙方具有獨立人格，但醫療決策能力有差別；雙方具有不同的價值、信念、利益和目標；雙方關係是自願建立，可隨雙方意願中斷。如果只認識到或只強調其行仁性，而沒有認識到其契約性，可能導致醫療中的家長主義（行仁—醫高於患），如果只認識到或只強調其契約性而沒有認識到行仁性，把會將醫學降低到法律條文主義和其最低綱領。

在信託模型中，醫療決策過程涉及到患者與醫務人員的相互信任。患者出於對醫生的信任而把自己的健康和生命託付給醫生。患者一旦進入醫患關係，便賦予醫生診治他的獨特權力。醫患關係的不對稱性，病人的脆弱、無

權地位決定了醫生對病人的特殊責任和信託義務，照管他的健康、生命。信託模型也強調病人（非醫務人員的）的目標、價值和願望，但醫生是利用自己的知識、經驗和智慧，作為病人的指導者而積極參與並積極主動地指導醫療決策的。信託模型既承認患者的決策能力也承認患者的脆弱性，因此要提高病人的理解力，方法包括醫務人員與患者公開的交換資訊和富有價值的對話，醫務人員個人對病人安康的承諾。這種模型中，病人與醫務人員將共同承擔結局的責任。

倫理學上勝任的醫務人員能夠值得患者信任來採取行動，以促進受託進行醫療的患者的最佳利益，為了維護患者的利益而工作。醫務人員對病人的「他性」（與自己不同的地方）持開放態度，對他所遇到的種種「境遇」具有敏感性，而不僅僅是擁有醫學專業知識。一個智慧的行醫者能夠認識並採用最好的方法來達到某個目的。醫生應該使用他們的權力負責任地關懷他們的患者，對醫療工作中可能面臨著的種種道德的不確定性給予合理的關注。這就是醫生的誠信。美國醫學專家委員會這樣描述醫生的能力：「醫生應該擁有醫學知識、判斷力、專業精神和臨床與交流的技能，為病人提供優質的醫療。對病人的醫療包括促進健康，預防疾病，診斷、治療和處理病情，對病人及其家屬的同情尊重。醫生應該通過畢生的學習和不斷提高的實踐來維持這種能力」。

## 醫學的專業精神

專業（Profession）與職業（Occupation）不同。職業是指作為人們常規謀生手段的一項活動，某種行當。專業（Profession），在詞源學上，來自於拉丁語“Professio”，意思是對公眾承諾的聲明。“Profession”是指一群對公眾所期待的社會責任有公開承諾的執業團體。他們與委託人之間的利益關係被界定為信託關係。傳統意義上，西方社會接納四種職業為專業：醫師、律師、教師、神職人員。通常是要求嚴格訓練和專門學習的職業，如法律、醫學和工程專業。社會學家認為，專業是這樣一種能自我調控的職業，它要求通過系統的、有既定目標或學院式的訓練，使執業者擁有專業技能知識，從而提供有倫理準則約束的、規範的服務，而這種服務遠比利益需求的定位要高。專業具有對內和對外兩種社會學功能：對內，是一種自存自衛的本能—專業共同體通過嚴格的自省自律，採取集體行動來維護專業的壟斷權

(執照行醫)以及在公眾心目中不可替代的地位(公眾的社會期待),諸如設定和強制實施高水準的行業標準、嚴格的專業准入制度等,從而保持專業的誠信;對外,體現服務社會的責任。它要求個體和專業共同體的行為能增加社會福利,推動社會進步,從而強化這種不可替代的社會地位。為什麼專業精神要強調本身對於社會的責任呢?根據社會契約論的觀點,權力和義務是一種類似契約的平衡關係。而專業所以要強調對於社會的責任,是因為在行業領域中,專業擁有排他性的壟斷特權以及由此獲得的社會尊重與信任。專業對社會貢獻的高品質服務也是建立在社會給予的尊重信任和壟斷特權基礎之上的。支撐和引導專業來實現它內在的高品質社會服務功能的是倫理法則。正是基於信託關係的倫理法則內在規定了專業對於社會所肩負的責任。在傳統上,醫學一直高度強調並踐行專業精神:李杲(1180-1251):「汝來學覓錢醫人乎?學傳道醫人乎?»;趙學敏:「醫本期以濟世」;徐大椿:「救人心,做不得謀生計」。「醫學界是一個道德共同體,醫學實踐是一項道德事業,而專業精神則是一種道德承諾。從希波克拉底誓言以來,醫師專業精神一直是醫學專業的核心內涵。」(Frederic W. Hafferty)

今天,世界各國醫療衛生都出現不同程度的危機,在解決醫療衛生福利制度中的問題時,都嘗試運用市場機制。但市場機制運用不適當,過度的商業化,使醫生越來越淡化對病人在道德上的同情心和對社會的責任,出現不同程度的醫學專業精神的缺失。

「商業」本身是一個中性術語。個人經濟獲益並不一定與服務于病人的宗旨不相容,但經濟上的野心決不能壓倒醫學專業的倫理。在美國文化中,醫學一直是商業活動(除了僧侶行醫時),因此永遠產生道德問題。今天的醫學一頭紮入商業之中,醫學的本身的道德高度一落千丈。美國的麻煩是雙重的:「其一,醫療衛生制度是有缺陷的,被投資者擁有的企業和市場競爭所統治,創造了一個新的商業化環境。這種制度與社會和個人醫療需要,與醫學專業精神不相容。其二,新一代的醫生很容易接受市場價值,以代替專業的價值,他們太願意相信醫療只不過是另一種經濟商品,他們只不過是商品「供應者」。這種醫療是令人無法承受地昂貴,不公平,對社會的需要無動於衷」。美國學者 Jerome Kassirer 在他的「重商主義與醫學綜述」(377-386)中指出,「金錢的吸引力是一個腐敗者,它將我們從對病人福利的關注引開。當醫療商業製造或惡化醫生的利益衝突時,醫療商業化就成為一個問題。歷史表明,醫生的企業家主義(entrepreneurialism)是醫生利益衝突的主要來源。

商業化的醫療消除了醫療中的關鍵成分：有益（beneficence），這就失去了醫患信任的基礎。商業化保留了醫學的客觀要素，但這像是感恩節的火雞，失去了心臟。」雖然在理論上商業化和競爭可能會節省一些費用，但是它對醫療衛生不起作用。而且不可能因此使醫療衛生就更加負擔得起的，不可能使基本醫療衛生更加普遍可及，品質更好。

中國大陸的醫學也面臨著專業精神嚴重流失的挑戰。前衛生部副部長張之強在《我的一生》（2006年版）這樣描述醫院承包制：「此口一開，如大河決堤，承包、創收之風大興。醫院承包，科室承包，為了賺錢，花樣翻新。救死扶傷，發揚革命人道主義精神，全心全意為傷病員服務等準則被逐漸置諸腦後，而代之以‘想方設法賺錢’。藥商趁機打入醫院，影響著藥房和醫生；醫生治病，做手術，收取紅包；給病人開大處方、多項檢查；急病一時交不夠押金不收住院，以致延誤治療。凡此種種，名目繁多，最終都是一個字：錢。」（302頁）

在權力和商業資本達成妥協後，對醫學專業施壓，迫使傳統的醫學專業精神和價值觀受到了市場化壓力的重大影響。政府財政投入不足大大加重了導致醫學實踐過程的過度商業化傾向，腐蝕了醫學的專業精神。醫患之間本質存在的信託關係被扭曲變形，嚴重的甚至淪為赤裸裸的商業關係。醫學只能在專業知識與技能領域保持著權威。醫患之間的互相不信任，醫療糾紛猛增。醫生本應該對合理分配資源負有專業責任，醫生在滿足病人診治疾病需要時，應該是基於明智的、成本效益的考慮來提供治療，避免過多的、不必要的檢查、藥物治療和手術。因為提供不必要的服務不僅使病人遭受本可避免的傷害，加重他們的負擔，而且浪費了本可以提供給其他病人的資源。但是，或出於醫學防禦目的，或由於商業化的驅動，醫生開出過多的不必要的醫療檢查，不僅加重醫療費用，而且造成醫療資源的浪費，藥品和醫療設備製造商對期望投資有合理回報的股東負有最終的信託責任，但如果通過與醫生或醫院建立不正當親密關係增加費用和加重病人負擔，不僅影響了醫學專業判斷和醫療行為的獨立性與無偏倚性，使利益衝突成為一個問題，破壞了醫學科學的誠信，惡化了醫患關係，導致醫患關係緊張到劍拔弩張的程度，也破壞了企業的誠信。醫學作為商業還是專業的界線越是模糊，追求利潤最大化傾向越是影響醫療決策，越有可能的就是：費用的考慮將不正當地影響醫療決策。

自 2000 年以來，美國以專業精神來對抗腐敗力量。按照醫學的專業精神，醫生的責任是將病人的最佳利益置於首位：(1) 經濟考慮永遠不應該影響醫生的決策，不管是在臨床實踐還是在研究之中(2) 醫療資訊必須擺脫經濟糾纏引起的偏見(3) 專業必須負責避免高額醫療費用(4) 如果經濟紐帶繼續存在，那麼一切醫療方案都應該透明，必須努力保護有傷害風險的病人。

2002 年歐洲內科聯合會、美國內科協會、美國內科醫師協會、美國內科理事會等共同發起和倡議的「醫師憲章：新千年的醫師專業精神」首次發表於《美國內科學年刊》和《柳葉刀》雜誌。目前為止，包括中國在內的 37 個國家和地區的 120 個國際醫學組織簽署了該憲章。醫學雖然植根于不同的文化和民族傳統之中，但醫生治病救人的任務是共同的，這就是憲章的共同基礎。

醫學專業精神要求將病人利益置於醫生個人利益之上，為此需要制訂培養能力和維護誠信的標準。2002 年醫師專業宣言中提出三項基本原則和十項專業責任。三項基本原則包括：病人利益放在首位；病人自主性；社會公正。十項承諾包括提高業務能力的承諾；對病人誠實的承諾；為病人保密的承諾；與病人保持適當關係的承諾；提高醫療品質的承諾；改善醫療可及的承諾；有限資源公正分配的承諾；對科學知識的承諾；在處理利益衝突時要維護信任的承諾；專業責任的承諾。

將病人利益放在首位的原則：是建立在為患者利益服務的基礎上。信任是醫患關係的核心，而利他主義是這種信任的基礎。市場力量、社會壓力以及管理的迫切需要都絕不能影響這一原則。

病人自主性原則要求醫師必須尊重病人的自主權。醫師必須誠實地對待病人並使病人在瞭解病情的基礎上有權對將要接受的治療做出決定。只要這些決定和倫理規範相符合，並且性質樣的要求不會導致不恰當的治療，那麼患者的這種決定就極為重要。在病人同意治療和在治療後醫生必須確保病人完全和真正地知情。這並不是要病人在細節上參與醫療決策，共同做出決定，而是對醫生的治療建議做出決定。

全國乃至在全世界，人們對四川汶川抗震救災中醫務人員所表現出來的那種醫學專業中最深刻的理性的光輝，最深刻的對人類痛苦的敏感性（同情

心) 深深地震撼和感動。在災難中，醫生無需在利益衝突和市場力量的困境中做出艱難的抉擇，道德考慮而不是財政考慮成為醫療優先選擇的主要基礎。在這樣的醫療環境中，患者信任醫生，把生命全部託付了醫生；醫生無愧地踐行了醫學專業精神和價值。人們在驚歎醫學專業精神和價值觀迅速回歸的同時，也不斷思考和期待著：紅旗到底能打多久？

重建醫患之間被破壞的信託關係不僅僅在於醫師、醫學專業內部的努力，也需要和患者與整個社會各個力量一起的努力；政府的財政支持與律法的權力支持對於專業壟斷地位也是必須的；必須在體制、資源分配上有所改變。在商業環境中堅持醫學的專業精神是不容易的，過度追求商業化，醫學不僅會出軌，而且會犯方向性錯誤。放鬆金錢霸權，堅持醫生的專業精神和角色，重建醫患信託關係，要求進行深刻的改革，包括重新確定醫療工作和醫療機構的目的和方向。

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## Book Review 書評

### 赤子心、關懷情：理想的國度-吳德朗醫師回憶錄

黃耀德 行政院衛生署胸腔病院 放射線診斷科醫事放射師

#### 摘要

一個來自彰化十三甲的農家子弟，靠著優異的天份和不懈的努力，在醫學教育開創一片天，不但成就為享譽國際的心臟醫學權威，並投身國內醫療研究，鍵利長庚醫院、醫學院的制度規模，推動台灣整個醫療系統走向現代化；更以無比愛心和熱誠，造福無數病患，實踐台塑企業精髓「勤勞樸實」的理念，他就是一吳德朗醫師。他畢業於台大醫科，赴美國芝加哥寇克郡醫院及伊理諾大學醫院完成實習醫師、內科住院醫師及心臟專科醫師訓練，獲有美國心臟學院及美國心臟學會院士，曾任美國伊理諾大學心臟內科副教授及南加州大學心臟內科教授，為國際有名之心臟學者，更在台塑企業王永慶董事長之邀約下，創立長庚紀念醫院，並先後籌設長庚醫學院、負責督導長庚醫療體系各醫院、長庚大學及長庚技術學院。

此書以充滿感性的筆調，縝密的敘事方式，細數求學過程中所有的人事物經歷，乃至留學研究、回國籌備長庚醫院等的點滴往事，包含講述現今各大教學醫院的興建改革、學士後醫學系的先例與停招，與社會現實層面等多種因素作通盤性的敘述；其間有動人的親情之愛、溫馨的師生之情，和對家庭、對人群的關懷之心，在詳細記錄長庚醫院及其醫學院創建歷程中，同時勾勒出台灣早期的社會環境今非昔比，急具歷史價值意義。本書分為三卷，依次敘述作者吳德朗成長、求學、留學、返國等歷程；卷一「求學」敘述其早年的求學過程，及青年時代赴美留學的經歷；卷二「歸鄉」是吳德朗應企業家王永慶先生的邀請，回國參與籌備長庚醫院的過程，對早期創建經過有鉅細靡遺的記載；卷三「回顧」則是記述作者對家庭、朋友的關懷之情及接任主委、指揮抗 SARS 的經過，作者對國內醫學養成教育、領導治學理念侃侃而談，是一本具有人文勵志、歷史意義的人物傳記。

## Book Review 書評

### 赤子心、關懷情：理想的國度-吳德朗醫師回憶錄

行政院衛生署胸腔病院 放射線診斷科醫事放射師

「醫學教育是培養以『人』為本的醫師，而不是製造『會看病的機器』」這是《理想的國度—吳德朗醫師回憶錄》一書中曾經說過的一句話，卻道盡了部份看診民眾的心聲。在台灣的醫療體制下，醫師一直被看作是崇高且極具社會地位的象徵，富有專業權威、尊嚴，亦屬具有優渥待遇的一群高知識份子，使得不少莘莘學子放棄築夢的理想，或順著家人與社會的期盼，選擇進入醫學院，但畢業後又有多少人擁有悲天憫人的胸懷和懸壺濟世的情操呢？

醫學系必修科目如生命意義學和醫學倫理學，不外乎在龐大繁重的課業壓力下，更要學會體驗病人心中的感受；「病人」，是器官出了問題的個體，「疾病」，則是生理出了問題的器官，診治病人的時候，不僅要重視生理出了問題的器官，也應注意到週遭環境及社會家人，對於這個生病的個體所產生的反應，這就是以人為本的醫學。醫師對生命的起承轉合，有歷經世事而成的價值觀，更要隨時做好明辨是非的能力；邱小妹事件中的林致男、劉奇樺兩位醫師因為沒有在值班時親自診視病患情況，便驟下判斷，甚至想掩蓋事實而聯合竄改文書規避責任，引起各界撻伐。成功大學醫學院創院院長黃崑巖教授也抨擊醫學教育缺乏全人教育，認為「醫生未必要有一流腦袋，但須知道社會脈動與疾苦所在」。人非聖賢，孰能無過，但可貴就在認錯的勇氣而不是欲蓋彌彰，這也點出了醫師對病人的生死存亡之際，有如判官改寫生死簿的權利，因此重視醫德倫理，不唯利是圖正考驗著脆弱的人性。在情、理、法之間如何做出最合理的行動，畢竟對患者或家屬而言，醫者父母心，是他們解決疾病的唯一希望。

人文醫學領域中像是生死學、醫病溝通、醫事法規、醫學與媒體都是用討論或是團體的方式授課，培養我們慎思明辨與組織的能力，透過人與人之間的交談與互動，可以清楚表達自己的意見，以及如何從對方身上獲得想要的消息；所以在言行舉止中，往往有些心理學和哲學可以解釋的部份。例如看診時可利用西方學者雅伯特·馬伯藍比(Albert Mebrabian)教授研究出的「7/38/55」定律：透過7%的談話內容、38%的輔助表達、55%的外在情況有助於了解病人的實際病因；相同的病人對醫師也適用此法。若能使用較少的專業術語、採用溫和聊天式的口語表達和解釋，其專業的素養更能受到病患的尊敬。

太宗謂梁公曰：「以銅為鏡，可以正衣冠；以古為鏡，可以知興替；以人為鏡，可以明得失。」跟到不同處事態度的指導老師或學長學姐，對日後價值觀影響甚鉅，尤其在懵懂剛踏入社會的時候。前陣子有醫師對女性患者做內診時，在沒有護理師陪同及患者的同意下，擅自讓實習醫師跟診，這便嚴重違反了病患隱私權，在醫學倫理上更站不住腳；看診時把女病患當作活教材外還揶揄嘲諷她，更是人權侵害，類似新聞在現實生活中不斷上演，提醒我們在醫療專業自認為理所當然的執業時，要用漸進的方式讓患者願意接受或相信我們的專業判斷。想起我在台大醫院腫瘤醫學部實習的時候，學姐對子宮內膜癌患者實行近接後荷治療時，或對乳癌患者進行放射治療時，也會事先告知病患徵求同意後，才會讓我們進入治療室實際講解一以人為本，視病猶親，這對於病人本身的心理準備和我們操作訓練上，似乎較為恰當。

說到實習期間，是我開始正視醫學倫理的時候，在實行檢查的時候必須有義務告知可能發生的情況或副作用；治療的程序需要配合的地方，哪怕是病人已經呈現瀰留狀態或意識不清。回想一件刻骨銘心的經歷，是在心導管室一個急診腦中風的病人送來，經過半個多小時的搶救後，逐漸恢復意識會要求喝水甚至抱怨連連。令我驚奇的是王大夫在治療好每個病人的時候，都會很亢奮的說：阿北～恭喜喔～攞唔通！然後滿心雀躍的接下一台檢查，有時後病人還不知道他在高興什麼，因此這樣的工作環境氣氛非常好，也可以看出學長對人本關懷的重視。在腫瘤醫學部常見癌症末期患者，多次化療和放療下已面黃肌瘦不成人型，鼻咽癌更是說話氣聲、溝通困難，口腔癌也有切除一整塊臉部肌肉不斷滲口水，但在醫護人員和家屬的關懷下仍勇敢的面對，最年輕的看過19歲的子宮頸癌女性患者，使我對目前生活的現況更知足惜福。

在《理想的國度》一書中，作者引用西方哲學家蘇格拉底（Socrates）的名言：「我什麼都不懂，只懂得什麼地方不懂」。吳醫師有大量閱讀的習慣，毅力更不輸任何人，在固有的知識和臨床的學習上皆有著墨；他對仁義禮智信相當重視，幫學生寫的推薦信函最常出現的字眼是「誠實、可靠、勤奮」，並點出台灣人不守時的陋習。時間就是生命，一個人會不會成功，主要看他會不會利用時間，如果你不能守時，你大概也不會時間規劃。此書作者看五六年級的見習醫師常缺席自行讀書，就拿駕車作比喻，認為就算多唸幾本書，依舊無法開好車，強調凡事在須盡責任時要扮演好你的角色。醫學是研究生老病死的學問，作者畫分了四個層次，最高層次是在疾病發生前將它杜絕，像是牛痘、小兒麻痺、瘧疾等疫苗的問世，根除了這些病原進而達到了預防醫學的目的；第二層次是疾病發生之餘，可以在最短的時間內醫治好，像是盤尼西林的發明醫治好了肺炎；第三層則是無法醫治的疾病，想辦法控制它，防止後遺症及副作用的發生，像是糖尿病、高血壓、愛滋病等；最後一層是在有必要的情況下，有效切除病灶以確保性命的安全，很多外科的療法多屬於這個層次。吳醫師也希望學生多參加課外活動，不要讓課業佔去全部時間，也可選修一些音樂概論、音樂欣賞、藝術概論、哲學概論等作為調劑身心的科目，因此在藝能、體育方面都常看到醫學系的學生獨佔鰲頭。

此書道盡吳德朗醫師求學和經營醫院的曲折過程，可見作者的崇高理想，經營之神王永慶慧眼識英雄重用他，自回國後積極招攬人才，從創辦長庚醫學院到長庚大學，大刀闊斧投入相當的人力物資，使得長庚醫學院可以在短期之內與台大醫學院、陽明醫學院分庭抗禮，學術地位，蜚聲國際。近年規劃出的桃園養生文化村及護理之家，亦提供了退休人士的養老園地，給予就近的醫療關懷與最適當的健康照護，在滿足社會需求與人性需要上，長庚醫療體系不遺餘力的徹底落實取之社會，用之社會的精神。至於後醫系是希望能夠篩選出有廣博通識教育、人格成熟健全、有志從事醫療工作的學生，然而台灣的專家制度有悖於創辦者原意的通識教育，加上有些學生具有社會經驗和年齡稍長，以功利主義導向的學生為數不少，有違後醫的宗旨並和一般醫科生大相逕庭的思維，因此後醫系各校陸續停招，目前只剩高醫大還有招生。

在經歷 SARS 風波之後，吳醫師很快的點出七大弊端，矯正長庚醫療體系的缺失：

- 一、醫院企業化、商業化追求業績與利潤的成果，降低了醫療水準損及病患權益，因此前衛生署長陳健仁 and 前台大醫院院長李源德醫師也特別強調醫院不能以營利為目的。
- 二、醫院教育太過職業化與專科化，忽略了全科的教育與文化涵養，人可是有七情六慾與思想的有機體而不只是生病的機器。
- 三、由於業績所造成的按件計酬效應，一味的追求數量往往犧牲了醫療品質。
- 四、大醫院拼業績，所以造成民眾無論大小病，都往大醫院掛號看診的惡習，也是 SARS 流行期時大醫院成為感染源的其中主因；現今的健保制度則強調資源分散和轉診制度，使得資源平均分配紓解了此一情況。
- 五、醫學中心企業化，為了控制成本流行外包作業，招標的不外乎伙食、看護、清潔、廢棄物處理等，容易造成醫療動線失控的防疫死角，之前新竹馬偕醫院病患資料外流疑似此原因。
- 六、急功近利風氣盛行，腐壞了住院醫師的培訓制度；依規定資淺住院醫師仍在受訓期間，不能單獨為病患進行插管。
- 七、由於競爭激烈及商業化的結果，常以利潤為導向，只重視治療而忽視預防，在 SARS 期間一度潰不成軍，此後醫療體系設計可考慮以公共衛生預防醫學為主體，針對各點吳醫師一一解釋來龍去脈及用國外的情況做舉例，說明現況的優缺點，並在各方面的考量尋求一個平衡點。

物理學家居里夫人 (Marie Curie) 曾說：「觀察自己的手骨，彷彿目睹自己的死亡。」X 光的發現至今也不過百餘年，算是一門相當新穎的科學，在醫學科技日新月異及通訊傳輸普及的時代，各項先進醫療器材，在謀求人類的福祉下逐一製造出來，舉凡 CT、MRI、PET 等在影像診斷上不停改良，隨時更新自己的學習思維，還不能忘記行醫的初衷才是難能可貴的。永遠對新事物抱持好奇和學習的心態，才不至於被後生晚輩迎頭趕上。在飽讀詩書、學富五車的努力下，能在醫學資訊中持續對醫學充滿興趣，方能滿腔熱誠面對自己和病患。當然在醫學的世界裡很多事情沒有絕對的，像醫事法規中談論到的「是否贊成安樂死？」、「優生是否該合法化？」等等還是有爭議的問題時，讓我們有重新思考：該不該決定另一人的生死或命運的權利？這類問

題並沒有正確答案，也會依地理國情和民族習性而有所變異，但卻暗示了人們想掌控生殺大權扮演造物主的角色。曾記得有部電影【絕地再生】敘述了一個極端，將複製人統一管理於某一個地方，當本人需要做移植或換內臟時，便處決複製人以代替本人，這看似血腥且不可思議的，但未來卻有可能就在人性的慾望下誕生；其他還有【魔鬼複製人】、【人工智慧】等都是過於依賴科技而泯滅了人性案例，當我們過度依賴生物科技或醫學工程的改良，而不能做到珍惜生命或把由血肉組成的人善加看待時，那是多麼悲哀的事啊？談諾貝爾醫學獎的課程中，老師們也不斷灌輸我們功成名就的人，本身所懷有的優良特質，有無私的奉獻精神、有無盡的付出努力，他們得獎是應該的。泰戈爾說：人生是不斷的奮鬥。得獎只是證明他們所作所為受到肯定，建立新的里程碑，他們並沒有因此停頓，畢竟像他們一樣努力的人也大有人在，不過絕大多數卻不為人知，只是默默的付出。世界還需要大家去關懷服務的，相信這也是從事醫療業者的目標和動力。

走筆至此，發現在我修過的五門醫學人文領域中，醫病溝通也好，兩性醫學也罷，說穿了不過是人與人之間對等的尊重，以誠相待，其中也有相當濃厚的哲學意味，這讓我在實習時一直抱持相當樂觀和認真的態度，最後，套一句任職機構胸腔病院的核心價值：胸懷服務，腔繫創新，病友為尊，院際合作，與醫療界的人員共勉之，也希望將來時常保有赤子心、關懷情。

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- <sup>6</sup> I have argued that this is the wrong way to frame the question, because it begs the question by presupposing that the involvement of the ethics consultant potentially overrides patient autonomy. See, Agich, George J. "Why Should Anyone Listen to Ethics Consultants?" In H. Tristram Engelhardt, Jr., ed. *The Philosophy of Medicine*. Dordrecht, Holland and Boston: Kluwer Academic Publishers, 2000, pp. 117-137.
- <sup>7</sup> American Society for Bioethics and Humanities. *Core competencies for healthcare ethics consultation*. Report of the American Society for Bioethics and Humanities 1998;1-48.
- <sup>8</sup> A paper by Stella Reiter-Theil ["Dealing with the Normative Dimension in Clinical Ethics Consultation." *Cambridge Quarterly of Healthcare Ethics* 2009, in press] is helpful in understanding this point. She argues that the normative element in ethics consultation has been misunderstood. She offers view of normativity as a pervasive dimension of ethics consultation and shows how the normative element in ethics consultation is actually quite complex. Rather than entering "all at once," she shows that the normative element functions in a graded fashion according to a hierarchical typology and argues that escalation up the scale of normative of the towards the authoritative imposition of outcome is actually quite rare.
- <sup>9</sup> Walker, Margaret Urban, "Keeping Moral Space Open: New Images of Ethics Consulting." *Hastings Center Report* 1993;23(2):33-40.
- <sup>10</sup> American Society for Bioethics and Humanities. *Core competencies for healthcare ethics consultation*. The Report of the American Society for Bioethics and Humanities 1998;1-48. Paradoxically, this characterization has itself come under criticism by those

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who insist that a stronger decision-making or advice-giving model of ethics consultation better captures the exercise of ethical expertise that the well-trained—read in here your favorite discipline—consultant brings. Ironically, such claims seem intended to elevate one discipline over another in what is essentially a multidisciplinary field. In my judgment, they do not offer much evidence about what ethics consultation actually involves and, correlatively, what skills and knowledge well-trained ethics consultant should possess. Instead, they seem to support what critics see both as unjustified claims to professional power and status, which creates the potential for abuse. This paradoxical situation is a bit beyond the scope for my exploration in this paper, even if it is not beyond explanation. I leave it to sociologists and social psychologists to attempt to explain what drives the continued promotion of professional status by some individuals and disciplines. The relevant point for this paper is that the controversy does raise an important question about the underlying assumptions about the nature of clinical ethics and the activities that legitimately comprise ethics consultation.

<sup>11</sup> Agich George J. The question of method in ethics consultation. *American Journal of Bioethics* 2001;1(4):31-41.

<sup>12</sup> Some thinkers have advocated casuistry as a remedy to this approach that is often associated with a theoretical or principle oriented approach. Surprising to some, casuistry, at least in its most common forms, does not usually address the ongoing or concrete circumstances of a case. It takes the case as presented or given considers the case over and against other paradigm cases and renders a judgment regarding the ethical probity or appropriateness of a course of action based on the consideration of this case, against others. The case, as I have argued elsewhere, is treated primarily as a given and the casuist is typically not an agent involved practically in the case as such, but rather functions as an adviser or coach outside the field of action or play. To use developed the sports metaphor, one could say that the function that I am trying to describe would be satisfied by one who not only in gauges in the game on the field, but does so as a coach, and, at the same time, is a commentator and analyst addressing the play-by-play and action as it proceeds. This analogy helps us to realize the difficult and complex nature of the phenomena that I am describing.

<sup>13</sup> Agich George J. "Authority in ethics consultation." *J Law Med Ethics* 1995;23(3):273-283; Casarett DJ, Daskal F, Lantos J. The authority of the clinical ethicist.

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