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Loma Linda University Center for Christian Bioethics

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Update

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Editorial

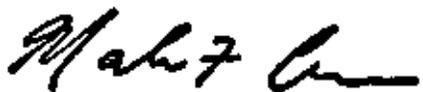
Mark F. Carr, PhD, MDiv

Director, Center for Christian Bioethics

The graduation ceremonies for the class of 2003 here at the Loma Linda University Graduate School were phenomenal. With a great deal of pride, I read out the names of the largest graduating class of students in biomedical and clinical ethics that we have ever seen. We count it a great privilege to be involved in the education of these fine people. You'll find a brief bio and picture of each 2003 graduate in this edition of UPDATE. And although students who finish with the certificate in biomedical and clinical ethics do not join us in the graduation ceremonies, we are nonetheless equally proud of them. Molly Gallagher and Rachel Mason deserve high praise for their efforts.

Our feature article this issue comes from the pen of one of the finest gentlemen in the business of the academic study of ethics and bioethics. Dr. Cromwell Crawford teaches at the University of Hawaii and has been a long time supporter of our Center. At our request Dr. Crawford presented a lecture for us at our Bioethics Grand Rounds on February 12, 2003 at LLUMC. Additionally, Dr. Crawford conversed with a number of us here at the Center over dinner. His knowledge of Seventh-day Adventist theology and experience we found to be extensive and quite engaging.

Ryan Gaines, the author of the article on the new HIPAA legislation, is one of our students in the combined degree program with medicine. Ryan has taken a year out of the routine progression of medical school courses to join us in the study of ethics. His work has been exemplary and we are delighted to run this article on the ethical issues associated with the HIPAA legislation.



Hindu Perspectives on Genetic Enhancements in Humans

S. Cromwell Crawford, MAT, ThD

Chair, department of religion

University of Hawaii

The current discussion of genetic enhancement in humans is rooted mainly, on the religious side, in the Judeo/Christian tradition, and on the secular side, in the Hippocratic medical tradition, along with other philosophical systems of the Anglo-American West. Yet there are other religious and philosophical alternatives, some with advanced systems; and the present impasse in the debate suggests that we bring these non-Western sources into the conversation, especially in view of the general acknowledgment that our ideas of key concepts, such as “nature” are largely culturally constructed.

It is my belief that the Hindu tradition can make a contribution to the difficult task of wrestling with issues pertaining to altering nature. In philosophical terms, its diverse schools of thought, such as Samkhya, Yoga, Nyaya, Vaisesika, and Vedanta, are admirably suited to the demands of our pluralistic age. In ethical terms, the contextual structure of the Hindu approach gives it flexibility and adaptability, and invests it with the type of dilemmatic thinking that is required by contemporary bioethics in a world of rapid technological change. In medical terms, while Hinduism shares

positive attitudes toward medicine and the healing arts with most other faith traditions, it has evolved its own system of medicine called Ayurveda, or the science of living to a ripe age, which is based on medical manuals that comment directly on health issues.

Hindu bioethics flow from three basic principles of Hindu philosophy and religion: 1) the transcendent character of human life, expressed through the principles of the sanctity and quality of life; 2) the duty to preserve and guard individual and communal health; and 3) the duty to rectify imbalances in the processes of nature that jeopardize the life and well-being of humans and all sentient beings. Equipped with these and additional principles, we will attempt to apply them consistently, comprehensively, and systematically to issues of genetic enhancement in humans.

Before going to the practical level of moral actions, let us look at a brief sketch of the Hindu understanding of persons, and the world from which these ethical principles are derived.

THE PERSON

The Hindu philosophy of human nature is dualistic. It precisely demarcates the essential self from the empirical self.

The empirical self

Our immediate, daily experience is of the empirical self. It constitutes our world of sense experience. Hindu psychology probes into the nature of the empirical self which the noumenal self takes on during its bondage in the phenomenal world. It makes a rigorous analysis of the body-mind complex and describes the person's role in the world in terms of three bodies—physical, subtle, and causal.

First there is the physical body, born of parents. It is fabricated of the five elements of earth, water, fire, wind, and ether. It is sustained by food in the form of environmental matter. It is the locus

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FAX: (909) 558-0336

Phone: (909) 558-4956

e-mail: hmorrison@ethicscenter.llu.edu

Website: bioethics.llu.edu

Letters to the editor and comments may be sent to:
CP 11121S, Loma Linda, California 92350

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of all the experiences that arise from our contact with the external world, and serves as the basis of consciousness in wakeful states. Death is only of the physical body, which then returns to its elemental source.

Second there is the subtle body, so called because it is composed of seventeen elements that are finer than those of the physical body. The subtle body is a composite of the vital, psychic, and intellectual functions. It serves as the basis of dream consciousness. The presence of the noumenal self is inferred from it. Most importantly, the subtle body acts as the instrument for the operation of the law of karma whereby moral consequences are passed on in the process of transmigration. Death is only the termination of the physical body; not of individuality. The just desserts of an individual's life proceed from one birth to the next through the continuity of the subtle body. It is the bearer of direct and indirect consequences; the first determining the body-type, family and hereditary conditions one will have in rebirth, and the other productive of innate tendencies that influence behavior in the next life.

The third body of the empirical self is known as the causal body. Its reality is deduced in the state of deep sleep during which time both the physical and subtle bodies are in suspension.

Actions of the empirical self are by agency of the body, mind, and speech. Actions issue in moral consequences. Actions are classified in terms of inertia, passion, and goodness, representing three basic properties of the empirical self. Actions characterized by inertia are biological, and therefore uncontrollable and unfree. Actions of the mode of passion are propelled by strong emotions of love or hate and are therefore also unfree, even though persons know these actions to be their own. Only actions having the property of goodness are voluntary and characterized by detachment. Depending on the degree of detachment, actions of goodness can be expressed in the form of socio-moral behavior, or, at a higher level, as spiritual activity.

The above remarks introduce the notion of karma. It stands for the universal law of causation as applied to the rational and moral aspects of human existence. It states that

good and bad actions bear within themselves their own consequences. By linking present with past, the law of karma attempts to explicate the mysteries behind individual inequalities, and the problem of suffering.

Traditionally, two types of karma have been distinguished (*anarabdha-karma* and *prarabdha-karma*). The first type refers to karma that has not begun to bear fruit; and the second refers to karma that has already come to fruition. The latent karma of the first type (*anarabdha*) could either refer to our accumulated karma from past lives (*sancita*), or the karma generated in the present (*virtamana-karma*). The tradition also states that only interested activity arising from selfish motives produces karma. Disinterested actions performed in the present (*virtamana-karma*) not only are free of binding consequences but can help to dissipate the karma of

our past and present life which has not yet begun to bear fruit. Only the results of the karma (*prarabdha*) that has begun to exfoliate cannot be avoided, and must be endured until fully depleted.

The medical manuals of Ayurveda dismiss any vestige of fatalism that might be attached to the notion of karma. According to Caraka, a first century physician, only the consequences of extreme evil cannot be arrested by good deeds. Philosopher Dasgupta explains:

The fruits of all ordinary actions can be arrested by normal physical ways of well-balanced conduct, the administration of proper medicines and the like. This implies that our ordinary non-moral actions in the proper care of health, taking proper tonics, medicines, and the like, can modify or arrest the ordinary course of the fruition of our karma. Thus, according to the effects of my ordinary karma I may have fallen ill; but, if I take due care I may avoid such effects and may still be in good health. According to other theories the law of karma is immutable. Only the fruits of unripe karma can be destroyed by true knowledge. The fruit of ripe karma have to be experienced in any case, even if true knowledge is attained. The peculiar features of Caraka's theory consist in this that he does not introduce this immutability of ripe karmas. The effects of all karmas, excepting those which are extremely strong, can be modified an apparently non-moral

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“Death is only the termination of the physical body; not of individuality. The just desserts of an individual's life proceed from one birth to the next through the continuity of the subtle body.”

course of conduct, involving the observance of the ordinary daily duties of life.

The theory of rebirth is deduced from the law of karma. Since the universe is morally structured insofar as good and evil acts are not without appropriate consequences, it must be assumed that an action without consequence is still in the process of maturation, and that eventually in some future life what has been sown will be reaped. Whereas other religions teach "it is appointed unto man once to die and after that the judgment" (Hebrews 9:27), Hinduism believes that the immortal spirit of humans reincarnates itself in a better or worse life form, according to the claims of one's psychological aspirations, and the necessity of moral rewards and punishments for one's actions. For Hindus this reconciles the demand for justice in the face of the disparities into which persons are born. The fact is that something cannot come out of nothing, and something cannot become nothing; hence a person must be said to maintain his individual identity before he is born and after he dies. The individual moves from one life to the next until the psychological forces which perpetuate his quest for private existence are dissolved, and he gains enlightenment (*moksha*), and is thence freed from the cycle of suffering and rebirth.

The Essential Self

Enlightenment is basically the act of becoming aware of one's real self (*atman*) as being radically different from the empirical self, ignorance of which keeps individuals in bondage. Salvation is not the acquisition of something new, but becoming wise to what is already there. The characteristics of the essential self are clearly stated. It transcends the body-mind complex and is thereby free from all the limitations, changes, and experiences to which the body and mind are subjected. It is eternal and immutable existence (*sat*), pure consciousness (*chit*), and pure bliss (*ananda*). As such, the essential self in the person (*atman*) is none other than Cosmic Reality (Brahman). Humans are one of the many forms in which the Supreme Reality (existence-consciousness-bliss) manifests itself in the universe. The Upanishads state: "The essential self or the vital essence in man is the same as that in an ant, the same as that in a gnat, the same as that in an elephant, the same as that in these three worlds, indeed the same as that in the whole universe." Thus the Hindu outlook on the cosmos leaves no room for anthropocentrism. Humans do not stand apart from the universe, nor are they allotted any place of privilege in it. This brings us to Hindu views of the world.

Hindu speculative wisdom has entertained diverse theories about the nature of the world, its origin, maintenance, and destruction. The world system is called Brahmananda or "the egg of Brahma." Brahma is a personification of divine creative energy from which the universe evolves, comprising seven regions, including the earth and solar system. Beyond the world humans occupy, there are infinite world systems which rise and fall across endless tracts of time, but all evolve in the same way. Through picturesque analogies, the scriptures describe the evolution, sustenance, and dissolution of the world. "Just as the spider weaves its web from within itself and draws it in, the herbs spring from the earth, and hair grows out of a man's body, so does the world come out of the immutable God." More philosophically, God is conceived as the origin and end of the universe. His lower nature is differentiated into eight forms: earth, water, fire, etc., and his higher nature is manifested as the world of individual selves.

In Samkhya theory, during the course of evolution there emerges from inert matter certain subtle materials (*tanmatras*), which, although imperceptible, have definite characteristics. They are the generic essences of physical energy represented by sound, touch, colour, taste, and smell. When these subtle essences begin to compound, gross matter manifests itself in variegated forms. The production of the five gross physical elements takes place in the following manner. First, the sound energy produces the Space element (*akasa*), which has sound quality perceived by the ear. Second, the energy of Touch, combined with the movement of Space, produces Air (*vayu*), which has the qualities of sound and touch. Third, the energy of Colour, combining with the energies of Sound and Touch, produce Fire (*agni*), which has the qualities of sound, touch, and colour. Fourth, the energy of Taste, in combination of the essences of sound, touch, and colour, produces Water (*jala*), which has the qualities of sound, touch, colour, and taste. Fifth, the energy of Smell, combining with all of the above essences, produces Earth (*prithvi*), which incorporates the qualities of sound, touch, colour, taste, and smell. The subsequent evolution of the world, including the human constitution, is from these five elementary principles of Space, Air, Fire, Water, and Earth. Needless to say, one should not attribute commonplace meanings to these elemental substances.

The five elements enter the body through food and become reconstituted in the physiology and anatomy of the individual. As with the rest of nature, the human body is in a continuous state of transformation. Death is the final act by which the organism is returned to its original state.

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The ethical significance of the Samkhya theory is that the universe and the human body form a river of life that has its source in creation. We are not strangers in a universe that is alien, or, at best neutral to human projects; rather nature is the very womb from whence we have come. This understanding of the place of humans in nature has important implications for how we relate to our bodies, to proper food and drugs, to animal life, and to sun and soil. The bottom line is: the universe, and all of us in it, is of five basic elements (*pancamahabhutika*).

It follows from the above that Hindus believe there is a moral structure to the universe, because of divine immanence. The world is not the evolution of some unconscious material force, but one that is permeated by moral values that flow from the sakti or power of God. In its ancient form this notion is expressed in the concept of Ritam, which refers to order in the universe, to which the gods themselves are subject.

However, as in the later idea of Dharma, divine law, truth, and so on, are dynamically understood and seen as subject to changes.

The philosophical assumptions pertaining to the person and the world underlie Hindu conceptions of medicine and morals and serve to create a symbiosis between the two. Structurally, there are no conceptual conflicts between medicine and morals. Following is a summary of some salient features of the Indian medical system of Ayurveda. Its concepts of health are especially important for our discussion, because it is in the definition of health that we get to know what it means to go beyond health to enhancement. Ethically, it functions as a line of demarcation between needs and wants.

Ayurveda is rational in its approach to medicine. In place of the supernatural therapy (*daiva-vyapasraya*) of the Vedic phase, it introduced rational therapy (*yukti-vyapasraya*) to make the system logical and scientific.

Ayurveda is holistic. It views the person as an integrated whole and not just as an aggregate of several body parts that are the domain of specialists.

Ayurveda sees the person as grounded in nature: a microcosm within the macrocosm. Diet, climate, soil, season, time and place are all factors with which to reckon. Health and

healing are regarded as acts of nature. In medical-ethical terms: the natural is the good.

Health is identified as a positive state, not just the absence of disease. Health is multidimensional: physical, mental, social, and spiritual.

Ayurveda apprehends the person as an individual, having a unique constitutional type, and as the bearer of an unmatched set of life experiences.

Ayurveda gives prominence to the notion of balance. It promotes an ethic of moderation in matters of sex and abstinence, food and drink, work and play, sleeping and waking, faith and common sense.

Medicine is essentially preventive and promotive, elevating caring above curing.

Longevity is measured not in number of days, but quality of time.

*“Health and disease,
happiness and suffering,
life and death, are the
consequences of an
individual’s karma,
hence the emphasis on
human responsibility.”*

Death is an inevitable part of the natural process, and is therefore not an evil or the object of divine punishment. Death is the opposite of birth; not of life.

Health and disease, happiness and suffering, life and death, are the consequences of an individual’s karma, hence the emphasis on human responsibility.

Health is more than what the doctor does; it is a total life-style that carries one from the cradle to the grave.

Health is not the ultimate good but the penultimate good.

Enlightenment is the summum bonum, because spirituality exceeds vitality on the scale of being human.

**APPLICATION OF PHILOSOPHICAL AND MEDICAL
THEORY TO ISSUES OF GENETIC ENHANCEMENT**

Hindu bioethics distinguishes between somatic cell gene therapy and enhancement genetic engineering.

In terms of somatic cell gene therapy, many diseases, such as ADA deficiency, sickle cell anemia, hemophilia, and Gaucher disease, are caused by a defect in a single gene. In all such cases, Hindu bioethics supports treatment on the grounds of its principle of beneficence (*daya*). The patients are desperately ill, or they are facing the attack of a monstrous illness, so everything must be done to relieve suffering. Gene therapy is their only hope. To be sure, there are risks involved. Cutting edge medical research is always risky; but relative to severe privations and certain

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death, the risks and uncertainties of gene therapy are at acceptable levels.

The salient Hindu values in support of this therapy relate to the familial principle of obligation (*rina*) to ensure survival of present and future generations. Hindu bioethics has no special problem with death; only with premature death. Therefore victims of cancer, viral diseases such as AIDS, and some forms of cardiovascular disease, are all considered appropriate candidates for treatment.

Somatic cell gene therapy also has the potential for enhancement genetic engineering—for supplying a specific characteristic that individuals might want for themselves (somatic cell engineering) or for their children (germline engineering) which would not involve the treatment of a disease. The slide from correction to perfection is already underway. The human-growth hormone was devised to help children with prospects of dwarfism reach a more normal size; but it was soon used by children who only thought they were “dwarfs” for their age, and were blessed with wealthy parents who could pay \$30,000 for a year’s treatment of growth hormones.

Hindu bioethics believes there is a medical and moral divide, which must not be crossed, between somatic cell gene therapy and enhancement genetic engineering. This serves as a marker for how far genetic engineering should go at this stage of development.

Discussion of the pros and cons of this stance was recently precipitated by a report in the journal *Nature*, of a study which sheds light on how memory works, and raises questions pertaining to the morality of using genetics to make people brainier. Summarily stated, scientists established a theory about how brain synapses make connections and store knowledge; but the research also anticipated the day when genetic adjustment of memory and intelligence will be possible for humans.

That day may not be so far away. Today doctors can screen fetuses for genetic diseases; tomorrow they will be able to correct the problem in utero. But a boundary is crossed when doctors move from treatment to enhancement.

So far as therapeutic possibilities are concerned, the evolutionary orientation of Hindu bioethics puts it on the side of scientific progress. We should hope that this research may lead to practical medical results for humans, targeting learning and memory disorders among older people, including Alzheimer’s disease. However, there is a difference between using such treatment to reverse an elderly person’s Alzheimer’s disease and helping a college student get an ‘A’ on an examination. It is one thing for a lad to want to be on

par with his classmates to compete in high school basketball, it is another thing for a boy to receive human-growth hormones because the latest teenage fad is “I want to be like Mike!” The difference is between values and vanity. This divide between correcting and perfecting gives rise to many ethical quandaries, which Hindu bioethics confronts.

First, a fact that must be reckoned with is that self-improvement is as much of an American religion as being Baptist. Hindu bioethics has no problem with that, as long as one has a clear notion of the nature of the self that is to be improved. Arguing from one view of the self, a person can legitimately say, “There is absolutely no difference between getting one’s child into the best school and getting one’s child a perfect gene. What is the big fuss?”

Erik Parens of the Hastings Center thinks that there is a difference, which is the difference “between cultivating and purchasing capacities.” Buying a Harvard education could very well enhance a child’s natural gifts, but it is different from buying the capacities. The Bhagavad-Gita said the same a long time ago: “Let a man lift himself by himself; let him not degrade himself; for the Self alone is the friend of the self [person] and Self is the enemy of the self.”

The meaning of the Gita for us is that divinity in all its riches resides within the ordinary self, and that it can work for us (friend) or against us (enemy), depending on how much it is part of our consciousness. There is no stasis in nature. Personal transformation is a function of the inner life—seeing with the “third eye” is not an acquisition of reconstructive laser surgery. To uplift oneself an individual must therefore engage creative forces that are within, and not simply rely on appendages that can be purchased at a price. In brief: self-improvement is improvement of the self.

Second, on medical grounds, Hindu ethics proceeds on the principle: “Do no harm” (*ahimsa*). Somatic cell enhancement engineering threatens human values because our limited knowledge makes it risky business at this juncture. Pioneer geneticist French Anderson cautions that though we have a rough idea of how simple genes work, and know that there are thousands of housekeeping genes that do the job of running cells; yet our understanding is limited when it comes to how an organ develops into its particular size and shape. Similarly, we know how the nervous system works in terms of electric circuits, memory storage, and transmission of signals; yet we are far removed from understanding thought and consciousness, to say nothing of the “spiritual side of our existence.”

Though we have few clues as to how a thinking, loving, interacting organism can be derived from its molecules, the day is coming when we will be able to change some of those

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molecules. This prospect has Anderson worried. There are probably genes that influence the brain's organization, structure, metabolism and circuitry, making possible a human's capacity to think abstractly, morally and existentially. Mathematics, ideas of good and evil, anticipation of death and visions of 'God' are all involved. But "what if in our innocent attempts to improve our genetic makeup we alter one or more of those genes? Could we test for the alteration? Certainly not at present. If we caused a problem that would affect the individual or their offspring, could we repair the damage? Certainly not at present. Every parent who has several children knows that some babies accept and give more affection than others, in the same environment. Do genes control this? What if these genes were accidentally altered? How would we even know if such a gene were altered?"

Third, Hindu bioethics responds to enhancement engineering with reference to its principle of consequentialism. It is axiomatic to the Indian mind that everything has its own store of karma which eventually plays itself out. Enhancement research, as just mentioned, is not at the point that we know all outcomes—Frankenstein movies always warn the jittery audience—"These experiments may not go as originally planned." It would not be a scare tactic to say that parents on behalf of their children would be making decisions over which they had no control and whose long-term effects would be uncertain or even dangerous. Who can predict all side effects? What if a child engineered to become intellectually sharp would actually turn out to be morally mean? What happens when the 'Supermice' get old? Scientists already fear that altered mice might be more prone to strokes, chronic pain, and premature death. There are other possible complications which indicate we must reckon with the karmic function of nature.

Fourth, Hindu bioethics appeals to the principle of justice, based on our common spiritual heritage and the connectivity of existence. All life comes from one source called Parameswara. The Bhagavad-Gita says: "When one sees Me everywhere and everything in Me, I am never lost to him and he is never lost to Me." This thought invests each individual with equality, and raises questions of social fairness. Do we wish to usher in a society where the rich get smarter? Who will have a right to access the technology once it becomes financially out of reach for the common person? Every parent would want his or her child to be intellectually enhanced, but only a minority would be able to afford it. Would this not create a new "caste system" in which the wealthy Brahmins of society would constitute a new intellectual aristocracy who would look down upon children whose brains were not enhanced?

Fifth, even if the fairness question were resolved, is enhancing our abilities medically sound? The Ayurvedic view that health must be understood in terms of the principle of balance, suggests that changes brought about by genetic engineering in one area could adversely affect balance in other areas. UCLA neurobiologist Alcino Silva argues, "everything comes at a price. Very often when there's a genetic change where we improve something, something else gets hit by it, so it's never a clean thing." With more alarm, Jeremy Rifkin asks: "How do you know you're not going to create a mental monster? We may be on the road to programming our own extinction."

Sixth, the pluralistic approach of Hindu ethics values diversity, and finds richness in individuality, devised by the evolutionary wisdom of Mother Nature who does not put all of her eggs in one basket. Therefore the prospect of a homogenized society, shaped by certain dominant traits and values, is a little frightening.

Seventh, Hindu bioethics adopts an inclusive approach toward humans and other forms of beings; unlike the Western approach which limits genetic engineering to human considerations and concerns. Harold Coward states:

Proponents of genetic engineering often look at the process of animal engineering and its results strictly from the human perspective—from the benefits that will accrue to humans. For example, genetically engineered 'super pigs and chickens' may increase the amount of food for human consumption. But what about the effect upon the animals themselves. Or consider medical research. Animals are genetically engineered to model some of the most devastating diseases that afflict humans. To accomplish this goal, however, requires that large numbers of animals live lives of intense pain and suffering. The ethics of inflicting such suffering upon animals so as to potentially benefit humans has received little attention.

Hindu bioethics addresses the genetic engineering of animals from the perspective of unity, interconnectedness, and interdependence.

The principle of unity is formed on the basis of the notion that the Supreme Being cosmically manifests itself in evolutionary terms. All levels of existence are manifestations of a single Reality. It is the same evolving Spirit that ascends from the level of consciousness in the animal kingdom to the level of intelligence in the kingdom of humans. Therefore, while there is a distinction between humans and animals, there is no separation. Humans are intrinsically related to animals, as parts of nature, and hence there can be no basis for pretensions of dominance. Philosophically the unitive worldview of Hindu ethics avoids the dichotomy between

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humans and animals present in Western religious, philosophic, and scientific thinking, and the exploitation it justifies.

The principle of oneness sets the stage for viewing animal and human processes in terms of the principle of interconnectedness. Animals and humans belong to one web of life. Being connected, all forms of life impact one another, hence the importance of acknowledging the consequences of human actions on animal life forms.

Since life is one, and all of its myriad parts are interconnected, it follows that the model of our relationships with animals must rest on principles of interdependence and reciprocity. For example, pharmacists have used the venom of the Brazilian pit viper to develop Capoten for high blood pressure, among hundreds of other remedies. Caraka lists animals and birds as important medical resources. The place given to the cow in Indian culture is the best-known example of interdependence. Gandhi held to the view that “Cow protection is the gift of Hinduism to the world. It is a distinctive contribution to the world’s religious ideas.” Gandhi scholar Seshagiri Rao, explains that for Gandhi, “cow” meant the entire subhuman world, and stands for the protection of the weak and helpless. The principle of “cow protection” says to humans: Because you are smarter and stronger, you are doubly obligated to do good by creatures that are less endowed. Thus, for Hindu bioethics, privilege entails responsibility. Moral stakes are all the more enhanced when responsibility is reinforced by reciprocity.

In conclusion, the evolutionary orientation of Hindu bioethics does not permit it to make a blanket condemnation of genetic enhancement as intrinsically evil, on the grounds that it “meddles with nature” or “plays God,” and therefore must be banned forever. Instead, it counsels that we start with the person, holistically understood, which then necessitates an evaluation of all means of genetics enhancement by the moral yardstick of whether they do indeed contribute to

the betterment of ourselves and our children, or whether they have karmic consequences that are hidden from our present view. Given the present limitations of our knowledge in the field, Hindu ethics goes beyond current debates about what is “normal” and “abnormal,” or the fine distinctions between “therapy” and “enhancement” and gets to the bottom line dictated by the universal principle of ahimsa—do no harm. In a situation where life is threatened by disease, the risk of harm may justify the treatment, but in a scenario where the end of gene therapy is not the treatment of a serious disease, but solely for the purpose of enhancement that is nonessential, the therapy is not supported by ahimsa, because risks loom larger than benefits. Further, given the Hindu understanding of health as the condition of spiritual well-being, all efforts at genetic enhancement of human beings must ultimately help, and not hinder, the process whereby the human spirit may flourish. Thus the concept of health helps distinguish between needs and wants. The betterment of humanity is not in question; only the means which must be consistent with the end of human wholeness. How we ought to proceed to address this general goal is not revealed to us by some deity who has dictated the details of what we are supposed to do. Therefore we must use our own intelligence to apply spiritual wisdom to the special circumstances in which we and those who we serve find ourselves. The essence of that wisdom is best captured in these words of Gandhi: “As human beings, our greatness lies not so much in being able to remake the world as in being able to remake ourselves.” ■



S. Cromwell Crawford, MAT, ThD, serves as chair of the department of religion, University of Hawaii, Honolulu. In addition to English, Dr. Crawford is fluent in Latin, Greek, French, and Hindi. In 1978, Dr. Crawford received a citation from the U.S. Senate for his conference “Islam and its impact on today’s world” held during the Iran hostage crisis.

HIPAA: Privacy and Public Good

*Ryan Gaines, MA, MD candidate
Loma Linda University*

Our interconnected and information driven world has made the Health Information Portability and Accountability Act (HIPAA) a necessary first step in addressing increased concerns about health information privacy. These concerns stem from the growing number of individuals who require access to sensitive patient information in the modern hospital, and the increasing number of non-hospital organizations that would like to put patient information to use. George Annas observed that some people consider individual control of personal information in the computer age to be an illusion and privacy to be a dead concept, but the HIPAA regulations do not take this view. They are based on the premise that the public cares about privacy, especially the privacy of medical records. Therefore, “the rule provides the first systematic nationwide privacy protection for health information.”

In addition to protecting privacy, HIPAA changes the way public endeavors such as medical research proceed and how public benefits are derived from them. HIPAA has made the regulatory scheme more complicated and increased the amount of oversight for all types of medical research that involve patient data. These changes are direct results of efforts to protect the privacy of patient medical information. The debates sparked by these changes mark the beginning of what will likely be an ongoing process of reflection and refinement of our considered judgements about the appropriate tradeoffs between personal information privacy and the social benefits derived from information sharing and clinical research.

One author views the regulations in terms of “protection” for sensitive personal information.³ Another thinks they are more concerned with ensuring “access” for agencies and bureaucracies to patient records.¹ At odds is a robust sense of the right to privacy, the right to control access to information about oneself, and the tangible social benefits acquired through information sharing in the public sector. In short HIPAA tries to balance these competing interests. If HIPAA does not prove to be the final word on this subject, it may, at least serve as the basis for future negotiations.¹

What is the ethical foundation of an individual’s right to privacy? What is the ethical basis for being concerned about public benefits and the common good? In the remainder of this paper I will attempt to answer these questions and show how the HIPAA regulations take reasonable steps to build on these foundations and balance these two important concerns.

The concept of privacy indicates a condition where the access others have to an individual is limited. Privacy concerns not only the amount of access to an individual, but additionally entails the kind of access, who has access, through what means, and to what aspect of the person.⁴ Private life exists within a delimited zone to which others may or may not be admitted. Related, but different is the right to privacy that concerns a person’s right to control access to the private realm of self.⁴ According to Beauchamp and Childress, the justification for a right to privacy resides, in the principle of respect for autonomy. This principle involves recognizing the capacity and the right of persons to make autonomous choices. Persons choose autonomously when they are free from constraining influences. Thus, each person requires a region of sovereignty surrounding the self within which free choice can occur.⁴ Each person controls this zone of privacy, and access to it. “When individual’s voluntarily grant others some form of access to themselves, their act is an exercise of the right to privacy, not a waiver of that right.”⁴ When physicians, for example, are granted access to personal information and a person’s own body for the purpose of diagnosis and treatment that person is exercising “the right to privacy by reducing privacy in order to achieve other goals.”⁴

When a person discloses private information to a physician as an exercise of one’s privacy right a corresponding duty of confidentiality is created on the physician’s part. Confidentiality “prevents redisclosure of information that was originally disclosed within a confidential relationship.”⁴ This traditional understanding has governed patient-physician relationships since the formulation of the Hippocratic oath. However, Mark Siegler has called medical confidentiality a “decrepit concept.” He shows that the traditional understanding of confidentiality between a patient and a physician is—in the modern hospital—“compromised systematically in the course of routine medical care.”⁵ There are so many different physicians that may be involved in one patient’s care—not to mention nurses, medical students, and those responsible for billing—that a patient’s medical record cannot be kept confidential in the traditional sense. This presents a problem for the protection of sensitive patient information.

The problem is fundamentally ethical. The current institutional situation threatens the relationship of trust that patients have with their physicians and undermines patient privacy and respect for autonomy. These principles are basic for healthcare and can-

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not be abandoned even in a new institutional environment. Trust is still essential to foster open communication between patients and doctors, but it seems unlikely that it can be based on an understanding of confidentiality from the past. Privacy and respect for autonomy, however, are readily applicable to the modern environment. Respect for autonomy serves as the foundation for an individual's right to control access to private information and constitutes privacy as such. Though the number of persons requiring access to patient information in the modern hospital has increased there still exists this ethical basis from which patients can seek to control access to themselves and their information. It is no surprise then that the Privacy Rule in the HIPAA regulations utilizes the language of privacy and privacy rights that have their basis in the principle of respect for autonomy.

In addition to privacy there is a strong interest in public welfare. The ethical foundation of this concern for public good can be located in the concept of general beneficence. Distinct from specific beneficence that is concerned with identified persons such as friends or patients, general beneficence "is directed beyond these special relationships to all persons."⁴ The thesis is that there is an obligation to produce good consequences or provide benefit for the whole society. A concern for the common good can also be located in the principle of utility. It suggests that we should bring into existence the greatest possible benefit for the most people. Neither general beneficence nor the principle of utility should be regarded as unqualified obligations however.⁴ Realization of the common good is limited and does not necessarily override the rights and interests of individuals. Nevertheless it is a moral end for which society can work.

The HIPAA Privacy Rule explicitly advances protections for the individual interest in privacy and control of access to personal information, but these guidelines have clear implications for public interest in the knowledge gained through research, security and law enforcement, and public health. The HIPAA Privacy Rule, therefore, has also taken steps to accommodate these important public interests.

One area where public and private interests needed to be balanced concerned the level of access to medical records that should be provided to law enforcement officials. The Secretary of Health and Human Services for the Clinton Administration advocated that no new burdens should be imposed on law enforcement by the privacy regulations. In fact, she seemed to favor essentially unhindered access for law enforcement officials. This position met considerable resistance. But how has the final rule handled the public interest in security? The regulations permit a covered entity to disclose health information without an individual's autho-

rization for judicial or administrative proceedings based on a court order, subpoena, or other legal process provided assurances are given about notifying the individual. Limited information may also be disclosed to law enforcement officials for law enforcement purposes under six specified conditions.⁷ Among these conditions are requests made in order to locate a suspect, fugitive, or missing person, when protected health information may be evidence of a crime, and when a patient is or is suspected to be the victim of a crime.⁷ Most significant for privacy protection is that the regulations permit covered entities to disclose protected health information to law enforcement officials in response to simple administrative requests in addition to those required by law such as court orders, subpoenas, and warrants.⁷ In cases of administrative request it appears that no legal process, warrant, court order or judicial review of any kind is necessary.³

These specified conditions indicate how the Privacy Rule has tried to provide protection for health information and accommodate the common interest in safety. It is widely accepted that a physician may sometimes override a patient's right to confidentiality when a serious threat to a third party exists.⁴ The Privacy Rule seems to build on this principle and extend permission to override an individual's right to control access to their health information to covered entities when the general public faces a threat. Writing prior the final promulgation of HIPAA, Amitai Etzioni, understood that disclosures of health information to law enforcement officials would continue to be necessary even with increased privacy protection, but argued that the justifications and means for doing so already existed in the American legal tradition. There are two examples that illustrate the point. The first is an instance where it appears a crime has been committed. Current practice would allow medical records to be searched if a reasonable case withstands judicial scrutiny. "There seems to be no reason that medical records, correctly considered more intimate [than, say, corporate financial records] and hence having a higher claim for privacy, should be accessed more easily. If there is a legitimate need, a warrant can be obtained."⁶ The second case arises when police are in "hot pursuit" of a suspect who may have been treated in an emergency room. The law allows police to search records immediately and justify it after the fact.⁶ The law already covers these exceptional cases, and the Privacy Rule incorporates this fact into the specified conditions under which protected health information may be disclosed to law enforcement officials. Therefore, increased privacy protection does not hinder public safety.

However, the Privacy Rule may permit covered entities to give greater access than before by permitting disclosures in

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response to administrative requests. It is not clear that, apart from judicial review, this kind of disclosure can be justified. Additionally, such “disclosure of sensitive health information to law enforcement officials may weaken public trust in the healthcare system.”³ The infringement of patient privacy made possible by this provision of the Privacy Rule may not be sufficiently balanced by gains in public safety. Reasonable means already exist to grant law enforcement officials access to information in appropriate circumstances.

It should be noted, however, that while HIPAA permits disclosure in response to an administrative request it is not required. Thus, a great deal of discretion is left in the hands of health care professionals and other covered entities. Even if requests for disclosure are made by law enforcement and “other entities” authorized under the HIPAA regulations to make such requests [they] need not be acceded to by clinicians without patient consent, unless required by some other law.⁸ Specifically, physicians should release medical information only when a court issues a warrant. In this new regulatory environment the commitment of physicians to the principle of medical privacy remains one of the most important protections that can be offered to patients.⁸

The social benefits acquired through the work of public health agencies and disease registries were also considered in the formulation of the HIPAA regulations. Prior to the promulgation of the final rule there was much discussion about whether increased privacy protection would decrease the flow of information to public health agencies. It was argued that increased protection could seriously retard the progress of these agencies and the social benefits they produce. Others suggested that reasonable measures for privacy protection would ensure the integrity and reliability of health information.²

Furthermore, privacy protection would engender public trust and prevent “privacy-protective” behaviors such as “doctor-hopping” that individuals might adopt in order to avoid entrusting all of one’s information to a single provider.¹³ Such behavior would compromise the reliability and integrity of information used for public health purposes and diminishes expected benefits. Therefore, privacy should not be a barrier to improving the public’s health, but a “first principle” of ensuring quality care, for both individuals and communities.¹³

The HIPAA regulations have accommodated society’s public health interests by permitting covered entities to disclose patient information to a number of public health authorities without patient authorization or permission. These include agencies that receive information for the prevention of disease and those concerned with child abuse and neglect.⁷ Covered entities are also permitted to disclose protected health information to the FDA and its regulated entities, and employers for the purpose of OSHA compliance, although in this case the person must be notified.^{3,7} These accommodations are aimed at securing the social benefits public health activities generate. In terms of privacy protection, however, significant gaps remain for information collected by government agencies for public health purposes. The reason is that “public health is quintessentially a state function, [and] federal privacy rules defer to state public health law under principles of federalism.”¹⁴ The Privacy

Rule, therefore, does not offer the same protection for information used and disclosed by public health agencies as it does for other public activities. This is not an oversight on the part of the Department of Health and Human Services.

On the contrary, it has funded a project at Georgetown University Law Center to draft and promote a model law that would provide adequate privacy protection at the state level for information used by public health agencies should states

choose to adopt it.¹⁴ In this case the states are made responsible to protect individual’s privacy and ability to control access to personal health information. The end result is that public health activities will move forward, but that the security of health information disclosed to these agencies is still somewhat uncertain. The ethical principle of respect for the autonomy would seem to require that states close this gap in privacy protection as the statutory situation in each requires.

The most contentious debate engendered by HIPAA has concerned the access medical researchers will have to patient information. Prior to HIPAA only federally funded research was regulated. The Common Rule provided regulatory guidance, but did not provide substantive privacy protections. The Common Rule made “adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data” a criterion for IRB approval. It also stipulated that “the

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“The most contentious debate engendered by HIPAA has concerned the access medical researchers will have to patient information.”

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extent, if any, to which confidentiality of records identifying the subject will be maintained" be disclosed to subjects as part of proper informed consent.¹⁵

These sentences are the full extent of guidance provided by the Common Rule for the protection of health information. There is no guidance about how patient information should be protected, kept confidential, and ultimately destroyed. Furthermore, though a researcher may make the information she recorded anonymous when reporting her results the patient's privacy is never protected from the researcher or research team itself under the Common Rule. Therefore, these provisions did not amount to substantive privacy standards.³ By contrast, the HIPAA regulations take steps to close these "gaps in privacy protection for records-based research."³ First, HIPAA applies, irrespective of funding source, to all medical research.¹ Second, under these regulations a covered entity may not disclose identifiable information except for treatment, payment, or health-care operations purposes without specific, written authorization from the patient. This means release of identifiable patient information to researchers now requires authorization.² This requirement is intended to provide substantive privacy protection by securing the patient's control of access to her information and diminishing the number of persons that can access such information without specific authorization. As compared to the Common Rule researcher's access to patient information is more limited.

However, the Privacy Rule also recognizes the social benefits of research and tries to provide reasonable means by which researchers may continue to access medical records. One of these is for researchers to obtain a waiver of the authorization requirement from an IRB or privacy board that has reviewed the research proposal and determined that it meets several criteria set forth in the regulations.³ Among these criteria is that it can be shown the research could not practically be conducted without a waiver. Additionally, IRB review and authorization can be avoided altogether if the records are de-identified by removing eighteen specific patient identifiers.¹

There have been many strong objections to the new regulatory scheme. The most common objection was that the new regulations would unnecessarily complicate the administrative process required to begin and maintain a research project.^{10, 11, 12} Though increased administrative burdens do impose a greater cost on research endeavors this does not in itself override patient's rights. On the other hand, because of the great social benefits of such research the Privacy Rule makes concessions for "activities preparatory to research." Covered entities may disclose protected health information

to researchers without authorization, waivers, or other formal review provided that information is used solely for preparation of a research protocol, information does not leave the covered entity, and the protected information is necessary for the research.¹⁶ Additionally, when a researcher is a member of the covered entities' workforce protected health information may be used to contact persons for the purpose of gaining their authorization.¹⁶ These kinds of provisions show how HIPAA tries to provide substantial privacy protection without overburdening research endeavors that may have significant public benefits.

The HIPAA regulations try to balance privacy and the social benefits of public activities like medical research. One may or may not approve the particular means by which that balance has been struck, but what is clear is that at the center of the problem are the ethical considerations of respect for autonomy and the common good. As we struggle to understand and implement the new privacy regulations we are wrestling with these principles. Privacy is important, but it is traded at some level for the goods attained through social cooperation and information sharing. Ascertaining the true cost of this tradeoff and how best to put it into practical effect is as important as it is difficult. ■

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Ryan Gaines is a fourth year medical student at Loma Linda University's School of Medicine. He is also an alumnus of the Witherspoon Fellowship.

2003 Graduates

Beryl Bull, MA, MD (right, picture to right), lives in Loma Linda. and faithfully attends the monthly Grand Rounds hosted by the Center. Dr. Bull graduated from Loma Linda University School of Medicine in 1994, and works full-time for the Jerry L. Pettis Memorial VA Medical Center in Loma Linda as a staff physician in PM&R. Her paper was on the method of casuistry in clinical ethics. Dr. Bull's interest in clinical ethics will no doubt prompt her continued involvement here at the Center for Christian Bioethics. We welcome her involvement.



Joffre "Lincoln" Castillo, MA (left, picture to left), lives in Los Angeles. Mr. Castillo graduated from California State University with a BS in health science. He currently works full-time as a radiation technologist and was doing so while in our program. While taking one class per quarter, Lincoln commuted between Los Angeles and Loma Linda for a span of five years. Courage and stamina have marked the excellence with which Lincoln has accomplished his graduate program. Lincoln enjoys being the First United Methodist Church organist each Sunday and holds a weekly Bible study.



2003 Graduates, continued...

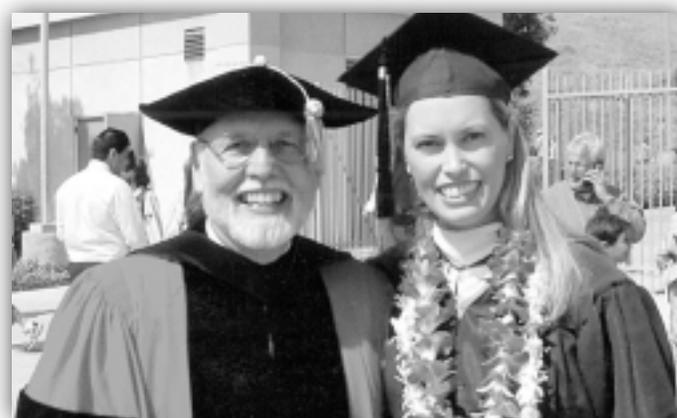
Sharon Fraser, MS, MA (left, picture to right), currently lives in Loma Linda and is also a citizen of New Zealand. Sharon graduated from Loma Linda University with an master's degree in speech/language pathology in 1991. She currently works as a speech pathologist for LLUMC's department of speech/language pathology. Sharon completed the second part of her clinical practicum with Helen Sharp at the University of Iowa. Sharon was co-author of a joint article with James W. Walters, PhD, professor of Christian ethics, Faculty of Religion, titled "Death—whose decision? Euthanasia and the terminally ill." It was published in the *Journal of Medical Ethics* in 2000. We anticipate Sharon's continued involvement with ethics education here at Loma Linda University.



John Hanson, MA (right, picture to left), currently lives in Loma Linda. He attended California State University–San Bernardino concurrently to obtain a master of science in health services administration. John contributed a great deal of time and effort at the Center while he studied at Loma Linda University. He is also responsible for creating one of our favorite social events here at the Center. Our spring graduation social will remind us of John for a great many years. His paper was titled "No more John Moores: The need for genetic patenting legislation."



Tricia Williams, MA, DDS (right, picture to right), lives in Laguna Niguel, California. She graduated from Loma Linda University School of Dentistry in 1997, and practices in Laguna Niguel. Tricia presented her paper at the 2001 Contributor's Convocation, titled "Paternalism and autonomy in dentistry." Tricia's determination to finish her MA was extraordinary. She kept after her goal of the full MA, despite challenges that most students face after classes and before comprehensive exams. We expect to hear more from Tricia in her professional life.



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Wednesday, November 12, 2003
Wednesday, December 3, 2003
Wednesday, January 14, 2004
Wednesday, February 11, 2004
Wednesday, April 14, 2004
Wednesday, May 12, 2004
- **2003 Contributor's Convocation**
Saturday, November 1, 2003
9:15 a.m. to 3:00 p.m.
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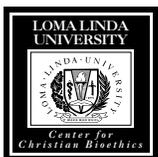


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