Autonomy or Economy?
A Paper written more to provoke re-thinking, than to enlighten or educate!

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This one doctrine, the autonomy of the individual to take decisions, of the medical model of health has, perhaps, influenced ethical decision making more than others. We swear by this sacred tenet whenever we have to take decisions in conflicting clinical situations. Our dilemmas in modern medicine are compounded by the precept and practice of the autonomy of the individual in health care decisions. European philosophers and ethicists have upheld the theory of the autonomy of the individual and our frame of reference is invariably to this philosophical position. The industrial civilizations of the west have arrived at the slogan of the welfare state by promoting health as a right of the individual. The exclusive rights of the patient to demand heath care is a fundamental one in our parleys. However, there are only illusions about personal autonomy. Decisions are made by a host of people and demands of many factors in the situation. Issues regarding life, death and health have been decided on the basis of the doctrine of the autonomy of persons and it has, perhaps, contributed immensely to a cultural imperialism. Ethical decisions are taken, as a result, and are divorced from their cultural and contextual moorings, one must confess. The values of the family, the cultural understanding of the patient on health and death, those of her community, and those of the faith traditions are hardly considered factors which determine an ethical discussion or decision during clinical practice. Where human relationships are strongest, doctrine and dogmatic assumptions on personal autonomy do not hold water. Is it an exaggeration to say rules are observed in their breach than in their observance? The assumptions of modern medicine are such that individuals have the last say, apparently, in maters of life and death questions. Health care is, to the western mind and to those who practice it in the developing world, part of the social security system or the insurance cover. These enviable ideals are set in motion as the process of care in the hospital begins and continues, and they conclude by decisions by the clinical practitioners assenting to the right of the individual.

Informed consent is coupled with patient rights as it gives a standing and a stature to the medical code of conduct. The Hippocratic Oath or codes in the east do not endorse such a view, but we have claimed this tradition as the legacy has been handed down to us by the industrial culture. The French revolution and the Protestant Reformation too have contributed to this far too individualistic understanding of heath. The search for liberty and equality for the individual bereft us of the values of our fraternity, community and humanity among us. Specialized medicine has furthered fragmented our understanding of life, health and death. How much of a fraction are we, we should honestly ask ourselves and as professionals in health care. Medicine, like the development theories, has been working towards something we already have. The values of our relationships in our cultural context have been grossly thrown over board, and we have not created an alternative in our practice of medicine, at least in the third world. We have professionalized health to such an extent that our communication is not communicating enough, and our care is not caring enough and our conclusions are not concluding enough. We are left with half-baked decisions, and the process of decision making becomes an imposed and enforced

exercise to those who come from the east and the Southern hemisphere. The hold of technology and the cultural imperialism on those in the South are frighteningly dehumanizing. There is something rotten in the state of the medical model of health, one should cry foul like Hamlet. The apparitions of autonomy, perhaps, have long reigned and ruled over our decision making in conflicting ethical clinical situations. It is time to rethink the imposed assumptions of the doctrine of autonomy in the western sense of the term and reflect on the values which determine decision taking in health care in cultures other than the industrialized world. The overpowering onslaughts of globalization in the third world, and the medicine which is being grossly privatized and commercialized in the poorer countries of the South compels the third world to challenge the assumptions underlying the practice of modern medicine. The paradigm shift has to be more towards the values of the family, community, the understanding of suffering, faith traditions and cultural values of the people.

Buta Singh is a small time farmer, owning ten acres of land in Punjab. He is the proud father of three daughters and two sons, who are helping him in his cultivation of wheat and vegetable production. He can afford to pay for the private care available in the tertiary care center where he is admitted with renal complaints. Doctors, after a week of investigations, suggested a kidney transplant. His son, Balwant, is prepared to be the donor. The ethical committee has met, and they have recommended the transplant on sound ethical and economic principles. The sixty-five year old farmer who comes from the Sikh faith is not impressed. He consults his dear wife, and his three daughters and the two sons, and, some time later, had closed-door discussions with his priest for confirmation and clarity of the family's decision. At the end of the day the doctors were told something like this "I have lived a healthy and fulfilling life of sixty- five years, even though I came as a refugee from Pakistan. I have a wonderful family, and I am a proud father of three beautiful young daughters of marriageable age. My boys have the ability to look after themselves. My immediate concern is the marriage of my three daughters which means paying my share of the property or, dowry, as you call it, and paying for all the accompanying expenses as the father of the girls. So we are not prepared for a kidney transplant, even though I can afford to pay the 200,000 rupees needed. I have lived a full life, and I must see fulfillment in living for my children, and die a death of whatever form when it comes, I am prepared... This is a family decision and we are all together in this decision. We have taken decisions as a family, life or death. My wife, my daughters, my sons and my local priest have an equal share in this decision, besides the support of our gurus and the strength of our faith."

Arun Wankade is a petty shop keeper, selling cigarettes and pan masala, some soap and a few pouches of hair-dye and shampoo. His two kids are in high school doing fairly well, and he dreams about sending them to college when the time comes. He has a bank balance for the same, and he has no house of his own. He has a piece of land in his village, but it is not very highly valued. He might give it to his younger brother, who is the village barber. The recent bouts of breathing difficulties which he experienced, say the doctors, are due to some serious cardiac disease, and he is advised an angiogram and a bypass surgery in the city hospital run by a private trust in Pune city. It would cost his family nearly I50 thousand rupees. He is dejected and depressed, the future of his two sons is what bothers him most, not his disease. He is determined that he will not touch the money in the bank. He and his wife went to see the local MLA, but there was no promise of help, and no help was at sight .He and his wife have decided that they should accept the writing on their head, as they say. God has sketched the boundary lines on his

skull, and soon it might have to come to its end. So the proposed heart operation is not the option the family has decided. Neither has he any plans to seek help anymore, he has tried his best to get help, he says. His family claims that they can live with the problem. We have faced life together, why not death when it comes, they ask. The wheel will come full circle, and, they believe, they have enough strength in the Buddhist faith, they profess. The children and their future are their priority, and not that of the individual, they tell the doctors .My wife can look after them when I am not there. We have made a pact. Let us see what comes on our way. We have decided to face it together for now."

Raghav Bapu has cancer. He is fifty four. The family keeps a meaningful silence over his illness. They have not mentioned the diagnosis to him. Neither have the doctors. They were told not to tell Raghav Bapu. But he has heard them speak in hushed tones to their neighbors about his disease. The children console him about finding a cure soon without mentioning the disease. He knows it, all about it, and he has told his buddies about it over a glass of toddy in the village white hall. He and his friends in the neighborhood have talked about it among themselves. He can understand the family predicament about not telling him the truth. But in his culture there are other channels of communication. He has talked about this new unwelcome guest on his body, and the whole village knows about his illness. True, the family has not told him about it, but that is acceptable and understandable. More over, Raghav Bapu has seen so many deaths and births in the village. Death is no strange experience, it is not hidden, it happens on a daily basis in one form or other all the time. The burning ghat has no holiday, they say. There was a communal riot when he was a young man in the village. Two of his brothers died in the fire. His neighbor's children were stabbed by the members of the other community. Then, there was this boat tragedy and thirty of his school mates perished in that tragedy. His uncle and his two cousins lost their lives in the land dispute a few years ago. Life has become so cheap thanks to the communal riots, which claim a few lives whenever they take place. The temple and the mosque have cleverly poisoned the minds of the communities. Death is a very frequent visitor in this rural belt. So this disease is like the only bus which makes rare its appearances on the village road. Whenever it comes, people welcome the bus, travel on it, and disappear from the scene to the city, or to the next village. This disease is going to usurp his place, and soon it will overpower him. He will slowly but surely soon submit to its powers. The friends and neighbors have been a great strength. His daily temple worship reminds him of his next birth, and the cleansing of his soul. The Sanskrit hymns and the bells of the temple warmly welcome him closer to his final destination, he claims. Raghav Bapu says he has the trust and confidence of a community, the blessings of the local goddess and the company of his childhood friends who stand by him. The medical science can only worsen his condition by radiation or chemotherapy, he has told his buddies. No one dares to suggest an alternative .Such is the power of his culture and community over his decisions. Life and death are defined, in terms of going out and coming back, like the village bus.

Marian is a missionary nurse in a remote Indian village, where life is very primitive and health care very scarce. She has been in the small local mission hospital for donkey's years. Her aged mother had come to stay with her for Christmas, and remained with her beyond the season for reasons of health. Later she was diagnosed with cancer, and another year she suffered with excruciating pain. Palliative care was all she could get, but the company of village dancing children and the chatter of the tribal girls helped her cope with the pain and the loneliness

accompanying the disease in the corner of Marian's bungalow. She died after a prolonged illness and was to be buried in the village graveyard. As the tribal custom went, the members of the women's group sat vigil over the dead body during the whole night and day; they decorated the body with wild flowers and leafy wreaths, which the village girls weaved. The Youth Group dug the grave, the elders carried the body on their bare shoulders to the graveyard, and on the third day the small congregation went in the early morning to the cemetery to light diyas on the heap of mud and stones with which they had the grave. During the whole experience of death in the family the neighbors cooked for Marian, and looked after her with great sensitivity and in silence. Marian wrote back something like this to her church and the mission body back home. "Mamma died of cancer, and after suffering for so long. But her death was so beautiful. The people of this village gave her a dignity and beauty which her own people in England would not have given. There was this poor community rejoicing over the death of a fellow believer. What a great faith, what a wonderful way of saying good-bye. They were in solidarity with me, and my grief was shared by the community. I am glad Mamma died in this Indian village, where I worked, than at home in my own country."

Insurance companies are, no doubt, hand in glove with the medical lobby. The pharmaceutical companies, technology, and the marketing forces are making heath care, slowly but surely, an exclusively private enterprise. Vested political interests protect and promote privatization of medical education and clinical practice in the third world; it is no secret. Medical tourism in India and other countries is a good example of the silent abdication of the health care to corporate houses. The hidden agenda is to deprive the poor the right to health care and this policy has assumed, by now, a great halo around it. The responsibility of the governments in protecting health as a right has been eclipsed by the private hospitals which sell their shares in the market. Heath, in many countries and cultures in the South, as a result, has become a family responsibility today. You are healthy because your family, immediate or larger, can support the costs of your hospitalization. Your economic status determines your health or ill health. If you have insurance you are a fortunate and privileged one. More and more the families are going to bear the burden of health care costs in the third world. The AIDS/HIV scenario reinforces this family and community dimension of health care in Asia and Africa. The response of the faith communities and families in Africa and other parts of the world has reaffirmed the weight of our cultural values and faith traditions in the care of the sick and the dying. The community hospices for HIV/AIDS reiterate the principle of the autonomy of the families and cultural practices rather than the right of the individuals in determining health status as promoted by the philosophy of the medical establishment.

The economics of care are determining the ethics of care in communities where health is the responsibility of the family. In a world of poverty, ill health and violence, both man-made and natural death is not likely to be determined by clinicians, insurance companies or death and dying experts, but by families and communities. The discussion on death and decisions on prolonging life is a collective decision taken in a culturally sound environ. The faith traditions and cultural understanding of death and suffering, and the acceptance of death as an integral component of heath and life should govern our decision making. An unhealthy expectation about the autonomy of the individual in matters of health and death is not culturally rooted and grounded. The medicalization of culture is both a threat to our human and cultural understanding of life and death.

The understanding of our life cycle in terms of the four ashrams, in the Hindu religion, would add, perhaps, to this discussion. The childhood (saishav ashram),the adult stage (the bramacharya ashram), the married and family life (the grihast ashram) and the fourth stage, the stage of detachment and old age (vanprastha ashram) elicit the attitude to life in general. Old age and death have been defined as integral parts of a life cycle phenomenon, not as a geriatric problem. It is when this cultural realization is reached that one can accept death, or when it happens before old age due to accident or disease. Medicalizing what is already the strength of the community and culture can result in dehumanizing the inmates of the culture. Medicalization of our culture reduces the experience of death and dying to an academic exercise, a subject of curriculum text books, and a matter of communication challenge, and a topic of clinical management in schools of medicine. Death is being promoted (transferred) as a resident of the clinical and medical world, requiring the seal and stamp of specialized professional knowledge and expertise. At least it is couched in a language akin to medical vocabulary and clinical idiom. Death is now concealed, more and more, under the cover of medical insurance, wrapped in the mystery of clinical procedures, and technological disguises. Is it any wonder how there is a guilty silence about death in our clinical corridors and academic circles? The conspiracy of silence only deceives the family, friends, the health team and the community of caretakers in a larger sense. From where the clinicians leave, the funeral parlors take over for a longer time of silence and denial. We have kept death at arms length and are handling it with kid gloves. It is no doubt, in our hospitals and health concepts and in the medical idiom, a colossal failure! We are not comfortable, and therefore, we cope by denying it all, and pretend we have got rid of another problem. The whole enterprise, the so-called undertaker in the west, too, is an ally in this conspiracy of silence. Why has a funeral, like medical treatment, become so costly? The professionalization of the funeral, the passage from life to death, and its accompanying rites, has added to the misery of the ordinary and the poor, one honestly thinks. The insurance companies, not necessarily doctors, who determine death and dying, might make the medical establishment more uprooted from human experience and its cultural moorings. The economics of the funeral arrangements make it a commercial enterprise, as opposed to a cultural experience for the bereaved and the mourning. Should we leave our grieving and bereavement needs at the mercy of the funeral director? In that process do those emotions become faithful hand maidens of the convenient system we have endorsed?

The concept of autonomy as an ethical tenet should, therefore, be re-examined in the light of economy and privatization of medicine, in particular in the third world. Respecting our differences is the key. We have defined autonomy to suit a particular cultural context, as in the case of the theories of development concept. The question of Autonomy, perhaps, is akin to the story of the Turtle and the Hare story. We have our own pace of reaching our destination, and need not compete with the Hare, and perhaps take more pride in our style of deciding and arriving at ethical decisions in situations of crisis in the family. Respect for differences itself is an ethical question, and our cultural and community dimensions should find their rightful place in ethical decisions. In a context where health is a family and community responsibility the burden of arriving at ethically sound decisions must also rest with the family and the community. In a greater sense caring for the sick, the dying, the aged, and those with HIV/AIDS, in our context, is a different story, and we have moral responsibility of discarding autonomy in terms of the industrial culture and civilization. The question of autonomy, in the European sense does not

hold water, perhaps, for the world where economics decide health care, and faith and cultural traditions determine the end of life questions. We shall, in any case, be better off with the cultural heritage, in the Southern hemisphere, than what has been imposed on us by the medical model of health. Here where poverty, calamities and diseases are part of our daily experience the autonomy of the individual, as spelled out by the medical establishment, and promoted by the clinical practitioners of modern medicine, is more of a myth woven around patients in order to create an illusion of fairness and justice. Or, is it an attempt to claim high moral ground? However, its foundations have already been shaken, and it is a matter of time, the edifice of autonomy crumbles under its own weight of contradictions, in theory and practice.