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Oratie uitgesproken door

Prof.dr. A. Kleinman

als Cleveringa hoogleraar aan de Universiteit Leiden op 26 november 2007



Overture: homage to a moral exemplar

Early in the Second World War, under the increasingly dangerous Nazi occupation of Holland, Professor Cleveringa stood up, and with what seems to me today remarkable bravery, spoke out against the brutal, racist policies of the occupiers and their oppressive interference in the professional, academic, and everyday life of Dutch men and women. He offered an heroic model of resistance, and he suffered the consequences. From what I understand, Cleveringa did not need to speak out. He could have chosen to live like so many others a life of compliant silence and passive collaboration. In most cases of military occupation by the Nazi forces, the vast majority of citizens went along with the heinous policies of the occupiers in order to protect themselves and their loved ones from the more immediate threat to their way of life. Even though they may have held thoughts of silent opposition, people complied, and many actively collaborated, seeking to get what they could from the morally compromised ethos. Open resistance was there, yet it only became substantial as it became clear that the German conquerors were in military trouble and might lose the war. This stark context makes even more impressive Cleveringa's (and his Leiden colleagues', for he was not alone) rebellious action at such an early point in the occupation.

For this reason, I am especially honored to deliver the Cleveringa Lecture - because it honors a rare academic leader who put the aspirations for justice, goodness and higher ethical standards ahead of personal safety, professional advancement and just getting on with one's life.

In my recent book, What Really Matters: Living a Moral Life Amidst Uncertainty and Danger (N.Y.: Oxford University Press, 2006), I include a picture by Pablo Picasso, entitled "The Head of a Medical Student." (Figure 1). This picture's distinguishing attribute is an African mask-like head with one eye closed and the other wide open. This juxtaposition of an open eye and closed eye creates the sense of tension so characteristic of medical students. One eye is open to the world of pain and suffering; the other shut tight, perhaps to protect the self from too much adversity, or perhaps to serve the self-interest of the budding physician. Professor Cleveringa's portrait would have to present both eyes open. For he clearly saw that the form of moral experience imposed by the German conquerors was unacceptable, unliveable because it undercut the ethical ideals that make a university one of society's truly crucial moral domains.



Figure 1 "The Head of a Medical Student." by Pablo Picasso

In his magisterial two-part biography of Adolf Hitler, Ian Kershaw demonstrates in monumental detail that the Holocaust of the Jews was the result of the willingness of ordinary Germans to go along with the Nazis' murderously anti-Semitic policies as long as their own lives, their families, their incomes, the things they personally held dear were protected from the feared Soviet threat. The Jews, Kershaw sadly concludes, simply didn't mean enough to ordinary Germans for them to risk what mattered much more to them by opposing Nazi policies. The famous Dutch willingness to protect the Jews aside, we might well ask why did Cleveringa stand up and speak out in defiance of Nazi laws and procedures, knowing what was likely to be the consequence? The answer to this disturbing question could only have been answered by Cleveringa himself. Yet, in this public lecture I will offer one possible answer. Cleveringa, for me, stands as an icon of the quest many of us undertake to somehow live a moral life in the midst of local worlds of moral experience that we find inadequate, oppressive, unjust, unbearable. That lifelong quest turns on our ethical, aesthetic and religious aspirations for remaking the world. Those aspirations I regard as just as fundamental to our existential condition as the dangers, uncertainties and things that matter most in our daily lives. Cleveringa was more heroic than most of us; but in a way I will later define as anti-heroic, we all engage this issue.

Now, because one of those ethical/aesthetic/religious aspirations involves caregiving, I will turn this opening gambit in a direction more appropriate to my own expertise: health catastrophes, suffering and medicine. Let there be no mistake, however. I see Cleveringa's example as a kind of caregiving, and therefore directly relevant for tonight's subject.

First movement: things as they are

I will first describe the current situation and the problems we face in the field of healthcare. Aside from skilled nursing, rehabilitation efforts by physical therapists and occupational therapists, and the practical assistance of social workers and home health aides, caregiving, especially for victims of health catastrophes and end-stage conditions, has relatively little to do with medicine. Caregiving is primarily a matter of families, close friends, and the afflicted individuals themselves. It is they who struggle with the activities of daily living such as bathing, feeding, toileting, dressing, and who spend the long hours of working around, through and with pain, functional limitations, memory loss, agitation, and the many other difficult realities of the most serious health problems.

To illustrate this point, I draw on my personal experience as the caregiver for my wife, Joan Kleinman, who is suffering from a severe neurodegenerative disorder that has affected her memory, motor functions, and restricted her independence. I wake her up in the morning, and assist her in toileting, bathing, and dressing. I make us breakfast and help her feed herself. I assist her in walking, placing her in a chair and in our car. I am with her nearly all the time, protecting her from injuring herself because she can neither see nor navigate safely either on the street or in our own home. I read the newspaper and books to her, explain stories on the TV, and select music for her to listen to, and make telephone calls for her to our children and grandchildren. I prepare lunch and dinner and help her eat; and I do all the things required to get her ready to go to bed at night. Of course, our children, my mother, my brother, and others call and help when they are able, and several times a week we are assisted by a professional home

healthcare helper who does the wash, cooks several meals and spends the day time hours with Joan.

Joan herself does as much as she is able to do. She rarely complains and, with the exception of occasional agitation that is beyond her control, she struggles to enjoy life, and usually succeeds in doing so. In this and several even more crucial ways she is her own caregiver. She keeps up on her part in our conversations, emotional exchanges, and moral relationship. While it is greatly disturbing to witness a once elegant, intellectually lively and highly independent companion of over four decades deteriorate, our emotional reactions from frustration and anger to sadness have been cushioned and sublimated by our work, the long rhythm of our days together, and most of all by the support of family and close friends. That "support" is as much a part of caregiving as all the mundane practices I have listed, and amounts to moral solidarity with our struggle and concern and responsibility for us. Without it, it is hard to imagine how either Joan or I would be able to endure and go forward.

I give you this highly personal sketch because it is the best I can do to illustrate what caregiving entails, and why it is so crucial to all of our lives and the human condition more generally. Caregiving, as illustrated by our case, is about acknowledgment, concern, affirmation, assistance, responsibility, solidarity, and all the emotional and practical acts that enable life. Caregiving also includes what happens when hope and consolation are abandoned, when theodicy is ended, and when all there is to do is to be present with the sufferer, sharing his/her suffering by simply and usually silently just being there. There is a painting that once upon a time hung in Children's Hospital in Boston; the sun is rising,

an exhausted pediatrician, in the pre-antibiotic era, holds the hand of a child who has just passed through crisis and lysis of a fever. This too is caregiving. Examine these three paintings of Rembrandt - 'Saskia in Bed', 'Dr. Bueno' and 'The Jewish Bride' (Figures 2, 3, and 4) - they also represent caregiving: as interpersonal experience, as the concern and compassion of the healer, and, in a larger sense, as love.

So, what is the status of caregiving for health catastrophes and other serious conditions in medicine today? While medical educators will claim that caregiving is still central to what it means to be a physician and will point to courses and practitioners who teach the art of caregiving to students, the on-the-ground reality is much more uncertain and fragile. Most physicians, outside of primary care providers, do little in the way of hands-on caregiving. Hospice doctors are caregivers; and physicians who routinely deal with end-of-life, such as oncologists and cardiologists and nephrologists and gerontologists, are surrounded by caregiving opportunities,



Figure 2 'Saskia in Bed' by Rembrandt



Figure 3 'Dr. Bueno' by Rembrandt



Figure 4 'The Jewish Bride' by Rembrandt

yet few participate in the nitty-gritty of caregiving - leaving the practical assistance and emotional tasks to nurses, social workers and the patient and his/her network of support. In medical school, the curriculum in both the basic science and clinical clerkship years places the great emphasis on understanding disease processes and high technology

treatments. The illness experience gets less and less pedagogic attention as the student progresses from classroom to inpatient ward and clinic. And in the broader system of healthcare, students can all-too-readily discern that medicine largely leaves caregiving to others. Those others include nurses whose professional science has made caregiving a central element of knowledge production and training. Yet, this knowledge is largely unavailable to young physicians and medical students. Its association with a lower status profession perhaps even provides it with something of a stigmatized status. It is notable that caregiving still has a strong gender bias. Most caregivers are women. And historically and crossculturally this is even more impressively true. What is particularly true of our time and especially in my own society is that the structure of service delivery and the funding of health services work to discourage professionals from the art of caregiving and can in fact undermine the practitioner's efforts. Part of the mistrust of doctors is the growing sense that they seem uninterested in caregiving.

Recognizing this tenuous and contested status of the knowledge and practice of caregiving in medicine, the late, great American physician-educator Walsh McDermott once proposed, perhaps tongue-in-cheek, that the caregiving and technological roles of the doctor might be separated, and the former dropped from medicine as a burdensome and poorly cultivated anachronism. Almost no educators would agree with McDermott's provocative suggestion - and even he probably would have withdrawn it from consideration if he thought it would be taken seriously, rather than to stimulate discussion of how to strengthen caregiving in the curriculum - but if we are willing to honestly look into the actual situation of caregiving in today's medicine, we must come away with the

accumulating sense that caregiving is at best inadequately taught and supported among students and physicians, and at worst is a hollow skill that has been emptied of content, commitment and competence. It is a vestigial component of medical training and practice that occupies an ambiguous and uncertain position in the profession, as marginal as clinical experience is in the age of "evidence-based" practice, and is in danger of becoming a platitude that is taught hypocritically and learned only to be unlearned as part of the hidden curriculum in medical student and residency education.

If this conclusion strikes the listener as overly bleak and unjustified, ask yourself the question what serious effort has been made in determining and operationalizing the knowledge basis needed to provide good care? What time has been allotted for acquiring this skill in medical school and residency training? Do, for example, students get placed in caregiving situations, say, in the homes of victims of health catastrophes, so that they actually experience caregiving? What provisions have been made to evaluate the doctor's skills in caregiving? And, overall, how has caregiving been developed as a crucial academic subject requiring theory-building, empirical research, and applied science contributions? How often is assessment of caregiving skills taken as seriously as assessment of basic and clinical science knowledge? Has medicine - under the great influence of global political economic, bureaucratic, technological, and cultural change - turned its back on the medical art and the thousands of years of humanistic approaches to medical practice cross culturally? Has the hugely powerful biotechnology-medical-industrial complex, the over bureaucratized health care system with its stark regime of efficiency on behalf of the god of cost-containment and its new culture of audit, and the global cultural revolution

of hyperindividualistic consumerism and Internet-spread marketing of the latest drugs and surgical procedures separated medicine from caregiving? Does the experience of competent caregiving mold doctors' careers nearly as much as the evidence of clinical science? Are medicine and caregiving incompatible to the point of divorce?

Second movement: experience

In What Really Matters: Living a Moral Life Amidst Uncertainty and Danger, I describe the local moral worlds of patients and physicians that have become ordinary realities in our time. These realities define what it means to be human amidst the dangers and uncertainties that are the existential universals in our shared human condition. So, what does the present situation tell us about this condition today, which my Harvard forebear William James referred to as "genuine reality".

For the medical anthropologist, people everywhere live in the flow of interpersonal interactions in local worlds - networks, families, institutions, communities. Experience is that flow of words, movements and emotions between us. Experience seen this way is not only local, it is inherently moral. Why so? Because living our lives is about animating and enacting values. We are constantly experiencing, negotiating, defending, and just living values. Those lived values are the things that are personally and collectively at stake for us: for example, status, reputation, resources, connections, religious and cultural practices, and so on.

Moral experience is the flow of things at stake in local worlds. Our own moral life may be consistent with or in conflict with our local worlds of experience. We can collaborate with such worlds or seek to resist and transcend them by our aspiration for ethical commitment.

Now, think of the clinic, the hospital, the HMO, the medical school, or the family setting of caregiving for victims of health catastrophes as just such local worlds of moral experience. What can we say about them that relates directly to tonight's topic.

First, those local worlds are deeply affected by the massive economic, political and cultural forces of our globalized era. One particularly egregious example is the hyping of claims by the biotechnology industry, by medical researchers, and by specialist practitioners of how much we know and can control in health and disease. The economic incentives for hyping are not difficult to appreciate. The cultural sources of hyping affect not only the medical industrial complex, but also the financial management industry, the insurance industry and the national and international policy domains. Much more is claimed than is actually known. It is often said that half of all cancers are curable, for example, but as social psychologists have shown, just turn it the other way around - half of all cancers are incurable - and excessive optimism is replaced by soberer reflections. Most chronic diseases can only be managed, not cured, and their sequelae in long-term, disabling consequences such as blindness, amputation, and kidney failure in diabetes cannot be controlled either. In my own specialty of psychiatry, for all the important advances of neuroscience, we still don't possess a single biological test for routine clinical use to diagnose depressive or anxiety disorders or schizophrenia. And while the drug treatment of serious depression has improved, still 35% of patients are treatment resistant and the placebo effect itself in most clinical trials accounts for a 45%

improvement over against 65% for antidepressants - nowhere near the huge claims made by the pharmaceutical companies. Prognosis not only for mental health conditions, but for most chronic disorders remains difficult and uncertain.

Now add to this picture all those things in the natural world - like forest fires and brushfires, earthquakes, floods, droughts, and climate change - that affect hundreds of millions of people, and the idea that we know, can predict, and can control events looks highly suspicious. Political violence, financial crises, outbreaks of food contamination, major accidents, and the dozens of other dangers that are a regular part of our lives only clarify more fully that the very idea of risk management is overblown and unsupported by the evidence. In fact, danger - natural and social - has been, and will for the foreseeable future continue to be, inadequately understood, poorly predicted, mostly uncontrolled, and largely unpreventable. That is to say, danger and uncertainty are an ordinary element in every day living everywhere - more notably among the poor, but affecting all of us.

This is a picture of a huge discrepancy in our local worlds between the dominant moral reality that encourages exaggeration of knowledge and treatment and the genuine reality of our existential condition. The implications of this reality gap for health and medicine are simply enormous. Patients are misled by the media's hyping into highly distorted views of what medicine can do, and health professionals and students are also the victims of routine hyping in the medical literature. It is understandable that researchers and medical research administrators will participate in this process in order to secure greater public and private funding, but it is nonetheless deeply troubling that the scientific enterprise itself

has been distorted by global economic and cultural interests. Add to this the corrosive, yet accurate popular idea that conflict of interest is rampant in medicine, and the widespread suspicion that health professionals are more interested in their own financial condition than in the conditions of their patients, and we all can understand why distrust of physicians has skyrocketed almost everywhere while the status and prestige of the profession has fallen.

But I want you to think of this tension in a local setting like a research lab or clinic. I think of the pressure on young researchers and young clinicians to collaborate with established practices as they write grant applications, explain research projects to the media or elicit informed consent from patients. Think of this as cultural influence on the way prognosis is explained to patients being offered a new medication or surgical procedure in a clinical trial or for treatment. What about young clinicians or students who challenge the conventional approach?

Now, consider societies in the twenty-first century where moral worlds are also ethnic and immigrant worlds. Intercultural communication across these worlds makes the moral concerns I am raising even more strident and complex. Here medical anthropology has a particular advantage in advancing intercultural communication concerning the moral issues surrounding health, illness, health care, and public health. Think of female genital cutting and all the other sources of crosscultural conflict and misunderstanding in the clinic and the community. But medical anthropology too can promise more than it can deliver. Many claims on behalf of cultural competence in health care are examples that hyping is not limited to biomedicine.

In the late 90s, I participated in a small global health meeting of researchers and funders to which I was invited to present a proposal for support of global mental health programs for the treatment of depressive and anxiety disorders, and the prevention of suicide. When the group's discussion came to the topic of AIDS in Africa and other poor societies, the discussants uniformly supported the then dominant position that only prevention, not treatment could be provided to patients in such societies. I tried to challenge this conclusion, invoking social justice and human rights arguments. I was dismissed as naïve, romantic and wrongheaded. And when the time came for me to present the mental health agenda, those criticisms soured the group's reception of my proposal so that it went unsupported. The lesson has been learned by each of us: moral experience is risky. Go against the tide of values and sentiments and you risk personal criticism and defeat for your own projects. Which brings us back to Professor Cleveringa. Heroism carries a price only a few are willing to pay.

The best that may be available for most of us is what, for want of a better word, I will call anti-heroism. Anti-heroic actions are ones that critique and resist the moral status quo by perturbing and disturbing our local world. They signal disaffection and raise questions in others. They indirectly challenge the taken-for-granted. They run against the moral grain. In place of actions that aim to change the world, anti-heroic practices aim to create a space for alternatives where critical self-reflection can thrive. In such a space, local protagonists can search for ways to live a moral life in spite of the shortcomings of the local moral world. And that quest for living one's own moral life can be generalized as an aspiration for ethical positions that offer an alternative vision of what

the local world might look like with respect to social justice and integrity and other trans-local values.

Medical practice is one setting where the anti-heroic can be, and has been, realized. W.H.R. Rivers, the early twentieth century British anthropologist-psychiatrist, introduced a humanistic, ethnographic form of psychotherapy into the medical care of traumatized officers during the First World War. That psychotherapy provided Sigfried Sassoon, the highly decorated yet anti-war poet, with a protected place to come to terms with his own rebellion against the carnage. Sassoon returned to the front without giving up his critical political views; Rivers, in turn, became an anti-war critic devoting the remainder of his life to political transformation on behalf of pacifism, workers' rights, and the legitimacy of psychological trauma as an honorable and compensable medical condition. Rivers' antiheroism did not change his world, yet he opened a moral space for many others to rethink their commitments and rework their practices in service of more availing ends and against the grain of the dominant values of that era: colonialism, racism, and jingoistic nationalism.

For patients and families faced with health catastrophes and the most serious chronic medical conditions, the experience of suffering is not just a personal one, but is strongly influenced by cultural and historical changes in the illness meanings, socialization, and self processes that contribute to moral life being distinctive in different eras and societies. Faced with a threat of pain, disfigurement, loss of function, and serious disability, individuals and families reframe the moral experience of suffering by remaking meanings, emotions and values via ethical, religious and aesthetic activities. The same holds for physicians. Faced with their own or their patients's

suffering, physicians rework meanings, emotions and values in their professional and personal lives. Ethical, religious and aesthetic practices contribute to professional caregiving by transforming the experience of the caregiver. Much of the great art of the bloody 20TH century chartered the growing disillusionment of communities and their fear of a progressive loss of their humanness as a result of wars, oppressive political systems, and deadening bureaucracies. Hence Abstract Expressionism depicted a dehumanized world, including the world of hospitals and clinics. Over the long run of Western civilization the very idea of suffering has changed, reflecting a progressive sense that suffering had lost its former religious and ethical meanings and had become utterly trivialized as an unnecessary experience that could simply be prevented or remedied with drugs. Advertisements for pharmaceuticals build on this central message that suffering holds no value and need not be experienced. This is a far cry from the sense of suffering in earlier times as a central struggle of the soul. Contemporary institutional structures in medicine further impede the religious, ethical and aesthetic processes that remake suffering by remaking meanings, values and emotions. The bureaucratic structures and financial constraints of care undermine the art of medicine and interfere with the ancient task of caregiving.

Third movement: caregiving and the medical humanities

So what is caregiving for the physician and what is the knowledge base for it to be practiced and taught? Boiling down a variety of studies of the frail elderly, dementia and terminal conditions, for example, we can say that caregiving begins with the clinical ethical act of acknowledging the situation of the sufferer, affirming their efforts and those of family and

friends to respond to pain and impairment, and demonstrating emotional and moral solidarity with those efforts. It moves on to involve the physician in pain management, symptom relief, treatment of intercurrent diseases (e.g., depressive disorder), and judicious management of the use of pertinent technology and control of unnecessary or futile interventions. It includes working within a network of advisors (legal, financial, religious), co-health professionals (physical therapists, occupational therapists, nurses, social workers, and home health care assistants), and family and network caregivers. It often involves advising on appropriate use of hospital and home health care technology. And it means spending real time with patients, empathically listening to their illness narratives, eliciting and responding to their explanatory models, and engaging the psychosocial coping processes involved in enduring or ending life. Managing the process of dying and being a presence at death and assisting, to the extent it is wanted, with bereavement are also part of caregiving. These involve moral; affective; and meaning-making activities that we have learned much more about in recent years. And included here is self management of the physician's own emotional and moral responses which may at times require debriefing by co-professionals, as well as attention to the practitioner's own ethical, religious and aesthetic needs.

Some of the knowledge required for professional caregiving comes from hospice programs, psychiatry, psychology, gerontology, nursing, and social work. But in this lecture I want to emphasize the role of the medical humanities. The medical humanities bundle together a disparate assortment of disciplines and programs: medical anthropology, medical sociology and medical history, medical ethics, pastoral counseling and religious studies, and programs as diverse as

narratives and the arts in medical education. I do not believe that any single discipline or program holds the answers. Rather after four decades of teaching medical students I am convinced that, however it is done, it is the contribution of the medical humanities to two educational objectives that matters.

The first objective is preparing students cognitively, affectively and morally to undertake the tasks I have sketched. This means teaching students how to listen, be with, emotionally respond to, and communicate with patients and their networks. It means learning how to interpret patient and family stories. It means learning how to explain and interpret treatment and prognosis. It means training doctors to use their personalities, emotions, cognitions and values therapeutically, It should go hand-in-glove with actual experiences of caregiving in patients' homes and institutions, not just in year one of medical training but throughout undergraduate and postgraduate medical training. And it means that student doctors must be evaluated for these competencies.

The second objective is of a somewhat different sort. Here the medical humanities aim to foster critical self-reflection. They do so, in my experience, by opening and authorizing a space for reflection, criticism and experimentation. That space of critical reflection is first present in the medical student's curriculum. Keeping it available and legitimated in the clinical training of the resident is a substantial challenge. But once again by legitimating the medical humanities in postgraduate training this can happen. Continuing medical education in medical humanities for the practitioner holds out the promise of keeping that space open during the career trajectory of doctors.

The habit of critical self-reflection enables the individual practitioner as well as groups of practitioners to interpret, interrogate and evaluate the local moral worlds of practice in the clinic, hospital and public health domains. Out of that effort comes the anti-heroism I mentioned earlier. Where the local world of practice is seen to be morally problematic or unacceptable, perturbing and disturbing that ethos enables others to come together over criticism of the moral issues in practice and in the quest or aspiration for ethically more availing practice.

Critical reflection on obstacles to performing the art of medicine might lead to interrogation of the health financing system, which in my own country is a leading barrier to make available the "time" required for responding to patient requests with full and understandable answers. The analytic light of criticism may focus on the sources of physician conflict of interest and patient/family distrust, including ethnic and class issues that lead to health disparities. But there are a number of other obstacles to the art of caregiving from the local culture of a clinical department to the interference of the bureaucratic culture of audit via excessive paperwork and the routinization of clinical behaviors. Again, using my own society as an example, fear of medical-legal suits can interfere with practice of the art of medicine. And the list goes on. The purpose of instilling critical reflections in clinicians is to lead them to interpret what are the locally conflicting or impeding structures.

Critical reflection empowers practitioners not just to identify the problems but to attempt to resist and correct them. This crucial clinical responsibility does not develop on account of a single medical humanities course, but requires an entire curriculum of medical humanities experiences to counteract the disabling qualities of medical education. In essence, the practitioner has to come to feel that the art of caregiving is as much at stake as the science and technology of diagnosis and treatment. And, in my view, that means reform of the very culture of contemporary biomedicine.

At the level of leadership and at the level of the ordinary practitioner, the profession needs to reclaim and revivify the art of healing, clinical experience, and caregiving as fundamental to the profession. Medical school deans and department chairs similarly need to reaffirm via educational and practice reform that caregiving is central to pedagogy and the paideia of the physician. This commitment needs to be reflected in the way students and residents are tested. The local worlds of medicine need to make clear in every way that caregiving is what matters most along with science and technology. Short of doing these things, the profession and its hospitals and schools need to seriously consider Walsh McDermott's Swiftian choice: divorce the art of medicine and give up caregiving to the other helping professions including alternative and complementary medicine. No one can imagine that happening when it is offered as a free choice. But I insist this is what is actually happening today on the ground, as the economics of health services, the political economy of research, the culture of bureaucracy, and moral worlds of medical schools and clinical institutions have effectively removed caregiving from what matters most in medicine. And to stop this social process of atrophy, we need to do all the things I have mentioned along with providing the medical humanities with the place in the curriculum and the resources they need to reclaim and revivify caregiving in the profession.

Fourth movement: remaking the moral world of medicine: the example of global health

That the situation though dire is not hopeless is illustrated by one new development on the broad stage of health that is at one-and-the-same time technologically, managerially and morally promising: namely, global health. There is a huge societal-wide social movement in my own country and others among students, faculty and practitioners to create a new kind of global health that is at the cutting edge of science, that is technologically mature, that also is committed to the highest level of clinical practice, that makes use of the latest managerial strategies to implement scaled-up programs, and that responds to the global ethical issues that are crucial to globalization such as social justice, equity, and in the simplest and bluntest terms, bringing good into the world of the poorest. The refocusing of attention is on disease as part of social suffering.

Social suffering is a term employed to break down the barriers across the separate fields of social and health policy, and to picture health (and medicine) as part of the large-scale political, economic, and cultural changes of our era that have widened the gap between rich and poor, contributed to emerging infectious diseases, worsened social and mental health problems, and at the very same time rocked health services and shaken health financing. Social suffering emphasizes the importance of poverty and health disparities across populations. It also draws attention to the fact that some problems are actually worsened by social and health policies.

Among the leaders of this field are several of my former medical anthropology M.D.-Ph.D. students, who started what is now a leading NGO: Partners in Health. PIH spends virtually all its resources on community projects amongst the poorest Haitian, Peruvian, Rwandan, Malawian and Siberian populations. It has been widely commended by the experts and the media for providing locally organized and culturally oriented services that include high technology care, first-rate clinical services and an emphasis as well on caregiving to patients with AIDS and MDRTB. The caregiving is not an afterthought or an appendage but an integral part of services that have shown outstanding outcome data at the same time that they have become training grounds for reforming local worlds of patients and practitioners, and building an indigenous generation of leaders. These anthropologistphysicians have become icons of doctors who have dedicated their lives to providing high technology treatment and humane caregiving to the sickest and poorest patients. And their commitment has attracted thousands of students and practitioners to global health as an ethical movement that prioritizes an approach to those without resources as advocacy for and practice of both social justice and caregiving.

The new global health differs from the old international health (and the still older tropical health) in a number of ways; but particularly by placing the care of the individual patient at the same level of priority as prevention for the population. This is a transvaluation of values that combines the values of social medicine with those of public health. By emphasizing local lay caregiving networks as an integral element in community health programs, technology, clinical expertise, prevention, and community ownership of programs are integrated in a critical clinical practice that builds clinics, roads, and essential drug programs and also incorporates local approaches to caregiving. I believe it is this critical practice that attracts such broad interest to global health and to Partners in Health in particular.

How have these medical anthropologists, and others like them, succeeded? And what lessons can be learned from these successes in global health that can be translated into ordinary health care in your country and mine? In my view their success turns on four factors that are of relevance: 1) they have criticized the status quo of local worlds at home and abroad, demanding social justice and public service; 2) they have modeled a form of collective caregiving based on caregiving of individuals in great distress and generalized to the population level; 3) they have mobilized young men and women, the media, the funding agencies, and governments to contribute to local programs; and 4) they have drawn on critical self-reflection and the anti-heroic in those worlds to recruit local leaders.

I believe we can apply these very same approaches to the reform of clinical medicine in medical schools, hospitals and clinics in rich societies like yours and mine. I have emphasized the medical humanities in my talk, but really all of us need to get involved, to be called to the ethical roots of what it means to be a doctor for those who have experienced the most serious, hopeless and therefore most human of health conditions. At bottom, that is an ethical call back to the roots of what is (and has long been) at stake for physicians. I believe this moral movement has the chance to remake medicine and medical education. And this is why I am arguing in this lecture that if we are in agreement that biomedicine and caregiving must not divorce, then we must advocate on moral grounds for the art of medicine and for caregiving for others in great need even more broadly as a crucial component of the human endeavor, as Cleveringa himself demonstrated.

References

- This essay builds on work by medical social scientists and humanists as well as critical theorists and practitioners of medicine. Salient publications include:
- Aaron Alterra: *The Caregiver: A Life with Alzheimer's.* Foreword by Arthur Kleinman. Ithaca, N.Y.: ILR Press (imprint of Cornell University Press) Jan. 2008.
- Allan Brandt and Paul Rozin, eds: *Morality and Health*. N.Y.: Routledge, 1997.
- João Biehl, Byron Good and Arthur Kleinman, eds.: *Subjectivity*. Berkeley: University of California Press 2007.
- Pierre Bourdieu, ed.: *La Misère du Monde*. Paris: Editions du Seuil, 1993.
- Victor Brombert: In Praise of Antiheroes. Chicago: University of Chicago Press, 1999.
- Georges Canguilhem: The *Normal and the Pathological*. N.Y.: Zone Books, 1991.
- Eric J. Cassell: The Nature of Suffering and the Goals of Medicine. N.Y.: Oxford University Press, 1991.
- Rebecca Chopp: The Praxis of Suffering: an Interpretation of Liberal and Political Theologies. Maryknoll N.Y.: Orbis Books, 1986.
- Sarah Coakley and Kay Shelemay, eds.: *Pain and Its Transformations*. Cambridge, MA: Harvard University Press, 2007.
- Paul Farmer: Pathologies of Power. Berkeley: University of California Press, 2005
- Byron Good: *Medicine, Rationality and Experience*. Cambridge: Cambridge University Press, 1994.
- Ian Kershaw: Hitler, 2 volumes. N.Y.: Norton: 1999, 2000.
- Jim Kim et al., eds.: *Dying for Growth*. Monroe, ME: Common Courage Press, 2000.
- Arthur Kleinman: *Patients and Healers in the Context of Culture*. Berkeley: University of California Press, 1980.
- Arthur Kleinman: The Illness Narratives. New York: Basic Books, 1988.
- Arthur Kleinman: Writing at the Margin: Discourse Between

 Anthropology and Medicine. Berkeley: University of California

 Press, 1995.

- Arthur Kleinman: What Really Matters: Living a Moral Life Amidst Uncertainty and Danger. New York: Oxford University Press, 2006.
- Arthur Kleinman, Veena Das, and Margaret Lock, eds.: Social Suffering. Berkeley: University of California Press, 1997.
- MM Leininger: Care: *The Essence of Nursing and Health*. Detroit, IL: Wayne State University Press, 1984.
- C. Levine, and TH Murray: The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers. Baltimore: Johns Hopkins University Press, 2004.
- Mack Lipkin: Care of Patients: Perspectives and Practices. New Haven, CT: Yale University Press, 1987.
- Margaret Lock: *Encounters with Aging*. Berkeley: University of California Press, 1993.
- FW Peabody:The care of the patient. *Journal of the American Medical Association* 1927; 88: 877-82; 1984; 252: 813-18.
- Adriana Petryna: *Life Exposed*. Princeton: Princeton University Press, 2002.
- Adriana Petryna, Andrew Lakoff and Arthur Kleinman: Global Pharmaceuticals. Durham, NC: Duke University Press, 2006.
- M. Simone Roach: The human act of caring: a blueprint for the health professions. Ottawa: Canadian Hospitals Association, 1997.
- Charles Rosenberg: Our Present Complaint: American Medicine, Then and Now. Baltimore: Johns Hopkins University Press, 2007.
- John Saunders: The practice of clinical medicine as an art and as science. *Journal of Medical Ethics*: Medical Humanities 2000; 26:18-22
- Howard Spito et al. eds.: Empathy and the Practice of Medicine: beyond pills and the scalpel. New Haven, CT: Yale University Press, 1993.

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