

‘Care’ in health care

Remaking the moral world of medicine

Arthur Kleinman & Sjaak van der Geest

This article raises the question to what extent health care as practised in biomedicine includes care as a moral and existential value. The text is at the same time a ‘teaser’ to draw attention to an up-coming symposium on ‘Care and Health Care’ (see under News). The authors argue that biomedicine needs a ‘remake’ to involve the care that characterises the moral world of human experience.

[care, health care, moral value, experience, biomedicine, symposium]

The gradual epidemiological transition from infectious to chronic disease has led to a widespread discussion on the shift of emphasis from cure to care. In this essay, however, the authors argue that care is – or should be – an indispensable part of dealing with any type of human suffering, including suffering that is treated by curative medicine.

Care

The term ‘care’ has various shades of meaning. Its two basic constituents are emotional and technical/practical. The latter refers to carrying out activities for others who may not be able to do them alone. Parents take care of their children by feeding them, providing shelter, educating and training them, and so forth. Healthy people take care of sick ones and young people of older ones. Technically, this type of care has a complementary character: one person completes another one. ‘Care’ also has an emotional meaning; it expresses concern, dedication, and attachment. To do something with care or carefully implies that one acts with special devotion. Depending on its context, one aspect may dominate, indeed overrule, the other. In ‘health care’ the term has assumed an almost entirely technical meaning. In personal relationships the emotional meaning prevails (“I care for you” / “I don’t care”).

The philosopher Heidegger chose the concept of ‘care’ (*Sorge*) to characterise the structure of being. In his *Sein und Zeit* he argues that ‘caring’ (*sorgen*) captures the

two basic movements of human existence: towards the other and towards the future. To *be*, for a human person, means to *be with others*, to be oriented towards the presence of other people. Dealing with others implies some measure of care, some degree of practical and emotional involvement. Being with others in the world necessarily includes caring for and being cared for.

Sorge, in its more practical meaning, also implies an orientation towards the future. Being human is moving forward, projecting oneself, being ahead of oneself, *sich vorweg schon sein*. If we understand him correctly, Heidegger argues that the act of caring for oneself and for others and the attitude of 'care-fulness' typifies being a 'human being'; to 'care' is the essence, the structure of being.

Tronto, a political scientist, also regards care as one of the central activities of human life. She distinguishes four, interconnected phases of care: caring about, taking care, caregiving and care-receiving, moving from awareness and intention to actual practice and response. The four phases parallel four ethical elements involved in care: attentiveness, responsibility, competence and responsiveness. Care is the process that sustains life. Care, according to Tronto, represents the moral quality of life, but that moral quality needs to be transformed into a political reality.

To be a morally good person requires, among other things, that a person strives to meet the demands of caring that present themselves in his or her life. For a society to be judged as a morally admirable society, it must, among other things, adequately provide for care of its members and its territory (Tronto 1993: 126).

The American philosopher Mayeroff (1971), in his long essay *On caring*, contrasts 'care' with 'power': "In the sense in which a man can ever be said to be at home in the world, he is at home not through dominating or explaining, but through caring and being cared for..." In his view, people actualise themselves by caring for others. Mayeroff (1971: 1): "To care for another person, in the most significant sense, is to help him grow and actualise himself... Caring is the antithesis of simply using the other person to satisfy one's own needs." In true caring, writes Mayeroff, the other person is experienced as both an extension of myself and as separate from me, someone to be respected in his own rights. In that idealistic picture caring is devotion to the other. The obligation to care, which derives from that devotion is not experienced as forced upon me. What I *want* to do and what I am *supposed* to do converge. He provides the following example: "The father who goes for the doctor in the middle of the night for his sick child does not experience this as a burden; he is simply caring for the child" (p. 9). It illustrates what he means by "the other as an extension of myself." Caregiving is indirect self-fulfilment.

Western notions of care should be handled with caution in a radically different social, cultural and economic environment. Tronto (1993: 103) warns that "the activity of caring is largely defined culturally, and will vary among different cultures." There is only one way to figure out what care is in a particular cultural setting: by listening to those who are directly involved in it and by observing their actions.

Giving care

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, we draw on the personal experience of one of us. Arthur Kleinman writes:

I am the caregiver for my wife, Joan, who is suffering from a severe neuro-degenerative 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 health care 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.

We quote this highly personal sketch because it illustrates what caregiving entails, and why it is so crucial to all of our lives and the human condition more generally. Caregiving 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. Caregiving is an interpersonal experience; it is concern and compassion, and, in a larger sense, love.

Care and biomedicine

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.

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, 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 health care, 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 stigmatised status. It is notable that caregiving still has a strong gender bias. Most caregivers are women. And historically and cross-culturally this is even more impressively true. What is particularly true of our time and especially in our societies 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.

If this conclusion strikes the reader 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 mould doctors' careers nearly as much as the evidence of clinical science? Are medicine and caregiving incompatible to the point of divorce?

The clinic and the hospital are – or should be – settings of caregiving. Unfortunately, contemporary institutional structures in medicine often 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.

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 explanations, 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.

Self reflection

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. 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 our societies 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 behaviours. Using America 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. 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. The local worlds of medicine need to make clear in every way that caregiving is what matters most along with science and technology. But 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. Is it possible to stop this social process of atrophy and to reclaim and revivify caregiving in the profession?

Remaking the moral world of medicine

One way to revivify care in health care may be to refocus the attention 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 medical anthropologists who started ‘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 practice and an emphasis as well on caregiving to patients with AIDS and multidrug-resistant TB. 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 anthropologist-physicians 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 our 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 modelled 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 in those worlds to recruit local leaders.

Is it possible to apply these very same approaches to the reform of clinical medicine in medical schools, hospitals and clinics in rich societies? It requires a return 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.

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 inherently moral. 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. Giving and receiving care are the most incisive values that structure our lives as moral beings, in family life as well as in medical settings.

Note

Arthur Kleinman is psychiatrist and medical anthropologist and a major figure in cultural psychiatry, global health, and social medicine. He is the Esther and Sidney Rabb Professor of Anthropology, Department of Anthropology, Faculty of Arts and Sciences and Professor of Medical Anthropology and Psychiatry at Harvard Medical School. E-mail: kleinman@wjh.harvard.edu

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This essay explores the theme of an up-coming symposium on 'Care and Health Care' (see under News, this issue). The text is largely a revised version of parts of two earlier publications by the authors and therefore it contains extensive quotations from those publications (Kleinman 2007; Van der Geest 2002).

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Selected readings for symposium

This essay builds on work by social scientists and humanists as well as critical theorists and practitioners of medicine. Salient publications include:

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- Biehl, João, Byron Good & Arthur Kleinman (eds)
2007 *Subjectivity*. Berkeley: University of California Press.
- Bourdieu, Pierre (ed.)
1993 *La misère du monde*. Paris: Editions du Seuil.
- Brandt, Allan M. & Paul Rozin (eds)
1997 *Morality and health*. New York: Routledge.

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1991 *The nature of suffering and the goals of medicine*. Oxford: Oxford University Press.
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1986 *The praxis of suffering*. Maryknoll, NY: Orbis Books.
- Coakley, Sarah & Kay Shelemay (eds)
2007 *Pain and its transformations*. Cambridge, MA: Harvard University Press.
- Du Preez, Corrie & Anke Niehof
2008 Caring for people living with AIDS. A labour of love. *Medische Antropologie* 20 (1): 87-104.
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2006 *Cash and care: Policy challenges in the welfare state*. Bristol: Policy Press.
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Tonkens, Evelien & Jennifer van den Broeke

2008 *In search of resonating joy: Cooperation between informal and formal care takers, care receivers and volunteers in the multicultural city*. Conference paper, Amsterdam.

Waerness, Kari (ed.)

2004 *Dialogue on care*. Bergen: Centre for Women's and Gender Studies, University of Bergen.

News / Berichten

In Memoriam

Els van Dongen (1946-2009)

In the evening of 4th February 2009, Els van Dongen, anthropologist, colleague and editor of this journal, died at the age of 62. Her death came after a long and painful sickness, a period of hope and desperation, of gratefulness for a rich life mixed with stubborn resistance to the unfairness of that same life.



Els was a gifted anthropologist and an unusual colleague. Students loved her teaching, original, sharp, concerned and full of entertainment. Colleagues admired her for her unbridled energy and productivity and her many talents. She was fast in everything she undertook and impatient if things went too slowly. She deeply disliked bureaucracy and its meetings.

Her anthropological life started late, at the age of 35. She first trained as primary school teacher, during which time she met her husband Leo Hulshof. From 1968 till 1978 she taught in two primary schools in the proximity of their beautiful house in the rural south of the Netherlands, near the Belgian border. In 1978 she decided to study geography. During that course she discovered anthropology, which she liked instantly. In 1982 she decided to join the new part-time evening course anthropology at the University of Utrecht. She combined the role of student with the care of her family. She completed her master's 'cum laude' in 1988 with a thesis on the semiotic approach in the study of illness [1988].* That approach revealed her later interest in illness as a social event and a metaphor of conflict.

Six years later, in 1994, she defended her PhD thesis based on conversations with psychotic people in a psychiatric hospital. The title of her thesis *Zwervers, knutselaars, strategien* (Tramps, handymen, strategists) betrayed her aversion to psychiatric labels: [1994a]. She regarded the people she met in her research first of all as people out of tune with the 'normal' society, but gifted with extraordinary skills and ideas. I am sure that she experienced 'kinship' with them in their common 'unusualness'. Provocative also was the quote from John L. Caughey that she chose as device for her book:

* Years between square brackets refer to the publications listed at the end of the obituary.

“‘Schizophrenic’ is perhaps best kept in its traditional sense, as a pejorative label for deviants whose visions we do not like.” A few years later she would write that ‘madness’ showed: “that otherness is present in all of us. The otherness we fear” [2002b: 10].

In her book, which ten years later was published in a slightly revised English version [2004a], she sought to describe and understand how psychiatric patients experienced their world. She did so from the patient’s point of view, focusing on the fears and hopes that characterise the life in a clinical mental ward. Dilemmas in that life are: How to express subjectivity in an atmosphere designed to restrain demonstrative emotion? And how to maintain personal integrity in a completely ordered regime? She portrayed the psychiatric patients as ‘wanderers’ – homeless people, as it were – in an alien and hostile country, creating a ‘bricolage’ reality from materials at hand. Although she often positioned the therapists and psychiatrists as representatives of an oppressive regime, she did not doubt *their* integrity either.

In 1996 she joined the staff of the Medical Anthropology Unit at the University of Amsterdam and began to play her key-role as teacher and researcher in our team. She taught both general courses in anthropology and specific medical anthropology modules on themes such as ‘anthropology and psychiatry’, ‘anthropology and chronic illness’ and ‘medical anthropological ethnography in Europe’.

She published a collection of six narratives by people she met in the closed wards of the mental hospital during her PhD research. The personal stories are alternated by her observations and comments. The book, she wrote in her prologue, was her debt to these people: “I became indebted because the people shared with me what they had: their stories and (part of) their lives” [2002b: 8]. A little further she reflects: “When I went into the hospital, my aim was to study how people deal with mental illness and how mental illness could be understood from the perspective of the people themselves. Now I must admit that madness taught me more about the power of culture and the power of people than about madness” [2002b: 9].

The power of culture... In 2000 she co-edited a volume with contributions about the way Europe treated migrants in need of health care [2000]. A central theme in that volume is exclusion. It proved a recurrent theme in all her work: exclusion and marginalization of ‘others’, such as psychiatric patients, migrant, refugees, victims of violence and older people.

When she turned her attention to older people in South Africa, she came home with touching stories about the beauty and warmth of old age but also with horrifying data of older people being abused and maltreated by their own children and grandchildren. In one article [2005a] she spoke of ‘social gerontocide’. Invisible dramas unfold in poor households where the young generation despise and reject their older relatives for their passive role in the Apartheid era and try to ‘kill’ them socially. But, she stressed, the older people are not helpless victims. They fight back and develop strategies to survive.

Research among older people drew her attention to remembrance. Being old consists of having many memories. Rejecting or silencing those memories, however, implies a rejection of the older people themselves. “It is almost as if the past never happened,” one person tells her. In one of her last published articles [2008a] she quotes

a common saying of the young silencing the old: "That was your time... This time is ours!" In other words: Shut up. The 'culture of silence' in which they were forced to live during Apartheid is thus prolonged into the post-Apartheid era. That awareness of muted memories inspired her and Monica Ferreira, with whom she collaborated throughout the South Africa years, to bring out a collection of 'untold stories' to give voice to the lives of older people in the new South African society [2004b].

Her last major publications were two edited books, one about lying and concealment in medical settings and one about distance and proximity during illness. The former, co-edited with her long-time friend and colleague Sylvie Fainzang, argued that lying is a way of dealing with major crises that people encounter, particularly during illness [2005b]. The theme connects with ideas she has been airing from the very beginning: health problems are not only about health; they are linked to shame, exclusion, suffering and social violence. Lying in such circumstances may be the most effective medicine to restore the damage. But lying is mutual; those with power in medical contexts may exploit the lie as well, to maintain their position in the medical hegemony.

Facing distress [2007], co-edited with Ruth Kutalek, brought together papers of a conference of the European Association of Social Anthropology in Vienna. Distance and proximity constitute the ambiguity of the illness experience. On the one hand, illness leads to loss of independence and need of help and care by others; on the other hand, illness makes one lonely as it isolates the patient from normal social encounters and may scare others away. The pain of the sick body will thus be aggravated or replaced by the distress of ostracism.

In 1998 Els and I organized the first conference on 'Medical Anthropology at Home' (MAAH). For Els doing fieldwork 'at home' was a personal experience. For about ten years she had been doing research 'around the corner' in a psychiatric hospital. For me, it was – and remained – mainly a dream. For both of us it was an attempt to contribute to the de-exoticisation of (medical) anthropology. The theme and format (small-scale / intensive discussions) proved successful and since 1998 the MAAH conference has been held every second year, in The Netherlands, Spain, Italy, Finland and Denmark. Els, Sylvie Fainzang and Josep Comelles, became the driving forces. Els co-edited two voluminous special issues with conference proceedings [2001, 2002a] and remained active as long as she could. She wrote a paper [2008b] for the last conference in Denmark focusing on her personal sickness and suffering, but was unable to present it. We discussed her moving self-reflection in her absence.

In 1990 Els published her first article in *Medische Antropologie*. She described the social meaning of medicines in the psychiatric ward where she did her research. The medicines, she wrote, had a binding as well as an oppressive effect in the interaction between patients and staff. Relations between these two parties had the character of a combat in which medicines (taken or refused) replaced words. [1990] The article became a key-text in our work on 'pharmaceutical anthropology'.

In 1994 she helped as guest editor to make a special issue about *Zintuigen* (The Senses) and in that same year she joined the team of editors. She kept that position till the end of her life. *Medische Antropologie* has been the main outlet for her ideas on health, culture and violence, certainly in the first decade of her career. She wrote

eighteen articles and comments and an uncounted number of book reviews for this journal and (co-)edited five special issues on 'the senses' [1994b], 'older people, well-being and care' [1997], 'shit, culture and well-being' [1999], 'medical technology and the body' [2002c] and 'violence and human rights' [2005c]. We, the editors, will miss her fast and sharp judgment in the evaluation of manuscripts, her invaluable editorial suggestions to the authors and her cheerful directness during our discussions. Another journal favourite journal for her was *Anthropology & Medicine*, in which she published about the creation of cultural difference, lying and illness, and bodywork in nursing.

From the beginning in 1994 she has also been one of the editors of the book series 'Health, Culture and Society' which has brought out sixteen titles so far.

Els was a person with many talents. She took lessons in drawing and painting and produced beautiful canvasses with symbolic objects and portraits of relatives, friends, and people she met during fieldwork. Many of her productions can still be viewed on her website. She was also a filmmaker and photographer. The topics she chose for her photographs and films were sometimes from her anthropological research but often focused also on other things such as nature, everyday life and unexpected details such as the movements of hands during a conference.

Els has lived a very full life and accomplished more than most of us will be able to achieve in a life twice as long as hers. Even so, she was not always a happy scholar, perhaps feeling that her close colleagues did not fully understand or appreciate what she was doing. Close colleagues are sometimes more distant than those who are far away. Nevertheless, in this space, she carried on with her own strong and positive energy, becoming a popular guest lecturer in universities abroad and serving on various international scientific committees. When her sickness grew more serious, about two months before her death, we decided to make a book of friends for her. Thirty-eight people, colleagues from Amsterdam, from other Dutch universities and from abroad, plus students and friends contributed brief essays (and one poem) that dealt with the themes that had been prominent during her academic life. They focused on people who are excluded or marginalised, because of their age, their illness, their 'madness' or because they are living in violent circumstances. Other contributions were about people who are oppressed because they do not fit in the dominant discourse: people with HIV/AIDS, victims of (sexual) violence, refugees and migrants.

The title of the book 'Theory and Action,' was the name of a famous core module that Els taught in the Master's of Medical Anthropology and Sociology. In one of her papers she stressed that theory and action are closely connected in medical anthropology. "Theory helps us to bear our ignorance of facts," she quoted George Santayana. Facts, she continued, acquire their meaning from what people do to them, in this case anthropologists and the people they are working with. Theory provides a way of finding pertinent meanings and making intelligent interpretations that open the door to relevant action. She then cited the famous line from Kurt Lewin that there is nothing so practical as a good theory. A good theory is practical because it enhances understanding and produces the questions that really matter in medical anthropological research.

In her module, Els discussed with the students that problems of ill-health and suffering should be regarded in their historical, political and economic contexts and how larger social and political forces shape relations and actions and cultural imagination at the local level. The necessary – but often difficult – cooperation between anthropology and health workers received special attention. Questions that were addressed during the course included: Why do we need theory? Which theories are relevant? How can we link macro, meso en micro theories with practical work?

‘Theory and Action’ constitutes both medical anthropology’s ambition and its weakness. The frequent criticism that medical anthropology receives from those who work in the heat of the day confirms that, unfortunately, much academic work remains largely or totally useless to ‘actors’ in health care. Nearly every contributor in the book struggled in one way or the other with this dilemma and with the challenge of proving the practical relevance of theory.

When her condition became critical, we decided to tell her about the book and gave her the list of authors and the titles of their contributions. She was overwhelmed and deeply moved when she saw the list of so many friends. She gave us one of her paintings for the cover of the book and allowed us to include one of her last essays that dealt with her own illness and the way people express their connectedness in times of suffering and uncertainty [2009]. Four weeks later we brought the book. I held a short speech and she responded directly and with humour. She was almost too weak to open the paper wrapped around the book. We drank a glass of wine and had a lovely lunch while she observed us from the sofa. She read the essays and reacted personally to many of the authors. Ten days later she died. On the 9th February we said farewell to her in a ceremony full of music and words of comfort.

Sjaak van der Geest



‘Older woman in mental hospital’ by Els van Dongen

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Els van Dongen, docent en begeleider

“We are all orphans now,” schreef Amina, een van de oud-studenten van Els in haar e-mail toen ze het bericht ontving dat Els was overleden. Het klinkt misschien wat pathetisch, maar op professioneel vlak voel ik me ook een beetje zo. Voor mij en vele andere studenten heeft Els een bepalende invloed gehad. Haar colleges waren zeer bijzonder. Het feit dat de laatste onderwijsmodule die ze heeft gegeven door studenten met een 10 werd beoordeeld, zegt voldoende. Ze gaf eigenlijk geen colleges, ze vertelde verhalen op een gepassioneerde wijze. En wij studenten hingen altijd aan haar lippen. De associatieve manier van denken en praten, haar belezenheid en het gemak waarmee ze in haar verhalen theoretische patronen over het leven van alledag kon leggen was uitzonderlijk. Ze was altijd zeer goed voorbereid. Al haar verhalen waren afgewogen en uitgeschreven. De passie waarmee ze vertelde was aanstekelijk. Ze heeft mij richting gegeven aan mijn denken en werken. Dit geldt ook voor vele andere studenten. Door haar is antropologie voor mij geen vak, maar een manier van leven geworden.

Ze begeleidde mij met mijn afstudeerscriptie. Ze was zorgzaam, bijna moederlijk af en toe. Gaf me een knuffel toen ik vertrok voor mijn veldwerk en in een van haar e-mails uitte ze haar zorg over dat ik te hard werkte. Ze schreef: “Ook genieten hoor! Niet alleen denken maar ook doen en pas goed op jezelf.” Maar thuis gekomen was het afgelopen met haar stimulans om te genieten. Ze eiste veel van ons studenten. Toen ik met enige trots het eerste hoofdstuk van mijn afstudeerscriptie had ingeleverd zei ze tijdens de bespreking, dat ik me er te simpel van afmaakte en me te veel op geplaveide paden begaf. Dat kon niet. “Kruip maar eens door de bramenstruiken”, zei ze en met die opmerking stond ik volkomen verward weer buiten de deur. Het kostte me altijd enige tijd dit soort cryptische opmerkingen van haar handen en voeten te geven, maar uiteindelijk bracht het me verder dan ik zelf ooit gedacht had.

Ze was ook mijn co-promotor. Ik had haar daarvoor gevraagd vanwege haar dwarse en creatieve geest. En ik werd niet teleurgesteld. Altijd weer kwam ze met bijzondere inzichten en suggesties.

In de afgelopen jaren is mijn relatie met haar veel intenser en persoonlijker geworden. In het najaar 2007 zouden we gaan vieren dat het erop leek dat ze de kanker had overwonnen. We zouden gaan wandelen en champagne drinken op het strand. We hadden al een datum: maandag 15 oktober om 11.00 's ochtends. Vroeg voor champagne, maar het maakte niet uit want we hadden reden genoeg om de dag in gepaste dronkenschap door te brengen. Een paar dagen daarvoor belde ze af. Ze had erg veel pijn en was zeer ongerust. Tot mijn grote verdriet is voor champagne drinken nooit meer een reden geweest.

Ondanks alle operaties, zorgen, verdriet en pijn heeft ze me tot aan enkele maanden voor haar overlijden nog met mijn proefschrift begeleid. Ik kan niet goed onder woorden brengen wat die inzet voor me betekent.

Beiden hadden wij zo gehoopt dat ze mijn rite de passage, het verdedigen van mijn proefschrift, nog mee zou kunnen maken. Het mocht niet zo zijn.

Ik zal het nu, net als de andere oud studenten, zonder haar moeten doen, als een soort weeskind, maar wel met onze bagage gevuld met visies, ideeën en ontvuchtende opmerkingen van Els. Ze heeft voor de rest van mijn leven een plek in mijn hart én in hoofd veroverd. Ik hoop dat ze me zo blijvend van het geplaveide pad houdt.

Marian Tankink*

In Memoriam

Bas Treffers 'de man zonder voetstappen' (1944-2008)

Bas Treffers stoelroller ten gevolge van polio heeft zich meer dan dertig jaar met humor en constructieve boosheid regionaal en (inter)nationaal ingezet voor een betere positie van mensen met een beperking. Zo was Bas bestuurslid van de Gehandicaptenraad, de voorloper van de Chronisch zieken en Gehandicapten Raad en medeoprichter en vice-voorzitter van het European Disability Forum (EDF) alwaar hij 'Toegankelijkheid' in zijn portefeuille had. Hij heeft onder andere bijgedragen aan de acceptatie van en certificering van toegankelijkheidsnormen en de instelling van de leerstoel Europees Gehandicaptenrecht.

Behalve belangenbehartiger was Bas vader, echtgenoot, schrijver, dichter en Huisenaar. Ik kende Bas in eerste instantie als straatgenoot en vader van een klasgenoot. Als klein meisje vond ik het wel handig dat ik me aan zijn rolstoel kon vastgrijpen en mijn hoofd niet in mijn nek hoefde te leggen om hem aan te kunnen kijken (een pre als je, zoals ik, een evenwichtsstoornis hebt). Pas vele jaren later spraken we elkaar over een gemeenschappelijke interesse: het gebrek aan toegankelijkheid van medische voorzieningen en procedures. Het komt nog steeds voor dat patiënten met makke niet volledig onderzocht worden omdat de gangbare medische procedures en voorzieningen, zoals behandelafels, niet ingesteld zijn op deze 'vaste klanten'. Bas is 24 december 2008 voortijdig overleden. Hij zal gemist worden niet alleen om de persoon die hij was maar ook omdat zijn werk nog lang niet af is.

Karen Mogendorff

In Memoriam

Cecil G. Helman (1944-2009)

Dr Cecil Helman, medical anthropologist and author of 'Culture, Health & Illness', died on Monday 16 June at the age of 65. A few months ago he was diagnosed with

* Bewerking van toespraak tijdens afscheidsdienst op 9 februari 2009.

motor neurone disease, which led to increasing speech debility and swallowing problems. For the last few months he was unable to speak and wrote on a pad. He had just retired as professor of Medical Anthropology at Brunel University, West London and senior lecturer at University College London, Medical School.

Cecil Helman was born in Cape Town, South Africa into a medical family, and qualified as a doctor at the University of Cape Town. He left South Africa because of the *apartheid* system, and then studied social anthropology at University College London. Over the years he had combined several different careers into a creative synthesis: family doctor, anthropologist, university lecturer, writer and poet.

After a brief spell as a ship's doctor in the Mediterranean, he worked as a family doctor for 27 years for the National Health Service, in an around London, combining his clinical practice with an academic career. He was an international expert on medical anthropology – the cross-cultural study of health, illness, and medical care – and on different forms of health care and healing. He did research on primary health care systems, and on traditional healers, in South Africa, Brazil, and elsewhere.

He lectured to medical students, doctors, and nurses and taught courses on cross-cultural health care. He was particularly interested in the humanistic side of medicine – especially the role of stories and narratives in medical care, and what they reveal about the inner worlds of both doctor and patient. Among his other interests were the role of metaphors and symbols in our understanding of the human body, in both illness and health; and what the Western industrialized world could learn from the healing systems of more traditional societies, when dealing with different aspects of human suffering.

His textbook '*Culture, Health and Illness*' (first published in 1984; now in its 5th edition) has been translated into seven languages and is being used in more than 40 countries, including in over 120 universities, medical schools and nursing colleges. Cecil Helman is well-known to students of medical anthropology in the Netherlands as his book has been used for more than twenty years in courses at the University of Amsterdam. Primarily written for health professionals, it is without doubt the most complete overview of medical anthropology. For anthropologists it contains perhaps insufficient theoretical discussion from a general cultural anthropological perspective, but as a textbook it offers a wealth of information, a precious overview and abundant suggestions for further reading.

On the literary side, Cecil Helman published both non-fiction and fiction, including a memoir '*Suburban Shaman: Tales from Medicine's Frontline*', a book of essays about the body, an anthology of stories about doctors and patients, a novella, and several books of prose poems. His poetry and other writings have appeared in many anthologies and literary journals.

We have lost a creative and inspiring colleague but his solid academic and sparkling literary work will be with us for many more years.

Sjaak van der Geest*

* Part of this text has been adjusted from Cecil Helman's personal website.

Invitation and call for papers

Symposium 'Care & Health Care', 18 December 2009 University of Amsterdam

The annual symposium of the journal *Medische Antropologie* (18 December 2009) will have as its theme 'Care & Health Care'. The editors invite you to contribute a paper on this theme. An invitational article by Arthur Kleinman and Sjaak van der Geest 'Care in health care: Remaking the moral world of medicine' appears in this June issue of the journal. The article that intends to motivate and encourage participation and writing of papers can be sent to paper writers on their request. At the end of this call you will find a brief sketch of the theme.

The symposium will take place at the University of Amsterdam. Venue is Het Spinhuis, Oudezijds Achterwal 185, Amsterdam. The symposium will consist of thematic discussions based on submitted papers of the participants. During the symposium there will be no formal presentation of papers, but only a short introduction to be followed by a discussion.

A selection of the symposium papers will be published in the summer 2010 issue of *Medische Antropologie*. Registration for the symposium is possible until 30 November via the website of Medical Anthropology & Sociology Unit www.medical-anthropology.nl under Agenda: 'Symposium Care & Health Care'; click: Register, fill the form and submit. Participation is limited to 35 people, and registration will be processed in order of arrival. The symposium fee is € 25 to be paid at the symposium. Participants will be given access to all papers no later than a week in advance of the symposium. They are expected to read all the papers in preparation of the symposium.

Those who are interested in submitting a paper should provide a title plus brief abstract together with their registration, before 1 November 2009. The complete paper should be sent as an attachment per email to: Janus Oomen, h.a.p.c.oomen@uva.nl before November 27, 2008. Papers should be in English. Drafts and work in progress are welcome.

Authors are invited to consider the following questions:

- What constitutes 'good care' in a given social or cultural situation?
- Are medicine and care compatible?
- Is there enough 'time' for care in today's health care system?
- To what extent does the concept of care vary in different cultural contexts?
- How can we understand the gender-based differences in care perception and practice?
- Is care related to reciprocity?
- Which conditions call for care and which ones do not?

- How does the concept of care evolve in relation to the development of medical technology?
- How does care evolve in conditions of radical cultural change and acculturation, e.g. in the life of migrants?
- What is the economic basis for caregiving?
- What explains the low social status of caregiving as a profession?
- What policy could enhance the quality of care?