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‘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

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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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