Introducing 'Care and Health Care'

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Rosie Read (2005) did research in a Czech nursing home for older people. The management of the home was in hands of catholic nuns, but most of the nurses and other care providers were 'lay' women. Read calls them 'civil nurses'. Her description of the daily practice in the home reveals different views on what constitutes 'good care' and what may be expected from the nurses employed in the institution. The nuns speak about care in terms of kinship. Having no children of their own, they emphasize that they are 'mothers' for all those that have been entrusted to their care. Care, for them, includes personal empathy. They criticize the civil nurses for their laziness as they are only prepared to deliver the 'bare minimum' of physical and medical care (pp. 149-150). The nurses, on the other hand complain about the nuns' laziness. One of them tells the researcher about a certain nun:

> She spends all her time holding patients' hands and comforting them, but in the meantime everyone else on the shift is left to do all the real work (p. 155).

The civil nurses accuse the nuns who spend too long at patients' bedsides of being 'work shy'. For them physical care is 'real work' and emotional care 'window dressing' (p. 156). Read concludes her article with the remark that care in the nursing home has become a daily *contested activity* (p. 157).

Read's vignette of nurses and nuns accusing each other of not caring properly is a telling example of the confusion and disagreement about what care is or should be. The contest about 'good care' was also the starting point of the symposium on 'Care and Health Care' (Amsterdam, December 2009) and dominated the discussions at the symposium. That contest is carried on in and between the papers that we selected for this special issue.

The theme 'Care and Health Care' had been set forth in a 'teaser' or 'curtain raiser' article (Kleinman & Van der Geest 2009) published six months ahead of the symposium. The text, partly based on an address that Kleinman delivered to a mainly medical audience, expressed strong doubts about the presence of 'care' in the highly technical environment of present-day health care. 'Health *care*', in other words, threatened to become a misnomer (or had already become one).

A few quotes from the article illustrate the authors' scepticism about care in today's health care:

> … 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 (p. 162).

> 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 (p. 163).

> 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… (p. 164).

Is there indeed a growing gulf between technical skill and 'true care'? Or, put differently, are personal dedication and empathy indeed an indispensable part of 'good care'? Arguments pro and con debated are abundant. The 'emotion-sociologist' Arlie Hochschild (2003) is one of the most prominent advocates of care as a social, emotional and moral activity. Her focus, however, is on 'informal care' carried out in the context of family life where care is indeed hard to imagine without the ingredients of emotion, concern and personalized reciprocity. Hochschild warns against a commercialisation of this type of care as this may take out the soul – or, in Mauss' (Maori) term, the *hau* – of caregiving. Paula England (2005), in her overview of theoretical perspectives on care work characterizes this view as "the dichotomy between love and money." Obviously, that dichotomistic perspective does not hold – if it ever does – when we speak about formal professional caregiving in hospitals and other institutions, and also in the home situation.

Evelien Tonkens and her colleagues, who study the complexities of informal care (*mantelzorg*) in the Netherlands, are much inspired by Hochschild's work on 'emotional labour' (Tonkens et al. 2009). They argue that this type of care would be impossible without the emotional gift it entails but they also point out that caregivers receive something in return, some sort of emotional satisfaction, which can hardly be reckoned to be 'reciprocity', however. They call it 'resonating joy' (*weerkaatst plezier*).

It would not be right to claim that this type of care based on long-term family relations is entirely different from the care that professionals are expected to deliver in formal institutions. But it would also be wrong to measure the quality of professional care by criteria of family-based care, as the nuns in the Czech study do (see also Huebner 2007).

Recent discussions on care, formal and informal, tend to hold a less 'romantic' view on care. Two arguments stand out. One refers to the point just made, that money and authentic care do not need to be one another's enemy. The second one rejects the common dichotomy between technology and care.

A striking example of the latter can be found in Gerhard Nijhof's reflection on his stay in a hospital where he was treated for cancer (Nijhof 2000). He remembers that social scientists had mainly written in negative terms about technology in hospitals; machines took away the attention of doctors from patients. Technology and care were seen as competitors. Technology had become an excuse for not giving proper care to the patient as a human person. He had never read anything about medical machinery giving the patient a feeling of security and safety, but that was what *he* experienced. He called it 'apparatus security' (*apparaatszekerheid*). In the Intensive Care Unit he had become attached to the many tubes, monitors and machines that were tied to his sick body. They were like umbilical cords that kept him alive. When the doctors inform him that he may now leave the Intensive Care, he begins to panic, afraid that he cannot live without the caring machinery. If 'feeling safe' can be regarded as the outcome – and proof – of good care (cf. Iedema 2009), Nijhof experienced that moment more care in the 'hands' of machines than of nurses and doctors.

Nijhof's experience inspired me when I wrote an article about hospitals as places full of magic and emotion thanks to – and not in spite of – science and technology. Feelings of hope in patients are not necessarily engendered by comforting words or a loving touch; high tech machinery and impersonal science also provide comfort and hope.

> Our visual imagination of emotion has conservatively stuck to conventional symbols such as sweet-scented flowers, cleft hearts, caring hands, colourful sunsets and smiling children. The cold and sterile machinery of intensive care units with their monitors, tubes and sensors and the forbidding appearance of the specialist with his gruff voice also conjure up emotions (Van der Geest 2005: 146).

Annemarie Mol (2008) in her *The logic of care* does not directly address the supposed conflict between 'cold technology' and 'warm care', but it is clear that she does not see this distinction as helpful in analysing what care is and does. On the first page of her essay she announces that she will skip the term 'cure' (in distinction to 'care') because the two boil down to the same thing; they largely overlap in daily medical practice:

> In scholarly discussions about health care, 'care' is often distinguished from 'cure'. If it is done, the first term, 'care', is used for activities such as washing, feeding, and dressing wounds, that are done to make daily life more bearable. The second term, 'cure', resonates with the possibility of healing, and is applied to interventions in the course of a disease…. In practice… the activities categorized as 'care' and 'cure' overlap. (Caring) food and (curing) drugs may have similar effects on a body. Caringly dressing a wound may help its cure (Mol 2008: 1).

Reading through a number of web logs discussing care, I noticed a similar trend: the quality of care depends on whether the activity benefits the patient, improves his condition. The rest – why, how, by who? – is of minor importance. Mol (2008: 89), it seems to me, finds herself on the same wavelength: "The logic of care itself is first and foremost practical. It is concerned with actively improving life."

The contributions to this special issue have been placed on a continuum, beginning with those in general agreement with the pessimistic and critical conclusion of the 'teaser' (Kleinman & Van der Geest 2009) and ending with those which reject that view and pointing out that care exists in unexpected places and takes unexpected appearances.

The first two articles are reflections of 'informal' caregivers (two daughters and one partner) on the type of care their relative received from professional health workers. It can hardly be coincidence that the most critical papers on the quality of care in health care were written by authors who themselves were (informal) caregivers. In their description, family care – based on long-lasting emotional attachment and familial reciprocity – meets (and clashes with) a more distanced style of (professional) care based on rationality and technical efficiency.

Athena McLean and Deanna Trakas write about their elderly parents in care institutions in the US. As daughters *and* authors they are particularly sensitive to inadequate care for the love ones. They perceive the contrast between moral care and 'instrumental care' as follows:

> Instrumental care giving, directed at contractually completing prescribed care tasks, ignores the subjectivity and appeals of the person receiving care; even worse, it denies her personhood, as it *uses* her as the very *means* by which the caregiver completes her/his tasks. Such is the epitome of the dehumanizing 'I-it' relation (Buber 1996) – one of power wherein the person is simply 'processed' by the caregiver.

However, they also point out that the very best formal caregivers were those who escaped this instrumental approach to care and moved from 'I-it' relations to intersubjective ones with the elder under their charge. Herein, they suggest, clues for more fully theorizing an ethic of late-life care might be located.

Martine Verwey writes about her experiences as primary caregiver of her seriously sick partner and her encounters with professional caregivers who came to visit her husband. Most of those encounters were rewarding and respectful; others were 'privacy encroachments', instances of 'institutional othering'. Her experiences of professional caregiving ranged from closeness to distance. Her expectation regarding professional caregivers is that they, above all, are humanitarian:

> We experienced caregivers who, so to speak, had eyes in their head, in their hands and in their back, and who made a point of maintaining a human relationship – caregivers who respected the team which Hannes and I formed and who regarded a family caretaker as a co-worker and not as a competitor.

Christine Böhmig looks at nurses on a hospital ward in Ghana. Her focus is on religious activities that are intermingled with the nurses' care practices. The Western reader may see this as an ideal of holistic care and healing, but in the Ghanaian context religion's presence in the hospital reflects a normal aspect of ordinary life. Prayers and spiritual advice do comfort patients and thus add to the quality of care, but they are also convenient tools to create distance and produce an excuse for the shortcomings in hospital care: if we cannot take care of you, someone in heaven will.

Winny Koster's contribution discusses the predicament of relatives in a Greek village who are expected to take the responsibility for the care of their elderly parents but may be unable due to logistic or economic impediments. Her exploration shows a number of options including hiring the assistance of immigrant women. Admission to a care institution, however, is not a real option as this will be severely criticised by the community. Decisions about (informal) caregiving are strongly influenced by norms of reciprocity and social pressure.

Giorgos Kostakiotis' paper also deals with Greece and examines how at-home care of frail elders is negotiated in families. The caregiving that results from that negotiation is linked to several lines of reciprocity (inheritance practices, kinship obligations, residence patterns, marriage expectations and wedding dowries) and public censure. Kostakiotis, who is both a social worker and an anthropologist, devotes special attention to the gendered character of caregiving and to the anxiety of caregivers concerning the burden of care when the elders' dependency (including incontinence) increases. Care is not always an act of love; relatives may be forced into it and resent it.

Annemiek Richters, Théoneste Rutayisire and Cora Dekker take the reader to an entirely different world. The community-based care for people in post-war Rwanda which they describe is hardly related to health care in the strict sense of the word but is an intervention that 'treats' what Kleinman has termed 'social suffering'. Concepts like 'therapy' and 'medicine' are mainly used in a metaphoric sense. The authors examine how after the erosion of social capital as a result of political violence social cohesion is recreated through the mediation of a program that they call 'sociotherapy'. Sociotherapy, consisting of group sessions for people who want to restore interest in each other, remakes their moral world. Care, in this perspective, helps people "to regain self-respect, rebuild trust, feel safe again, overcome unjustified self-blame, re-establish a moral equilibrium, have hope, live without terror, forgive those who have harmed them, apologize to those whom they have wronged, and regain their rightful place in the community."

Community-based care is also the topic of Henny Slegh's contribution about a support program for women in Southern Mozambique. She highlights the contradictions in the perception of care and respect (beating women, for example, is regarded as an expression of love) and shows how in the intervention women regain their self-respect. Through the program new concepts like gender-based violence and gender inequality were introduced and used as levers to remove the very same violence and inequality. Slegh concludes that Western notions of women's rights connect insufficiently to the real needs of women. Strengthened by the acknowledgment of their problems the women who participated in the program "… felt encouraged to search

for help, and take another position in life. In breaking the silence and isolation of suffering, they navigate their life in society, searching for different resources that may provide them with help and improve their possibilities."

Hannah Brown is perhaps most explicit in her rejection of the dichotomy between objective rational care (or rather 'cure') and emotional familial care. Care and technology, she insists, are not incompatible but are intertwined; meanwhile, 'emotional care can be cold and distant. She supports her argument with a rich ethnographic vignette of her research in a Kenyan rural hospital. She observes the harsh and hierarchical behaviour of a midwife toward a young woman in labour and enters into a discussion with the midwife. Why so rough and unfriendly? The midwife corrects her: "It's true we don't sympathise, although we do inside, because if we sympathise with them they'll relax" [i.e. they won't push hard enough]. She plays on *luoro* [Luo term for respect/fear] to provide the best care for the young woman and her baby. Brown concludes that there can be good care in 'cruelty':

> [In the hospital]… care in healthcare cannot be thought of as a singular set of practices within which it is easy to identify certain aspects as 'good'; 'good care' is relationally and contextually contingent. In this sense care in health care is very much like care outside of health care. I suggest that further exploration of how the intersection of how different types of care can work to produce outcomes which both patients and care-givers experience as good or successful, within similar medical contexts, may… ultimately provide us with observations which we can use to improve care outcomes by engaging with, and perhaps supporting, such divergent registers of meaning around care, even as we search for ways to improve patients' experience of health care and fight against cruel and abusive treatment.

The last article, by Jeannette Pols, also critiques the assumed opposition between health care technology and human care and contact. She examines a technical device, the Health Buddy (HB), which supports terminal cancer patients at home. Getting away from the common metaphoric adjectives of 'cold' (technology) and 'warm' (care), she introduces the concept of 'fit' to indicate good caring relations. 'Fit' refers to a good match between individual need and intervention. The patients told Pols that they loved the device because it watched over their condition. The experiences of the patients with the HB suggest that medical technology can indeed be understood as caring.

Kleinman and Van der Geest (2009: 165) closed their 'teaser' with the observation that "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." The contributions to this special issue confirm this but they also suggest that "giving and receiving care" should be understood in a wider sense than personal body care and explicit expressions of empathy. Good care travels under many disguises, including 'group sessions', 'commercial medicine', 'cold technology', 'harsh treatment', and 'impersonal clinical diagnosis'.

Note

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