

Proximity and distance in palliative care from the perspective of primary caregiver

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Caregiving which addresses a situation of serious illness at home is an interpersonal experience for the sick person, health professionals and family members. Before I go into a discussion about what constitutes 'good care' in this setting, my aim is to understand the boundary disturbances and tensions observed as primary caregiver in the relationship between professional caregivers and my lifelong partner. In the search for models, concepts and theories for clarification, this contribution bears witness to both painful and rich personal experiences. The power of negative images regarding a life worth living will be set against the grief of losing autonomy and the compelling need to live a self-determined life.

[palliative care, end-of-life care, home health care, family, network, professional caregiver, quality of life, amyotrophic lateral sclerosis, ALS, Switzerland]

When I started writing this personal paper, two articles were especially helpful: *Today's biomedicine and caregiving* by Arthur Kleinman (2007; see also Kleinman & Van der Geest 2009; Kleinman 2009b), and *Keeping the feet of the gods and the saints warm* by Els van Dongen (2009). In his Cleveringa Lecture, Kleinman draws on his personal experience as the caregiver for his wife, Joan Kleinman, who suffers from a progressive neurodegenerative disorder. Drawing on her own experience as a patient, Els van Dongen offers keen insight into times of suffering as she observed "the pragmatics of uncertainty" (Whyte 1997) surrounding her own severe cancer. Despite the inspiration provided by these authors, I knew it would be hard, but I didn't know it would be *that* hard to face the memories of my partner's three-year illness. Often I couldn't go on for any length of time and had to seek comfort again in the articles mentioned. This contribution is more a *témoignage* than an analytical paper based on research and fieldwork. It is the first step in communicating specific experiences in the process of caring for a person close to oneself who is suffering from a terminal illness. My interest, in the words of Els van Dongen, is to better understand what illness is about: the social relationships and the uncertainties of (social) life (2009: 8). Therefore my focus is on one of the manifold social relationships: the therapeutic

relationship between health professionals, on the one hand, and patient and family members on the other in the context of end-of-life care.

Shortly after the close person I speak of passed away, I planned to write a manual for families of people suffering from amyotrophic lateral sclerosis (see next section). I had in mind a handbook containing practical tips as well as personal experiences. One year later I realised that these two areas must be separated, and that I would not be able to finish the manual until I had come to terms myself with the multifaceted, painful experiences I had observed. Raising questions about boundary disturbances involving professionals during the course of my partner's illness, and thereby contributing to breaking a taboo, will be the entry point of this essay. I had the experiences I describe as observer and, more and more as his illness progressed, as mediator on behalf of my husband in the process of interfacing with the health-care system. As author, my position is threefold: partner, caregiver, and anthropologist on a continuum from an autoethnographic account to a medical anthropological perspective. Just the combination of participant, observer, and analyzer, as Tankink (2009: 321) points out, helps the ethnographer to "enter the psychic space of his or her subjects to capture the subtle and nuanced meanings of their actions and words" (Churchill 2005: 5-6). Roles as partner and caregiver, and activities such as participation, observation, and analysis are intertwined. Anthropology itself is a relational science, which implies struggling to find a balance between proximity and distance (Van Dongen 2007: 30).

The biomedical context of amyotrophic lateral sclerosis (ALS)

Motor neuron disease (MND) consists of a group of neurodegenerative disorders including progressive muscle atrophy, amyotrophic lateral sclerosis (ALS) and primary lateral sclerosis. ALS, also known as *Maladie du Charcot* or *Lou Gehrig's disease*, is a complex and multifactorial disease and is the most common form of motor neuron disease in adults. It is a chronic illness of the central nervous system, first described in 1869 by a French neurologist. In neurological nosology, ALS belongs to the category that includes Parkinson's and Alzheimer's disease but not multiple sclerosis. The degeneration of nerve cells in ALS and other neurodegenerative disorders begins prior to the appearance of symptoms. There is substantial loss of motor neurons during this pre-symptomatic phase of the disease. The disorder preferentially affects motor neurons, namely the motor nerve cells in the brain and the spinal cord. Nerves and muscles form a functional unity. The muscles are therefore affected indirectly, leading to progressive paralysis. People with ALS become severely disabled as the disease progresses. Just where the disorder breaks out is variable. If the muscles used for speaking, swallowing and breathing are affected, this is known as a bulbar form. Patients with limb onset form experience fine-motor disturbances and paralyses in the arms and legs. One cause may be environmental, but little is known about this. Several disease-causing genes have been identified. In any case, before the disorder breaks out, as just indicated, the nerve cells have already undergone degeneration. The course of the sickness varies considerably. Despite intensive research there is still no known

cure, but the progress of the disease can be slowed down with medication (Goldman n.d.). There is evidence that the quality of life of people living with ALS is often quite high and does not correlate with their physical status (Wasner 2008).

The more the sickness progresses, the more professionals become part of the multidisciplinary care. In the following diagram, health professionals involved during the course of the sickness are listed in the outer circle, while the core consists of the patient and informal family and network caregivers.



Both its diversity and its inner coherence are displayed in this model of the contacts within formal and informal caring for someone living with ALS/MND.

Relationship between health professionals, patient and caregiving family members

Before I can analyse what constitutes ‘good care’ for a seriously ill person in a home care setting, I want to understand the boundary disturbances and tensions I observed as primary caregiver in the relationship between professional caregivers and my life-long partner. Which concepts of ethnography and medical anthropology might be useful to bring clarity? I started my inquiry with ethnographic accounts of end-of-life care (Norwood 2006, 2007, 2009) and with an anthropology of bereavement (Macdonald 2009). My objective, however, was to describe the unclear power relationship in palliative care and the uneasiness that can occur in the face of dying. For this purpose I took up the work of the philosopher Michel Foucault (1973) and its application by Janet Heaton (1999) on informal care and by Kristin Bjornsdottir (2009) on home care. With the help of philosophers such as Alasdair Macintyre (2007), Annemarie Mol (2008) and the medical anthropologist and psychiatrist Arthur Kleinman (1999, 2006), I tried to clarify my own thinking about morality. This approach though was too broad, and it suited only partly my search to be able to explain the disturbances I experienced. In retrospect, most disturbing in my reflections were my own feelings.

My husband, Hannes, and I experienced at times (which are still painful to recall) helpers who seemed unaware of their own sense of helplessness in the face of challenging situations. Our perception was based on their pathologizing and reifying comments, which were hurtful rather than helpful. Whenever this occurred, we also felt that we were being dealt with by hyperactive and hyperanxious caregivers, instead of by professionals who are able to observe the actual situation and offer encouragement. Often when medical professionals know for certain that a patient is terminally ill, they see mainly the negative aspects, what lacks and what no longer works, thereby making the patient even weaker. When health professionals orient themselves to a deficit model, as we saw it, it can happen that while treating the patient they are writing a “protocol of decay” (my partner’s words) in their head and comment on this in the presence of the patient. This enraged me each time it happened. And once more in his thinking, Hannes had to convince himself of the opposite and reframe the meaning of what had been said. Fortunately, we also experienced professionals who respected our dignity, lent us courage and boosted our energy.

My flying into a rage again and again was strongly conditioned by my feelings of loss and helplessness towards the finality of my partner’s inevitable death. I write from the viewpoint of a family caregiver about situations and tensions I experienced myself. I do not want to merely say how things should *not* be done but rather discern the mechanisms that can lead to so much aggressiveness in response to the helplessness inherent in palliative care and caregiving at home. At the same time, I am aware that patients and those close to them may perceive care practice in an entirely different way than is intended by the practitioner.

Power relations in how professionals interact with patients and family caregivers in end-of-life care was the starting point of this essay. My inner, not yet conscious question was another one. In the process of rethinking my paper, I realised I had got caught up in boundary disturbances involving professionals that I had observed during the course of my partner’s illness. My task as ethnographer, however, is rather to consider the implications of these experiences for the knowledge that I hope to gain (McLean 2007: 281). In the meantime, in my search for different concepts relating to my experiences, I became aware of the link between knowledge and emotions. One could say that my experiences confirmed the neglected question of power in palliative care. Another aspect is the subconscious inner need to make a vulnerable person weaker than she or he is. To illustrate this I quote Hannes: “There are professionals who want to make themselves indispensable, and there are those who *are* indispensable.” But what about my feelings? The description of my husband’s and my experiences is one thing; to deal with feelings of suppressed rage is another. An anthropologist by training, I got acquainted with taking personal feelings during research into account as a reflective instrument. A great help on my way to coming to terms with the many-layered, painful memories was finally the work of anthropologists who focused on the question of how to deal with the ‘shadow side’ of fieldwork (McLean & Leibing 2007). Their publication was inspired by the quandary Athena McLean had faced when studying a topic (nursing home care) that mirrored events in her own life with her mother. Reading her reflections on conducting dementia research and at the same time caring for her mother

with dementia, I recognised her rage. I am not the only one, I thought. This enabled me to move away from my original aim to understand power relations and move towards myself to understand the pain, rage and helplessness I often felt in interactions with professional caregivers during Hannes' illness. The arguments and reflections compiled in the above-mentioned publication supported my notion that subjectivity must be set against the objectification of the human body, as Foucault (1973) analysed in his description of the development of pathological anatomy. In what follows, I attempt to set my subjectivity against medical objectification in palliative care. To move away from a deficit model, I finally propose an approach that focuses on 'caring as life practice' as opposed to 'caring as burden'.

Dignity, dependence and boundary-crossing

As my partner became weaker and increasingly reliant on the help of others, the boundary disturbances on the part of therapeutic professionals became more frequent. In the following sections I have drawn four sketches of health professionals in action and included a fifth personal vignette.

Stable phase

To be ill with ALS means that one can no longer rely on the security and familiar functions provided by the body over the years; one must find a way to adapt to disablement. Neurologists assure us that there is much evidence of stable phases occurring during the course of the illness. However, the adaptation process can proceed so rapidly that a person living with ALS needs a great deal of strength not to abandon hope that such stabilization is possible. As close family, I rather longed for this, but hardly dared to believe it possible.

While Hannes was still able to travel, against the advice of some disbelieving professional caregivers in our town in Switzerland, we often made long journeys by train through France and the Netherlands. It meant freedom and it gave us strength, knowing that in spite of everything we were still capable of intense enjoyment. After a lengthy summer absence, we were visited by the physiotherapist who had treated Hannes at the beginning in her practice and, with the advancing illness, later at home. "Have there been any new developments?" she asked, as usual. Her client stood smiling in front of her and answered: "Stabilization." It was his way of referring to the welcomed plateau that had lasted three months that summer. The physiotherapist had not seen him for a while and was no longer used to his speech, which had been deteriorating. "What?" she asked. Meanwhile, I had placed myself alongside the therapist and could observe the situation. The client repeated quietly, with a broad smile: "Stabilization." The therapist still would not understand him, and asked, "What do you mean?" For the third time the client, still smiling broadly, replied: "Stabilization." Abruptly, the therapist turned her head to me and said, "Speech doesn't function anymore either."

Relief for primary caregivers and burn-out prevention

It is known that the informal carers, most often spouses or close family members, play a central role in the patient's well-being (Wasner 2008). Humour and attention are as much needed as technical care. Therefore, it appears to be extremely important for caregivers to be given sufficient information on the illness, its course, terminal conditions, practical help options and technical interventions. Nutritional enteral feeding, for example, using a percutaneous endoscopic gastrostomy (PEG) tube and ventilatory support, using non-invasive ventilation (NIV), are being increasingly employed in the care of patients suffering from ALS/MND. Understandably, palliative care specialists are keen to prevent burn-out in family caregivers.

As long as it was still possible, I took advantage of opportunities to take a few days off and rest. In my absence friends, neighbours and professionals took over the necessary care during the day and through the night. As the illness progressed and care became more complex, the palliative care physician and palliative homecare nurse increasingly spoke of a possible short stay in a hospice for Hannes, even if only for one day. Hannes and I knew that the stress of the transfer would out-weigh the benefits of the rest for me as primary caregiver. These discussions with palliative care specialists frequently had undercurrents of tension. Once the general practitioner made it clear to me that I must take an afternoon off on a regular basis and should enlist the help of home health care assistants. In answer to my objection that too often my husband's needs and requirements were overlooked and that we therefore preferred professional caregivers, the GP commented to my husband: "Well, then just sit uncomfortably for a few hours." On another occasion, during an endless current-situation assessment and a strained discussion about staying in a hospice once a week, the palliative homecare nurse said irritably "In that case, Mr S. will just have to bite the bullet ('sour apple' in German)." [*"Herr S. muss dann halt in den sauren Apfel beißen."*]

In the communication between Hannes and myself from then on, we had only to spell out the words 'sour apple' and I knew that I had tried to do something against his will. In certain situations, if Hannes indicated the letter S, we both just broke into laughter. Thus the nurse's comment became our slogan of resistance. No doubt indeed, burn-out prevention in family caregivers is most important.

Palliative approach and therapeutic discourse on end-of-life decisions

After the death of my husband, his respiratory physician said to me: "I don't understand why more people with ALS don't commit suicide in Switzerland. Instead, they take a chance, and then we have a situation where someone ends up being overburdened, as in your case." Had Hannes and I evaded the subject of ending life voluntarily? Shortly after the definite diagnosis, our general practitioner asked my husband whether he would consider suicide as a possible way of dealing with his terminal illness. He would not, he said, "out of respect for life", as he told me afterwards.

In his Advance Decision to Refuse Treatment (preferences for medical decisions at the end-of-life, in German called *Patientenverfügung*) his wish for no life-sustaining treatment had been documented. But didn't we think beyond the written advance care directives? Were we reluctant to deal with the subject? Did we suppress the inevitable? When I ask myself such questions now, the following comes to mind.

Half a year before Hannes died, I spoke on the telephone with the palliative care physician regarding medication; it was a few days before Easter. During the talk he suddenly asked me whether my husband had ever said he'd had enough of life. Astonished, and without the slightest doubt, I answered: "No." The physician then explained that in the event my partner ever expressed the wish to die, this could be considered. I asked the physician whether in that case he would assist him. He said he was not permitted to, but there were viable alternatives aside from organisations for assisted suicide. At that time, Hannes was neither able to raise his arms nor swallow, and I realised that I was the one who would actively have to assist him in euthanasia and would afterwards have to live with the knowledge of my action. The physician ended the conversation by requesting that I discuss the subject with my partner during the Easter holidays. Several days went by before I found the courage to tell Hannes about the phone call with the physician, and to ask him directly whether he wished to end his life. Quietly and clearly he indicated that he did not. Easter passed calmly, without worries. We suspected it would be our last together.

Between the discussion with the general practitioner, shortly after Hannes had been informed about the definite diagnosis, and the GP first raised the question of considering suicide, and the telephone discussion above with the palliative care physician, more than two years went by. In the course of the advancing illness, the inner state of mind can change radically with regard to suicide. It is therefore important that the physician responsible tries to ascertain what the patient is considering and what his needs and requirements are. Whether a terminally ill person wishes to die is clearly a matter to be discussed between the palliative care professional and the patient together with family members. But it is quite possible that a conversation with the patient alone is also needed. However, in good palliative practice, the setting, in which the question of voluntary ending of life is discussed, is equally important. To raise this question on the phone can lead to misunderstandings.

Proximity and distance: Boundary-crossing of professional caregivers

Care management includes providing information concerning death and dying. In Switzerland (Goldman 2009) and elsewhere in Europe, the United States (Simmons 2009), Taiwan and Australia, care training is available for ALS patients and their family. Essential concrete knowledge, along with training in practical support methods, and acquiring confidence are the three mandatory tools for relatives giving assistance in terminal care. Professional palliative caregivers, however, must also concern themselves during end-stage conditions with the team formed by a close family member and the patient. The following illustrates that this cannot always be taken for granted.

Before he died at home, Hannes and I spent the last three weeks of his life in a convalescence sanatorium directed by a physician, located above a lake in southern Switzerland. At the request of the sanatorium, we had organized two professional home caregivers from outside to support the sanatorium's team. While we were preparing to make the drive back home with friends, breathing became increasingly difficult for Hannes, and we discussed various possibilities, including extra oxygen. I gathered telephone numbers and kept them ready. We arranged a round table meeting with all the professional staff involved at the sanatorium and one of the external professional home caregivers, in order to discuss further procedures with the physician and Hannes. Just before the meeting, I had had a session with a physiotherapist. When I returned, the external home caregiver informed me that she had asked permission from my husband and, with his consent, had already telephoned the oxygen supplier and made inquiries. She said that she had had a lot of experience with breathing problems and that she was convinced that it was the right time. I only needed to fix an appointment; whereupon she left us. From that moment my peace of mind vanished. Alone with Hannes, I asked him whether the decision made without me corresponded to his wishes. It did not, he indicated. We were both worried, and I didn't have the strength to reverse the decision. I discussed it with the attending physician and he consulted a physician in our town. After she completed her evening care duties, I asked the home caregiver if I could speak with her alone. I told her it was not a question of whether the decision of timing for the administration of oxygen was right or wrong, but that she had taken advantage of my absence, and that she should concern herself not only with the patient but also with the team which we, my husband and I, together formed. She reacted angrily, whereby I said that on the following day I would take over the caregiving myself, with the help of staff from the sanatorium.

Proximity and distance: Boundary-crossing of primary caregivers

To shed light on the ambivalence I often experienced as primary caregiver, I want to focus for a moment not on the therapeutic relationship between the health professionals and patient and family members, but on the relationship between primary caregiver and care-receiver. Hannes once asked, with a worried look: "Eighty percent of your time is spent living my life; that's not do-able. What about your life?" In dealing with a serious illness, I had learned, one has much more strength than could be imagined before. But there is a thin line between taking responsibility and wishing to get rid of it. My inner tension became so unbearable at times that I would whack my fist on a marble table, causing pain to myself in order not to cause pain to my partner. Since then I know that one can love another person very deeply and at the same time, out of desperation, want to kill that person. The line can be very thin indeed. There were moments when I shook Hannes vigorously and shouted: "I'm going to kill you!" He wasn't able to answer with his voice, but the moment he smiled, I came to my senses and apologized. Our relationship of thirty-one years, my husband's character, his smiling eyes, his affection and vitality empowered me and gave me the strength to accompany his increasingly arduous daily life. "I learned to be a caregiver by doing it,

because I had to do it; it was there to do,” writes Kleinman (2009a: 293). To illustrate what it means to bear the unbearable, I quote Kleinman again:

Caregiving is not easy. It consumes time, energy, and financial resources. It sucks out strength and determination. It turns simple ideas of efficacy and hope into big question marks. It can amplify anguish and desperation. It can divide the self. ... It is also far more complex, uncertain, and unbounded than professional medical and nursing models suggest (ibid.: 293).

Dignity, dependence and experienced ‘good care’

What made it possible for Hannes and I, along with the health professionals, to profit from such a multilateral learning process during his illness? Fortunately, we encountered professionals who respected our dignity, gave us courage and lifted our spirits. Unrelated to profession, discipline background or specialised education, there were self-aware people who were attentive and eager to learn. When things went badly during a caregiving session, they were the ones who apologized to the patient for the difficult situation he had been in, thereby showing him respect. With more experience in guidance and a higher level of training, some individuals were better able to cope with crisis situations. The moment a critical situation was settled they could joke and be silly. 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.

The importance of maintaining a human relationship is stressed over and over in disability studies. In her search for ways of including patients as subjects (as opposed to being seen as objects) in research, specifically in research of long-term mental health care in the Netherlands, Jeannette Pols (2005) analyses communication practices between nurses and patients. In order to illustrate her argument, she highlights a concrete situation where a patient has been treated as a subject by the nurses. Pols concludes that the patient in this practical situation “is not objectified as being determined by a medical condition, however ill he may be” (ibid.: 212). This is exactly the point I want to make for the particular home care situation I am writing about in this essay. The concept of “institutional othering”, used by McLean (2007: 274) in research on dementia care in nursing homes in the United States, applies also to home care. A focus on a patient as ‘the other’ and a view dominated by his or her medical condition harm a disabled person.

Unlike the focus on a patient as ‘the other’, an anthropological approach struggles with the nature of relations (Van Dongen 2007: 22). Kleinman (1999) believes that ethnography is a practice of sustaining empathy and engagement. Van Dongen argues “that empathically listening to the Other, to be involved in local moral worlds or to commit oneself to witnessing has unexpected effects that may be futile, if those activities do not have consequences” (2007: 33-34). She uses the concept of responsibility. This state-

ment puts anthropology on its feet. Here I do not merely wish to say how things should *not* be done. Based on my experiences, I feel responsible to discern the mechanisms and pitfalls which lead to aggressiveness and helplessness in palliative care and caregiving at home in order to contribute to better conditions. For example, this text might be used in care education or in extended vocational training on palliative care.

There are ways to avoid institutional othering. First, it is the responsibility of the management. It depends, furthermore, on the care culture of an institution and on the social and caring skills of the health professionals. Three examples show how respect and nearness can go hand in hand. During one hospital stay, the nurse who was Hannes' main contact person greeted him by touching her forehead to his. Thereafter, he thanked her for her care by touching his forehead to hers. This substitute for a handshake became a moving ritual, thanks to a respectful attitude. Another time Hannes was sitting in his wheelchair near some rose bushes in the garden at the convalescence sanatorium. With a gesture of serenity, a nurse sitting next to him slowly laid rose petals, one at a time, on his knees. A letter from a home health caregiver after my husband's death illustrates the proximity and vulnerability of the caregiving relationship.

Working with your husband was a very pleasant and enriching time for me. Even today I can see your husband lying on his bed in the evening with a certain mischievous look on his face, waiting to see whether I will lose patience with trying to find just the right position to get him comfortable... and then finally his smile when I'm successful...! I will certainly always remember those wonderful moments (Didier Bollier, author's translation).

Besides the support from professional caregivers, the help from friends and neighbours made it possible to get even this far in the context of end-of-life care. A supportive network of former work colleagues also helped keep us going. Half a year after Hannes' transition, a former co-worker remembered the times they had spent together during his illness. Her reflection starts from the moment of the diagnosis:

(...) Hannes faced his situation with incredible determination to remain as independent as possible. He continued to travel, visiting China and Hong Kong. When the strength in his arms was gone, he wrote using a special device on his glasses that allowed him to type on a virtual keyboard on his computer screen. When he lost the ability to speak, he communicated using a table of letters that someone would hold and pass over with a pen until Hannes would indicate the letter that he needed. Even if you guessed what he wanted to say, he would sometimes insist on continuing to spell out his thoughts. When the overall demands of work became too much for him, he stayed on in his job to mentor younger colleagues.

Once Hannes stopped working, Martine did as well so she could take care of him at home. It was clearly hard work that got harder as Hannes continued to lose muscle strength, but she did it out of love and respect for his wishes. I would come by often with groceries, to read to Hannes, or just to spend time together (...).

There were some very memorable visits during the final months. Once, shortly after Hannes lost the ability to speak, he could tell that I was feeling sad and he had someone move him closer to where I was sitting. From his wheelchair he stretched out his legs and wrapped them around mine. In German the word for hug is *Umarmung*. I told Hannes that this was an *Umbeinung* (the German word for leg is *Bein*). After that we shared many *Umbeinungen* (Ellen Savett, personal letter).

Caring as life practice

Motivated by both my interest as a medical anthropologist and as an individual personally affected, the topics and questions addressed in this paper, which analyse boundary disturbances involving professionals during the course of a terminal illness at home, have been thus far:

- power relations in how professionals interact with patients and family caregivers in end-of-life care;
- how cultural images and assumptions about ‘lives worth living’ affect and harm people with ALS and MNDs;
- how suicide as an option gets handled or presented in cases of terminal illness;
- what constitutes ‘good care’ and how family caregivers and health professionals can or should work together to make it happen.

The underlying question which moved me was the need to understand my own feelings. At this stage I will address the last three questions and begin by exploring the pressure put on people with serious disabilities to consider ending their life.

Society’s picture of ALS and a life ‘worth living’

One of the greatest difficulties in human relationships involving ALS is the dominant image of ALS held by society. Instead of considering what is at stake, people afflicted with ALS are often viewed by others in stereotypic images. In one series of these images ALS means: soon to die, this person is pre-determined to die, better to die now. Health professionals are not exempt from these images and often encounter a person suffering from ALS with a picture of death in their mind.

Beyond that, it appears to be hard for the medical profession to encounter a person whom they know will die without wishing to ‘shorten the suffering’. In the current public debate in Switzerland on comprehensive assistance to dying persons, a palliative physician stated “We are geared to medical success. That is why many people cannot bear to accept loss of the hope of healing and the resulting nearness of death connected with it.” (Roland Kunz, cited in Vögeli 2010, author’s translation).

In setting the power of negative images about a life ‘worth living’ against the grief of losing autonomy and the compelling need to live a self-determined life, crucial questions are raised: who decides what makes life worth living, and who judges the ‘quality’ of life – the so-called healthy human beings? As a professional once said to

me, “With this illness you don’t know which is better, to live on or die early.” Encouragers are few, even though more encouragement to exercise as much self-determination as possible is vitally needed.

In order to be able to lend encouragement, the objectifying pictures of ALS that people hold must first be erased. Unfortunately, dehumanising views on disability can become generalized. Quoting Kaufman (2006: 23), Janelle Taylor notes, in the case of hospitalized people with dementia, that the judgment that a person with dementia is “as good as dead” may become a self-fulfilling prophecy when it serves as “a rationale for facilitating death” (2008: 322). Robert Murphy faced the same life situation as Els van Dongen and asked in the beginning of the account of his own cancer, “would one really be better off dead?” (1987: 6). At the end of his exploration he answers the question, whether death is preferable to disablement, with determination as well as open-mindedness.

No, it is not, for this choice would deny the only meaning that we can attach to all life, whatever its limitations. The notion that one is better off dead than disabled is nothing less than the ultimate aspersion against the physically impaired, for it questions the value of their lives and their very right to exist. But exist we will, for if all other meanings and values are arbitrary and culturally relative, then the only transcendent value is life itself. Life is at once both its own means and its end, a gift that should neither be refused nor cast off, except in utmost extremity (Murphy 1987: 230).

In utmost extremity, the question of voluntarily ending life is a moral choice that a disabled or terminally ill person ought to be able to consider in inner freedom and not be influenced by current debates in cost-saving-driven health policy. Suicide as an option gets subtly or even openly handled or presented in cases of terminal illness. Is this the case, cultural images and assumptions about lives ‘worth living’ affect and harm people with ALS/MND.

‘Caring as life practice’ vs ‘caring as burden’

According to Sadler and McKevitt (2009) the medical literature reveals an overwhelming concern with the negative effects of caregiving on the individual who provides care. They point out that the physical and mental health of family caregivers has been widely surveyed and caregiving itself has been found to be a cause of morbidity:

Numerous studies have sought to measure ‘strain’, ‘stress’ and ‘burden’ using a range of specially designed and psychometrically validated tools. (...) On the one hand the concern with caring as burden reflects a clinical and public health concern to prevent disease and thereby to prevent potential use of health care resources but also to prevent experience of suffering. On the other hand, this also constitutes an extension of the clinical gaze to carers, mapping their actual or potential morbidity, monitoring the wellbeing of their individual psyche and assessing their fitness to continue their caring tasks (ibid.: 8-9).

As researchers in the field of health and social care in the UK, Sadler and McKeivitt conclude that within a policy context, the discourse on caregivers has increasingly focused on the relationship and interaction between the formal (public/state) and informal (private/family) caregiving sectors. Not only in the UK but equally so in Switzerland, the underlying idea might be that informal caregivers financially benefit the state. An international perspective (Guberman 2009) even states that though caregivers are generally not official clients of the health and social service systems, policy rather identifies them as resources that must be mobilized and educated to meet the needs of the person requiring care. More than twenty years ago, the trend of involving, supporting and training family members in the role of main caregivers was reflected in policy literature on caregiving and its practice in Britain. This is illustrated by Twigg's (1989) typology of different models of caregiver – care service provider relationships. Sadler and McKeivitt underline Twigg's argument that professionals respond to caregivers in several ways and adopt her perspective of three 'ideal types' of relationships between informal and formal carers: carers as resources, carers as co-workers and carers as co-clients. This typology is useful to identify how the ambiguous relationship between informal and formal caregivers has been variously conceptualised. It is also useful in understanding the disturbances and tensions I experienced as primary caregiver in my interactions with professional caregivers.

During Hannes' illness we were fortunate to meet professionals who gave us courage, although at times I also experienced an attitude of solicitude rather than confidence. Again, in practice and in literature, encouragement to exercise as much self-determination as possible is essential. To enable insight into another perspective and to move away from a deficit model, I propose a focus on 'caring as life practice' as opposed to 'caring as burden'. To illustrate this, let me end with Kleinman's view: "Faced with [illness] crisis, family and close friends become responsible for assistance with all the practical, mundane activities of daily living: dressing, feeding, bathing, toileting, ambulating, communicating, and interfacing with the health-care system" (2009a: 293). For Kleinman, caregivers protect the vulnerable and dependent individual. He states,

To use the experience-distorting technical language: they offer cognitive, behavioural, and emotional support. And because caregiving is so tiring and emotionally draining, effective caregiving requires that the caregivers themselves regularly receive practical and emotional support. But, to use the close experiential language of actually doing it, caregiving is also a defining moral practice. It is a practice of empathic imagination, responsibility, witnessing and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human (ibid.: 293).

Caring as life practice means that caring is part of life just as dying belongs to life. What constitutes 'good care' and how family caregivers and professionals can or should work together to make it happen depends on (among other factors) whether health professionals, instead of concentrating on the burden and risks involved in car-

ing, can support family caregivers and those closest with their actual presence. Having, for example, an experienced professional caregiver beside them during the last hours allows family and friends to focus on the passing away of their loved one. Rather than feeling insecure or afraid, they receive valuable strength and nothing less than an opportunity to peer into the brief opening between life and death and glimpse the mystery of life.

Note

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