ESSAY/PERSONAL REFLECTIONS

The time that remains: Self-identity and temporality in cancer and other life-threatening illnesses and in Messianic experience

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Until 60 years ago or thereabouts, death usually closely followed an infection or accident; now, most people die slowly of failing organs or cancer. Contact with death and dying occupies a gradually increasing space in the life of many families, which oftentimes feel unprepared to accompany the beloved one on this last journey.

The demand for palliative care is rising not only because of longer life expectancy and the stretching of the death process by chronic illnesses, but also because of the development of biomedical technology, which makes it possible to keep people at the limits of life for weeks or months.

Worldwide, most people spend most of their last year of life at home being cared for by family, family physicians, and community nurses, whereas in industrialized countries, most people will die in institutions such as hospitals and care homes. In either case, most "end of life care" occurs in a generalist setting and is provided by health or social care professionals other than palliative care specialists (Shipman et al., 2008). Therefore, adequate support for patients with advanced disease depends upon education and training for the whole team, including physicians, nurses, and social workers.

Reviews and reports have been published concerning the definition of "end-of-life care" and the access to high quality care, to be achieved with whole systems approaches, integrated services, enhanced research and funding. The quality of end-of-life care varies greatly, but in many cases patients are dissatisfied by the quality of attention they are receiving. There are different perceptions about what comprises a "good death," and no consensus on what can be considered "dignity in the terminally ill" (Chochi-

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nov et al., 2002; Clark, 2003; Curtis, 2003; Walter, 2003). Physicians tend to focus on patients' physical symptoms, whereas patients and their relatives give more importance to existential, emotional and spiritual issues.

Most health professionals avoid personal contact with "terminal" patients, and admit that they are not emotionally prepared to deal with people approaching death (Lloyd-Williams & Carter, 2003). However, those who choose to take on this task find it extremely rewarding (McPhee et al., 2000; Quill, 2000; Parker, 2002; Knowles, 2003). What is out there in palliative care that may be so scary and challenging, but that, at the same time, may offer the opportunity for close and mutually enriching encounters between patients and caregivers?

Palliative medicine does not have a specific organ or disease as a major focus; the heart of palliative care is the dying person. Illness brings one "close to the bone" of the soul's needs, which beg for attention when the question is, "How much time do I have, Doc?" At that moment, one's commitment to *chronos* lessens and one seeks *kairos*, and may begin to see time running backward as well as forward, with life spread out as on a landscape. We, health and social care professionals, might be able to offer some aid if we have looked closely at this phenomenon: the heterogeneous coexistence of *chronos* and *kairos* in human experience.

In this essay, as a contributory approach to this subject, I point out similarities between some aspects found in one recently cancer-diagnosed physicians's narrative about her feelings and thoughts regarding her "self" and her perception of time, and those components described by Agamben (2005) when studying human experience in the "Messianic time," beginning with a title that fits both: "the time that remains."

Modern medicine has been developed in a world where science and humanities are considered to be 166 Mendes

separate domains. The intimate relationship that medicine and philosophy have nurtured for ages seems to be lost or forgotten. Nevertheless, we should revive it if we are supposed to care for more than the biochemical being.

"When a life-threatening disease is diagnosed, patients may find that their sense of time, their view of the future are altered [...] with a reappraisal of the journey of life as a continuous line, to life spread out on a landscape that includes the past and the future," says Murray (2000). A life-threatening disease may suspend one from *chronos* – the shared time, the world of clocks and daily schedules – into an intensely private and solitary experience in the lands of *kairos* – the dimension of time where eternity can be touched in the here-and-now; where time is not a quantity that can be measured but rather a quality that can be felt and hardly described.

However, we are not foreigners in the lands of *kairos*. The search for meaning in human existence has been a familiar task for humanity for centuries, and has included the exploration of temporality, not only by the Greeks. Bergson described two times: the "objective time" and the "inner time," "private time" or "duration"; according to Freud, unconscious mental processes are "timeless"; Minkowski explored patients' "lived time" experiences; Heidegger emphasized "the way that past, present and future aspects coexist and interpenetrate" to create the temporal whole of human existence (Kern, 2000).

Agamben (2005) studied the structure of identity in "Messianic time" through Paul's Letters (Nestle, 1963). His work enlightens our understanding of the experience of dying patients, because it brings the particular conjunction of memory and hope, past and present, plenitude and lack.

Scannell (2000) so described her experience on receiving a cancer diagnosis at the moment before embarking on a year's sabbatical from work:

I drifted chaotically through future, past and present [...]. Thoughts and feelings [...] seemed to belong to someone else, to some body that I had inhabited", she said. "Life capsizes from the force of a single word. Erasing the certitude of my future [...] urging me to abandon plans of my past. My sense of my self as continuous through time began to fracture [...] Having failed dismally to plan my life, to structure time around it, I felt completely powerless in the insistent present.

Her words point out three aspects commonly felt in the "end-of-life" situation: the sense of contraction of time, the unfolding of one's own identity, and the surrender to powerlessness regarding life plans and control. Although these are often considered great difficulties, they are desired aims to be achieved after hard and long training in some religious and philosophical traditions.

The "syntonization" of one's consciousness to the time being — to the here-and-now, the only real space-and-time, free from remembrances of the past and from the necessities of the future — is the central aim of various kinds of meditation. The detachment of people from their *persona*, letting go of their purchases and even of their relations, is recognized as a sign of spiritual development in many religions. Moreover, surrender to destiny is commonly seen as a proof of faith.

Agamben (2005) describes the same three aspects when studying the tension between immanence and transcendence, the coexistence of *chronos* and *kairos*, in Messianic life in the primitive Christian community.

In the *Epistles of Paul*, the philosopher reads that the Messianic event – the resurrection – introduces a radical abbreviation in time (Cor I, 7:29): *chronos*, which moved slowly and regularly to the end of times – the *parousia* –, is invaded by *kairos*, which brings past and future to the present, creating a tension between *already* and *not yet*. The prophets announced that the *Mashiah* would come some day in the future: a point far away in the horizon line. The apostle announces that 'the *Christos*' – the *Mashiah* – has already come and that time begins already to end: the *parousia* is imminent. Everything that you are, you must be it now, because today maybe the last day.

Kletos, the "calling," translated by Luther as Beruf, meaning both the "vocation" and the "situation," describes the particular transformation that every juridical status and worldly condition undergoes because of its relation to the Messianic event: an internal shifting of each and every single condition by virtue of being "called," although it does not have any specific content. Every condition that is revoked or inactivated is not destructed, but kept to its completion. One no more coincides with oneself. On the other hand, one should stay in the same state or position at which one has been "called," and live the same life during the time that remains (Cor I, 7:20,24). The identity is duplicated or unfolded: it can no more coincide with the one that used to be, but it does not change into another one either. Life is then lived under hos me (as not) and chresai (make use). If you are a priest or a slave, Greek or Jewish, live *as not* because it does not really matter. If you have money, castles, nice clothes, make use, but be aware of impermanence.

There is yet a third point of similarity: for the servants of Jesus Christ, the potency arises from the weakness (Cor II, 12:9: *dynamis en astheneia teleitai*). The author of the Acts changes to The time that remains 167

Paulos – paulus in Latin means "small, of little significance" – the name of the character who up to that point had been called Saulos - Talut, the highest. This *metanomasia*, the substitution of *sigma* by pi, signifies no less than the passage from the regal to the insignificant, from grandeur to smallness. "The messianic separates the proper name from its bearer, who from this point on may bear only an improper name, a nickname. [...] Saulos qui et Paulos therefore carries within itself an onomastic prophecy[...]: those things that are weak and insignificant will, in the days of the Messiah, prevail over those things the world considers to be strong and important (Cor I, 1:27-28)" (Agamben, 2005, p. 10). Likewise, the vulnerability of the end-of-life condition uproots the patient from any form of competition or rules, and confers a kind of strength that intimidates us, as that patient is facing our most dreadful enemy. The "calling" of the fatal diagnosis suspends the patient from everyday obligations and abruptly impels that patient into a search for the sense of being. The main verb in life is no more "to do" or "to have", but "to be." Facing the landscape of the whole life, the instant moment may expand into an eternity of feelings and empowering understanding.

We do not intend to equate the "calling" by the Messianic event with the "calling" by a "fatal" diagnosis. We simply propose an analogy between the structure of self-identity and perception of time in the Messianic and terminal conditions. In both cases, there is a contraction of time, imposing a recapitulation of the past and a completion of the future in the time that remains, the only real time, where *chronos* and *kairos* heterogeneously coexist. In both, the worldly identities are revoked and life is lived under *hos me* (as not) and *chresai* (make use). In both, despite the weakness – or rather, because of it – all "impotential" may turn into potency.

Agamben uses the word "impotential," used by linguist Benjamin Whorf, to define a modal category of the verb that corresponds to a kind of "teleological ineffectiveness." Whorf studied the Hopi language, in which the verb is conjugated in a specific mode to signify that the action will probably not be completed. For example, if Hopi are reporting that somebody ran away, and they use the impotential mode, it implies that the person was captured, and did not succeed in escaping.

When somebody is "going to die," it seems that the moment of achievement of every plan from the past is irrevocably lost; life seems filled with a "negative potential": an 'impotential' mode of living. But the last months or weeks may turn into an eternity of creativity and accomplishments that include many ontological dimensions, as art, personal relationships, and individual insights.

I have read (Murray, 2000) and heard about, and personally witnessed, several bursts of artistic inspiration and creative production by patients who received a bad prognosis: dozens of pictures, poems, books, and pieces of music have been born in "end-oflife" situations. In the same way, the announcement of the probable shortening of one's life frequently brings one's personal relationships to degrees of intimacy and mutual understanding not experienced before. It seems that knowing that life already began to end makes one feel like living it, making something of it. One desires to leave something that is bigger or stronger than one's physical presence, such as a masterpiece or a revolutionary scientific concept; or just to make sure that a traditional family recipe will not be lost. One wants to do something worth being remembered by those who survive one's departure.

The time that remains, whatever its length, may be a time of fulfillment, of meaningful experiences.

If we believe that the three aspects depicted here – the suspension of *chronos* into *kairos*, the unfolding of identity in immanence and transcendence, and the powerlessness of controlling destiny – compose just another way of experiencing conscience, that is not intrinsically good or bad, maybe we can deal more easily with the end-of-life situation, our patients, our own relatives, and ourselves.

We all know we are going to die some day. Nevertheless, we avoid thinking about it and we do not prepare ourselves for this moment. When we are told that we have a disease that will probably bring our death soon, we are suddenly "called" to get into a closer contact with ourselves, our lives, our mission, if there is any. I have heard from half a dozen patients about how thankful they were for their illness, because it made them feel alive and savor each drop of life as never before.

These considerations can help us understand what our patients go through when they are told they are probably going to die soon. If we can offer them a piece of our presence both in *chronos* and *kairos*, both in weakness and strength, we might happen to share, in being, "the time that remains."

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REFERENCES

Agamben, G. (2005). The Time that Remains: a Commentary on the Letter to the Romans. Stanford: Stanford University Press.

168 Mendes

Chochinov, H., Hack, T., Hassard, T., et al. (2002). Dignity in the terminally ill: A cross-sectional, cohort study. *Lancet*, 360, 2026–2030.

- Clark, B.A. (2003). In search of a good death. Spiritual care is important for a good death. *British Medical Journal*, 327, 224.
- Curtis, M.J. (2003). In search of a good death. Good death is social construction. *British Medical Journal*, 327, 223–224.
- Kern, S. (2000). Time and Medicine. Annals of Internal Medicine, 132, 3–9.
- Knowles, S. (2003). In search of a good death. Each encounter with a dying patient is a unique privilege. *British Medical Journal*, 327, 224.
- Lloyd-Williams, M. & Carter, Y.H. (2003). In search of a good death. Medical education has important role in extending palliative care. *British Medical Journal*, 327, 221–222.
- McPhee, S.J., Rabow, M.W., Pantilat, S.Z., et al. (2000). Finding our way perspectives on care at the close of

- life. Journal of the American Medical Association, 284, 2512–2513.
- Murray, T.J. (2000). Personal time: The patient's experience. Annals of Internal Medicine, 132, 58.
- Nestle, E. (1963). Novum Testamentum Graece et Latine. London: United Bible Societies.
- Parker, R.A. (2002). Caring for patients at the end of life: Reflections after 12 years of practice. *Annals of Internal Medicine*, 136, 72–75.
- Quill, T.E. (2000). Initiating end-of-life discussions with seriously ill patients. *Journal of the American Medical Association*, 284, 2502–2507.
- Scannel, K.A. (2000). Leave of absence. *Annals of Internal Medicine*, 132, 55–57.
- Shipman, C., Gysels, M., White, P., et al. (2008). Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *British Medical Journal*, 337, 1720.
- Walter, T. (2003). Historical and cultural variants on the good death. *British Medical Journal*, 327, 218–220.