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“DEATH PRIMARILY BELONGS TO THE DYING”: A CONTRIBUTION TO THE ANTHROPOLOGY OF DEATH AND DYING

We derive meaning not only by working and loving, but also from the art of dying.

We learn about ourselves through the life and death of others.

Streets 1996:183

Through ethnography of the particular – by analysis of the experience of dying parents and the experience lived through by offspring during the process of their dying – this paper opens up certain issues regarding the contemporary stance towards illness, death, and the treatment and care of the sick. Within the framework of anthropological, historical and psychological literature, the author weighs the culturally constructed perceptions, the patterns and the emotions connected with particular diseases (cancer) and the question of the dying patient as the *intimate Other* within the family, but also ventures into certain relevant questions from the sphere of the medical and overall social treatment of patients and the dying, for example, that of the primacy of curative over the palliative medicine, of the deficit in holistic overview of the patient and his/her illness, and that of primary importance concerning the communication between patient and physician and the patient’s family and the physician.

Key words: anthropology of death, dying, patient, doctor

Over the last two years, I have witnessed the process of dying of both my parents. My mother was diagnosed with carcinoma at the beginning of 2006. She died within a year after unsuccessful conventional treatment, only six weeks after diagnosis of metastasis. Twenty months later, my father who had been a seriously ill patient for thirty years, died after brief hospitalization. They both died in a very short period of five to six weeks, although there was a considerable difference in the way in which they died: my mother died in hospital, never ever having dis-

cussed the subject of dying with me; my father died at home after having directly prepared for death for some time, preparations in which I, too, shared. I directly encountered both dying and two comprehensions of dying within my own family: according to one of these, death is a part of life and something for which a person (and that person's environment) is preparing; according to the other, it is a taboo, even in those moments when it is imminent (Rihtman-Auguštin 1988:116).

This paper may seem somewhat less scholarly than those I have written about other anthropological themes, even than those in which I have been a participant in a certain way (Čapo Žmegač 2006). Being beside the deathbeds of my parents – which included my presence at all aspects of their dying – has been the most intensive form of *insidership* (Čapo Žmegač, Gulin Zrnić and Šantek 2006) that I have experienced in any anthropological theme to date. Naturally enough, following the process of dying of those closest to me was not motivated by any scholarly interest: it was only later – primarily when coming to terms with the death of my mother and thinking about that first dying that I had witnessed – that I decided to describe that experience within the framework of my discipline. My father also died in the interim and that in a way that seems to me to be paradigmatic for the dying that Philippe Ariès (1989; 2004) ascribes to another time, calling it “tamed death”, so that it was quite understandable that my father's dying and death be included in this article.

I make no attempt to conceal the therapeutic purpose of this article and my dealing with the anthropology of death. I hope that they will both help in the framing of death (McCullough 1996) and, thereby, in distancing myself from those harrowing experiences and lead to the end of the period of mourning. Clive Seale (1998) sees the essence of statements by bereaved persons in their need to depict in a positive light their actions during the dying of people close to them, by which they also try to ease their pain and bridge the gulf of discord that death has caused and to reconstruct their sense of security that has been disrupted by death. Statements of the bereaved show their need to rid themselves of the sense of guilt they may feel because of the way in which their loved ones died. At the same time, they make it possible for the researcher to study how the bereaved reconstruct their identity by speaking about the death of those close to them.

The roles of researcher and the researched are blurred and overlap in this article (Gulin Zrnić 2005; Halilovich 2008): I am the researcher, that is, the one who observes the dying of her loved ones, but, as a bereaved person in search of the meaningfulness of dying, I am also the one being observed. It is not a matter here of writing about one's own dying (comp. Kuzmanović 1979), but of notations of my experience of the dying of those closest to me (comp. Rieff 2008; Didion 2009). Writing about the dying of my parents, I shall try to understand the events

and relations that were established during the period of their dying, to look into the meaning they had for me and to examine my own attitude towards dying. Through such definition of the research questions, this text corresponds with an earlier, but still current, criticism of death research in anthropology, formulated by Johannes Fabian in 1973. The author posited the thesis that approaches to death are exposed to parochialisation and folklorisation – that is, onwards from Tylor, Frazer, Boas and Malinowski, anthropology abandoned research into death as a universal issue of human existence and became oriented towards research into singular posthumous ceremonies and customs, which resulted in the discarding of the transcendental and universal conceptualization of the problem and the failure to formulate “a theoretical plane on which to face challenges such as the problem of death” (Fabian 2004:51). In order for the experience of the termination of individual life to be restored to its full problematic status within anthropology, continues Fabian, “would call for an anthropology for which social reality and subjective participation in that reality are irreducible conceptual poles of inquiry” (ibid.:54).

By bringing them face to face with human existence in its last moments, this article will perhaps prompt readers to lose some of their own fear of dying and death, as foreseen by the psychiatrist Elisabeth Kübler-Ross (2007), a person who has made an exceptional contribution to changing the way in which the medical profession looks at dying. By observing seriously ill patients, establishing their reactions and their needs, and the attitude of their environment towards such patients, she sought to enhance our sensitivity to the needs of fatally ill patients and the humanisation of dying in the contemporary technical world (ibid.:25–26, 135; Palgi and Abramovitch 1984:402–403). Through this ethnography of the particular – by description of the process of dying of my parents and analysis of my own experience during that process – I am touching on certain of the above themes in the Croatian context. They include, for example, the question of communication and the relation between the medical staff and patients; the treatment of patients exclusively as physiological beings; the bureaucratic nature of the health system that hinders a more humane stance towards patients and their families; giving precedence to curative rather than palliative medicine as death approaches, and the like. These are themes to which ethnologists and cultural anthropologists, through their specific ethnographic methodology, could make a considerable contribution in researching clinical practice in Croatia, and thereby, to changing it. Apart from that, within the framework of the anthropological discipline, but also with some insights into the historical and psychological literature, the culturally constructed notions of death and its tabooisation, particularly in relation to certain diseases (cancer), are discussed, as well as the patient, the *intimate Other* here, and the attitude of the family towards such Other.

My Mother

*O Lord, give everyone his own death,
A death stemming from his own life.*

R. M. Rilke

My mother was an exceptionally vital, energetic and active woman and, despite her advanced eighth decade of life and the classic ailments that come with age, she was largely healthy. For almost thirty years she had taken care of her increasingly immobile and communicationally handicapped husband, reducing her own activities outside the house in those last years in order to devote herself to what was, because of his illness, a very demanding care. At the beginning of 2006, my mother was diagnosed with breast cancer that had spread to the lymph glands.

Our first meeting, after her diagnosis had been confirmed, was symptomatic of our entire further communication during her illness. Having learnt of the diagnosis from her general practitioner,¹ I hurried to visit her: she was pale, weak, quiet and extremely dejected. Right up until she realized that I had already been informed, we spent half an hour in trivial chat: neither was she able to communicate this crushing information, nor was I able to initiate a conversation about it. During the following year, our meetings, although very frequent, unfolded in a similar way: we did not speak about her illness or the prospects for her recovery. At the same time, my mother tried to conceal her difficulties from me, her reaction to the chemotherapy and radiation treatment, not permitting me to take regular care of her until she herself was no longer able to do so, two to three weeks prior to her death. In retrospect, I understand that, as far as she was able, she tried to retain her independence and dignity. I accepted that indirect communication and consented to avoiding any discussion of her illness – since, obviously, that made things easier for me, too.

The brisk and efficacious activity that followed was in contrast to the silence that shrouded the fact that she was suffering from cancer. She was very soon operated upon and she recovered quickly. Along with classical medical treatment, she agreed to the application of several naturopathic treatment methods. She went alone to her laboratory tests, but someone always accompanied her to chemotherapy sessions. She went to those sessions fearfully, so anxious about their after-effects that she could hardly walk after therapy. When a few days had passed from chemotherapy, she no longer permitted me to help take care of her or my father, until the next cycle of chemotherapy.

¹ In an effort to protect their identities, I am referring to all the physicians in this article in the male gender, while I have also changed some of the elements related to the situations I am describing.

Apart from the days after chemotherapy, it seemed that little had changed in her everyday life. Nonetheless, it had. She was less prepared to take care of her husband who, for his part, sensing that her priorities had changed – and feeling worse himself – became more demanding. It was only later, reading the Croatian translation of the book *Razgovori s umirućima* (Kübler-Ross 2007),² that I understood my mother’s occasional anger at my father and her refusal to look after him. People who have developed cancer feel anger and envy (ibid.:53) towards those close to them, asking themselves “Why me, and not him/her?” (comp. Kuzmanović 1979). With that question patients express that they are the victims of injustice, while it also contains the idea that cancer is an illness that punishes (Sontag 1979:37; Ramšak 2007) since, in the notions of ordinary people, that particular illness is regarded as a synonym for death (Sontag 1979:6, 8; Komp 1996:67; Kurent 2001) and as the “invincible predator” (Sontag 1979:6). Both my mother and I subscribed to those images.

My father reacted to my mother’s occasional anger at him in the manner of a long-term patient: he could not understand that she needed rest and that he had become too great a burden for her. On one occasion he voiced what was to me an unbelievable sentence at the time: “What’s she thinking of? How is it that she has got sick now, when *I* need to be taken care of?” (himself emphasizing the *I*). I can understand that statement today when I view it in the context of the drastic life changes that they both underwent after their retirement and in the light of their relationship that had become (re)defined during the quarter century of my father’s illness and the dependence on my mother that he developed, and her self-effacement and sacrifice. My father was sincerely expressing his feeling of loss since my mother was no longer capable of fulfilling her role of care-giver in their relationship.

E. Kübler-Ross constructed five phases of the dying of critically ill patients:³ denial, anger, bargaining, depression, and acceptance. She called them “defence mechanisms in the psychological sense” (ibid.:136). Although that is frequently overlooked, the author states that all of them are active in unequally long periods, they often interchange, but can also exist one beside another (ibid.). Consequently, if we comprehend them as being flexible and not as linear and disjunct categories but rather as “a very useful guide to understanding the different phases that dying patients may go through” (Mauksch in Palgi and Abramovitch 1984:402), individual aspects of my mother’s life after her diagnosis can be more readily

² The English edition is entitled *On Death and Dying*.

³ On the path of Joanna Lynn (1996), I am avoiding use of the “terminally ill” syntagm. That author believes that, because of our arrogance, we have set up the category of the “Other” that we have called “terminally ill”. This is the metaphor by which we distance ourselves from the fact that we are all mortal, that is, that we will all die one day, some of us also from illnesses of prolonged duration.

understood. Her entire experience from the moment that the cancer diagnosis was confirmed, and not just the process of dying, can be observed in the light of the proposed phases. So it seems to me that the fact that her illness was discovered only at a time when there was already a large tumour in the lymph glands can be interpreted as denial of the signs of the illness. After that, my mother was more or less angry for a time. However, it also seems that she accepted her illness, because she did everything in her power to get well: she relied on advancements in medicine and the possibility of being cured. I think that she believed that she would be definitely cured after the chemotherapy and radiation sessions came to an end. This is supported by the fact that, when she started to experience arthritis-type pain in her bones around only a month after the last treatments, it did not occur to her that the cancer had metastasised. For that matter, neither did her doctors think of that, and nor did I. If my mother and I were denying the possibility of the cancer metastasising or if we simply did not have the necessary knowledge of medicine, what about her doctors?

When the metastases were confirmed, my mother was once again in a phase of denying the new status of her illness and suppression of information. Medical, hermetical physician-type expressions that spoke of “secondarisms” (*sekundarizmi* in Croatian) seemed to provide for the possibility of a different interpretation and outcome. No-one in the family could summon up the courage to tell her that metastases were in question. It seems to me that the word was never uttered. She then went with her findings to a consultation with an oncologist, convinced that the pain in her back was being caused by long-term problems with her spine. Since she did not want me to be present, I was unable to hear how the specialist spoke to her. She came out from the consultation depressed and distraught, and was quite feeble. When talking with me, the specialist spoke comfortingly, saying that metastases in the bones were not “the worst” that could happen and that the processes could be helped with radiation treatment. He did not mention death.

Did the specialist tell us half-truths, blocking further possibilities for communication, while giving intensive palliative biological treatment to my mother (comp. Palgi and Abramovitch 1984:402)? Susan Sontag (1979:8) wrote: “The policy of equivocating about the nature of their disease with cancer patients reflects the conviction that dying people are best spared the news that they are dying, and that the good death is the sudden one, best of all if it happens while we’re unconscious or asleep”. However, has nothing changed in communication between physician and patient (and/or physician and patient’s family) from the time that the above sentence was written, more than thirty years ago? I have learnt from accessible literature that since the 1980s, physicians in certain countries have preferred to have a direct and open conversation with their patients who are suffering from cancer, and to do their best to explain the disease to them along with the positive and negative sides of therapy, offering hope “in other ways, more realistic

ways, than in the pursuit of elusive and danger-filled cures” (Nuland 1994:233). Apart from that, patients (and their families) in the Anglo-Saxon world have access to a whole series of professionals, who help them to confront the illness and the therapies (comp. Harding and Higginson 2009). No-one in either of the two clinics in which my mother was treated throughout her illness ever mentioned psychological support, while the physicians as a rule avoided not only open but even any communication at all. They were “untouchably aloof and self-absorbed” (Nuland 1994:226). It was only on the day of my mother’s death that I learnt from the doctor that she could expect two weeks more of life at the most, unless she undertook a new cycle of chemotherapy. He communicated this to me without any tact or consideration, as completely understandable, as the most banal item of information, probably having no inkling that that was the first time that I had heard the word “death” in connection with my mother’s illness. I was deeply shocked, almost paralyzed. The silence maintained by her doctors until then coincided with the inability of my mother and me to speak openly. There was no-one to help us bridge that gap that had stood between us (comp. Kübler-Ross 2007:155ff), and when I finally realized that the end was near, it was already too late. My mother died three hours after my conversation with the doctor.

In the last six weeks of her life after the diagnosis of the metastases, my mother became a “difficult” patient. My reactions to her behaviour were sometimes rough and nervy; unfortunately, I did not understand that those were psychic reactions connected with her serious illness and that I should calmly tolerate her justified (and unjustified) behaviour and demands (ibid.). Apart from that, I think that I was subconsciously adhering to a certain popular mythology of the disease, which was astutely fathomed by Sontag in her work referred to several times above (1979:42ff). The comprehension is that cancer is a redemptive disease, which finally offers those suffering from it a chance to redeem themselves for the failures and self-deceptions in their lives. I had expected that her illness would indeed change my mother and that her desperation and loss of hope would be replaced by “internal balance and peace” (Erikson in Salajpal 2004:47) that would help us both to speak out about her illness and to cease suppressing our feelings.

My mother complained of severe pain in her back. She lost weight after she started receiving radiation therapy and had trouble with her breathing, elevated pulse and blood pressure, high temperatures, night sweats, trembling hands, headaches and anxiety. She moved around slowly, saying that she had to take care not to fall and suffer a bone fracture. On the recordings that I made at our last joint family Christmas, she had an unrecognisable, quiet, hesitant and shaky voice. She soon became listless and depressed. She was often absent in spirit, taciturn, and showed no interest in anything. I did not know then that this was a typical reaction among critically ill patients (Kübler-Ross 2007:89ff) and that people nearing death are expressing in that phase the sadness and pain at the loss of “all their dear

persons and things” (ibid.:90). According to the same author, that is an essential phase in which the person in question is preparing to accept death (ibid.).

However, not understanding my mother’s state and, in an effort to bring her out of it, I uttered a terrible sentence at one moment of her illness, a sentence that I immediately regretted, as I often did later: “Mama, we all have to die!” What I actually wanted to say was “Accept it and fight”, or “Accept it and please let us use the time remaining in the best possible way”, or “Please let us prepare if this has to be the end”. My mother looked at me sadly, and I turned to stone, unable to say anything more or even to explain my unintentionally cruel message. I was engulfed by guilt. My mother and I sank once again into our tacitly agreed non-communication about her illness and her possible death. That sentence of mine hid the well-known cultural script (Seale 1998), my expectation, in other words, that during her fight with cancer my mother would face her illness, accept it and, if it came to that, die *awarely*, saying her farewells and sharing her thoughts, fears and feelings with me. I wanted us to live the remaining time, which was possibly going to be very short, in an intensive exchange and closeness that should have made dying easier for her, while preparing me for her possible death. However, my mother confronted her serious illness in her own way, herself choosing how to accept it and how to die. Her defence mechanism relied upon denial from time to time, and upon circumventing verbalisation of the subject right through the duration of her ill health. She never spoke the word death in front of me. However, that should not lead one to the conclusion that she was in denial right up until the end; in any case, while already very weak and ill, she told her sister that it was difficult to die. I believe that avoidance of certain difficult subjects was in keeping with her role in life: throughout her life, my mother always tried to avoid burdening others, especially her children. That was her role in life, and then also in its last phase – dying.

However, I am quite certain that, nonetheless, my mother accepted the inevitability of death in the last two weeks of her life that she spent in hospital. After several difficult days in the hospital, during which she cried uncontrollably, perhaps for the first time since she had heard her diagnosis, she became calm and she changed. For example, she received the psychiatrist in good spirits, explaining to him that she was afraid of nothing and that she did not need him. She calmly accepted the suggestion that a priest visit her. And she informed us about that, too, with a smile. However, I saw the most changes in the manner in which she spoke – quietly, without the anger and restlessness that had characterized her communication throughout her illness. She was relaxed, peaceful and gentle, she did not complain about anything, did not criticize anything, was not afraid of anything, and she was not depressed. That was how I described her several days after her death in the notes that I then made about her dying. Those expressions

coincide with the ones with which Kübler-Ross (2007) described the final stage of illness – acceptance.

Apart from that, my mother planned what she would do when she was discharged from hospital. With more resignation than anger, she stated several times that she had been given the wrong treatment before her admission to hospital. She returned to her childhood. However, sometimes she could not articulate words and we did not understand her. Sometimes she would speak in a manner that was so completely unfamiliar to me that it made me worry at first that she was losing her mind; however, when I accepted her new way of speaking, our communication improved.

We spent the day before her death together: I fed her, held her hand while she slept, massaged her, and we watched television. I can remember the atmosphere of benignancy, gentleness and love. I recognized for the first time – only in those moments in which she was practically dying – my mother's strength, courage and patience. And I recognized the consistency of her choices in life, also in relation to her severe illness. In those moments, we both found ourselves in a particular liminal state (Turner 1967; van Gennep 2004), separated from the everyday misunderstandings that can often transform into dramas; my mother – because she really was in a time of transition – and me – because I probably felt on some subconscious level that I was living through an inimitable and powerful experience – the dying of my mother. At the end of her life, my mother – just as I had wished in the foregoing stages of her illness – found peace and accepted her death. And she showed me that "dying is not as terrible as people usually think" (Kübler-Ross 2007:112–13).

My mother's death was sudden and unexpected for everyone around her, including, I believe, the hospital staff. Following puncture of a pleural discharge, she started to cough up blood. Together with a young nurse, I spent two hours collecting the blood that she was ejecting, trying to sustain her with the words "Everything will be alright, Mama". She still had the strength left to push herself against the bed so as to be able more easily to rid herself of the blood that was rising from her lungs. Her last words, before the doctors asked me to leave the room because of an intervention that they wanted to carry out, were "Children, I can't do this any more". According to the medical report, she died half an hour after my departure.

My Father

Death primarily belongs to the dying. The only really significant event that occurs at the time of death is the death itself, not medical attempts to subvert it. In our attempts to prolong life, we often prolong dying.
Nuland 1996:4

My father had lived with severe illness for more than a third of his life. In his 52nd year, after a fall and loss of consciousness that was never medically explained, he was left deaf and with an impaired nervous system that affected his maintenance of balance. He later suffered several strokes and developed Parkinson's Disease; after a weakening of his heart a couple of years ago, he had had a pacemaker inserted and was also subsequently treated as a cardiac patient. At one moment – perhaps that happened after a worsening of his neurological condition – it seems to me that death became an ever-present part of his life. My father wrote his will⁴ in 2003, and had long since given instructions about what he should be dressed in when he died. Every year, on the day of his wedding anniversary, he had put on his wedding suit and mentioned in passing that he wanted to be buried in it. After his wife's death, his life underwent a drastic change: not only was he then left without his 24-hour care-giver but my mother's death coincided with his increased uncertainty in walking and the impossibility of his leaving the house alone.

My father was hospitalised on the evening before his 80th birthday. The diagnosis: pneumonia and cardiac arrest. He did not react to medication for several days, found breathing difficult and needed oxygen, but he looked no worse than he had before. For his age and his general state caused by long-term neurological impairments, he was in good physical condition.

After eight days he was discharged from hospital, very much weakened and still with swollen legs because of his weak heart. On returning home he became very restless, dissatisfied, and I would say angry and even incensed (for that matter, just as my mother had been on returning home after her operation). Not recognising his condition, at one moment he refused to use his walking frame and insisted on aiding himself in walking with only one cane; he fell and I did not manage to hold him. I shall never forget how he toppled, while the sound of his bones hitting the parquet flooring will remain in my memory.

My father's weakness increased with every day of the three and a half weeks of his remaining life. He walked with the help of the walking frame or a cane during the first few days, more slowly and with more difficulty than before, but his life seemed to return to the state in which it had been before his hospital treatment. But that was only seemingly. I would say that he became more irritable during those

⁴ My mother also wrote a will, but I believe that was only because my father suggested it to her.

first days because he could not adapt to his new situation or realistically assess his own strength and possibilities. The loss of control of his own life was probably at the base of my father’s rage. His strength ebbed because his illness was taking full hold, he ate less and less (as I realized only later, he was losing the reflex to swallow), and I think that the strong doses of diuretic medication were also exhausting him and, as I learnt again too late, leading to dehydration. He started to suffer from pain in his muscles and bones, he walked with increasing difficulty and slowness, and, a week before his death, was no longer able to stand.

In addition, during his stay in hospital my father had begun to speak increasingly softly and by some ten days before his death had lost virtually any capability of producing sound, by which the possibility of almost any conversation with him was lost. It was only with the greatest concentration and my intuition that I sometimes managed to understand what he wanted to say, after he had voicelessly repeated it several times. He could no longer read or write. He also lost the capability of understanding words that were spoken slowly and clearly articulated and the sign-language that we had used during the thirty years of his deafness. Despite the fact that he could not hear himself, he probably understood that he could no longer produce sound, and for some time he frequently asked “What is happening to me?” No-one was able to explain that phenomenon to us: I mentioned it to a series of doctors, but none of them found it appropriate (or they didn’t know?) to tell me anything about it.⁵ This fact of him not being able to communicate at all – neither could he say anything nor understand anything – was perhaps the hardest and most tragic part for me of my father’s process of dying.

At first, after his return home from hospital, he was irritated because of his weakness and lack of understanding for the cause of his condition worsening so quickly; the second part of his process of dying passed in constant complaints about the pain in his muscles. Some of his physicians claimed that he could not be experiencing the pain of which he was complaining, while for a prolonged time they refused to alleviate the pain with the appropriate medication because of interaction between analgesics and sedatives with his Parkinson’s Disease. One of my father’s doctors rebuked me, saying that by insisting on palliatives, I wanted to help my father in the wrong way, since he was not suffering from cancer. Together with Joanne Lynn (1996:99), I consider it “an outrage” that doctors do not respect the fact that their dying patients can suffer great pain and that they should stop connecting pain only with patients suffering from cancer. During one phase of my insisting that my father’s pain be alleviated the doctor referred to above asked me what I consider to be two incomprehensively cruel questions: “Do you want us to alleviate his pain for your sake or for his?” and “Do you want to kill him [with

⁵ It was only several days before my father’s death, reading the Internet pages of an American society for Parkinson’s Disease sufferers that I understood that his voice loss could have been a symptom of the disease (<http://www.pdring.com/>; <http://www.pdf.org/>).

sedatives, J.Č.Ž.]?” I would have wished that my father’s doctors supported the following viewpoint: “Pain and suffering must be treated until they are relieved and by any means necessary, even at the risk of side effects including sedation, respiratory depression, hypotension, and death” (Krakauer 1996:31).

My father sank into a state that I could describe as being “between sleep and being awake” or as a type of delirium that manifested itself off and on. I think he was largely aware of what was happening around him, but he often relived certain episodes from the past – his reminiscences were largely from the period of his early youth and included people I did not know and situations in which he would sometimes sing.

Five days before his death he bid farewell to each member of the family individually. After that, he asked for a priest. Calmly and with complete awareness, cooperating as much as he could considering his deafness and his inability to speak, he received the last rites. However, the next day, during a medical examination, he was completely lost and frightened. Since I was unsuccessful in trying to explain that the doctor was coming to examine him, he was terribly alarmed and started frantically fighting against the examination. He fell into a serious psychotic state in which he thought that the doctor wanted to kill him.⁶ His words – “Do you want to kill me?” – had their logic if viewed from the aspect of a seriously ill and weak man, fully isolated from his immediate environment by deafness and weakness, whose only wish was that he be left in peace (comp. Kübler-Ross 2007:116ff).

Although all the signs supported that conclusion, I did not realise that my father would soon die. For that matter, this was as had been the case with my mother. In the last week of his life, my father said good-bye to the people closest to him and to the world at large, showing no interest at all in what had until then represented his customary world (comp. Kübler-Ross 2007:112ff). Although I still had fresh experience of my mother’s dying, I did not become aware that death was at hand. However, I did not avoid that thought as I had with my mother. With my father’s foreshadowing and acceptance of death, he had helped me to cope with it.

In those few weeks of my father’s process of dying, I did not have time to think about everything that was happening. Namely, every new day brought new deterioration and called for appropriate and brisk reaction, leaving little time for anything other than organisation of the best care. I functioned like an automaton geared to perform particular and necessary assignments, but I was insufficiently trained for many of them. Both during hospitalisation and later, it seemed to me that it was impossible to obtain full information and timely intervention from the doctors, whether medication or palliatives were in question. Unfortunately,

⁶ Unfortunately, I have to say that the doctor treated his patient with insufficient attention to and consideration for his overall state. Concentrated on his specialist area of expertise, armed with medical technology, he showed “fundamental inattention to dying” (Krakauer 1996:23), in fact, he did not acknowledge it.

almost none of his physicians showed empathy either with the patient or with me, who had largely undertaken the care of my dying father. They saw my father as a mere biological organism, and me as an ignoramus and individual overcome with emotion. I believe that they, too, were not aware of the closeness of his death (or perhaps they did not want to say so openly?), so one really should give some thought to Joanne Lynn’s admonition (in Curnen McCrea and Spiro 1996:21). She warns her readers that we will be dying at ever-advancing years in the near future, while the process of dying will become harder, probably without anyone to acknowledge the approach of death, to manage it or to assist us to come to terms with it.

During his last few days my father suffered from pain but also from severe psychomotorical agitation. His doctors finally agreed to give him stronger treatment against the pain, and later to relieve his acute psychomotorical agitation. This helped him, he became calm, and he died within 12 hours of its administration.

My father died a death that had many similarities with the “tame death” of Mediaeval knights, whose elements were reconstructed by Philippe Ariès. For example, he had a premonition that he would soon die and announced his coming death to several of his diverse collocutors, either directly, or by way of the instructions that he gave to me or my brother about his funeral. According to Ariès (1989), announcement of imminent death has no connection with any supernatural or magical premonition; it is instead a spontaneous comprehension arrived at through natural signs or intimate convictions. Since my father’s condition was worsening, it was not surprising that he had arrived at such a conclusion. As I have mentioned, it seems to me that, perhaps just because of his long-term illness, my father had developed a stance according to which death was a part of his life. It could be said that my father was in no hurry to die; to the contrary, he loved life and wanted to go on living for a long time. However, at the juncture when he saw that death was drawing near, he “died fittingly”. It was just that manner of dying that Ariès described, not only in reference to the Middle Ages but also to a later period, during the 19th century (ibid.).

When he began to die, some three weeks before his death actually occurred, my father knew that he was dying and undertook certain steps in that connection. He was aware of his impending death when he gave advice to the nephews and nieces and grandchildren, who came to visit him, about the duty of respecting one’s parents while he also wished them a successful end to their education. That awareness was obvious from the stories that he told about the key events in his life, while he was still able to speak more or less. It was more than evident at the moment that he asked for a priest and took his leave of the members of his immediate family. Despite the extent to which he was definitely in a transitional stage at times, perhaps not so much in command of his faculties as we conceive in our rational logic, at certain junctures, he still said good-bye to life and to the people

who would outlive him. I could not say that he showed signs of fear of death in that process. My father never complained that he was dying. In a certain way, he was intimate with death (Ariès 1989:29), both when he spoke about it and when it started to draw near. He accepted death calmly and easily, as an inevitability of human destiny (comp. Krakauer 1996:27; Ariès 1989), and also perhaps as a conclusive solution to many years of invalidity, the infirmity that accompanied old age and the loneliness he found very difficult to bear after the death of his wife.

There was another particularity in my father’s dying and death: he died in the way he wanted to, in his own home and not in a hospital or a retirement home, more or less constantly surrounded by his children, grandchildren and other kin-folk, and by neighbours and friends from time to time. My father died encircled by people who loved him, secure and without fear, except during one moment impeded by medical intervention. I feel privileged to have been able to give him support and to participate in the process of his dying.

Dying in Diverse Ways

My first encounter with dying was at the bedsides of my parents, keeping vigil over both of them practically during the entire final periods of their lives. They died at an interval of something more than a year and a half, after almost fifty years of shared life. Despite their long lives together, the histories of their dying differed considerably: the nature of their illnesses and their personal dispositions (comp. Kastenbaum [2009]; Wandel 1996) lay at the base of their diverse attitudes towards death and its comprehension, and in the way they surmounted the challenges that confront a human being in the last phase of life.

The last three decades of my father’s life were marked by chronic ailments, occasionally accompanied by depression. Despite his illnesses, he lived to a relatively advanced old age, surviving his wife by a short period. Although it could not be said that he died from “old age”, but probably rather from worsening of his chronic illnesses, his death appeared as a natural conclusion of the life cycle (comp. Cátedra 2004). As one of our female relatives said, my father “ripened”:⁷ not only was he finding it increasingly difficult to move towards the end because of his Parkinson’s Disease causing him to be prone to falls, but more importantly, he no longer had any zest for life, was rarely happy and, particularly after his wife’s death, complained of loneliness and fear of being placed in a retirement home. Sensing that death was near, he was able to accept the moment as well as the naturalness of death (Imhof 1996:115). Not even once did he express fear of death. In the real sense of the words, he died in the manner of Mediaeval knights:

⁷ Comp. Jefferson’s letter to John Adams in which he speaks of “a ripeness of time for death” (Nuland 1994:73).

awarely, bravely and resignedly (Ariès 1989). As he wished, he died at home surrounded by the care and attention of his close family. During his life and prior to the beginning of the process of dying, he had had enough time to prepare for death. My father died not only awarely but he died the death that he himself had orchestrated. Right up until the end, he almost never permitted control to slip out of his hands and, even after his death, he was indirectly present in directing his own funeral, having left instructions for my brother and me regarding both how to dress him and whom to invite to the funeral and the wake, and which songs should be sung at the funeral. With this attitude towards death, and also the fact that he had been seriously ill for a very long time, my father also prepared me for his death. I think that it was due to that very state of preparedness that I felt peace of mind at the moments of my father’s death (and later). They were not moments of extreme agitation but rather of extreme composure.

While I was tranquil during the time of my father’s process of dying, I felt immeasurable sadness and non-acceptance when my mother was dying. Those feelings had a counterpart in the manner in which my mother was dying. My feelings reflected her denial, anger and depression. With her life and her relative good health even in quite advanced age, my mother had denied the certainty of her own death. With the two of us being unable after the first diagnosis of cancer, and particularly after the diagnosis of metastases, to speak openly about her illness and possible death, “an unutterable foreboding and concealed sadness imposed itself between us, which we tried to hide from one another” (Salajpal 2004:51). Were we trying through silence to preserve each other’s hope? Were we also trying to save ourselves from the anxiety that the loss of hope brings? (Nuland 1994:227).⁸ Our reactions were influenced by the culturally constructed perception of cancer as a fateful disease that brings death. My perception also included the concept of cancer as being redemptive and the cultural script of “aware dying” (Seale 1998).

While my father came gradually to the stage of accepting death, preparing for it during the long series of years of his chronic ailments, my mother’s illness was acute in nature and left her little time to prepare for death. My mother travelled the path from denial to acceptance over a very short period. Since she had fallen ill from a disease that she experienced as her death sentence, that time was even more condensed, full of denial, struggle, hope and its loss, nausea, and loss of her hair, appetite, strength, dignity and independence. The fact that we did not manage together to confront her more or less imminent death had major consequences for me. I did not, as I did in my father’s case, start to mourn during her illness and process of dying and, after her death, I was overwhelmed by feelings of anger, followed by guilt and soul-searching and, finally, by a sense of deep

⁸ By sparing my mother from the anxiety experienced by patients who know there is no hope for them, as I realise only in retrospect, I was also trying to protect myself from the same anxiety.

bereavement, which was more profound two years after her death than that for my father who had just died.⁹

Unlike my father, my mother died in hospital. My father objected to our hospitalising her since his notion of a “good death” was death at home. However, as my mother’s illness was worsening so rapidly, it became impossible for us to provide at home all the care she needed. I think she was satisfied that we had her admitted to hospital, since she felt more secure there. As it happened, her general condition improved after several days of infusions and transfusions and I believe that her stay in hospital extended her life by those last two weeks – exactly the time that she needed to prepare for death. Since I spent the greater part of the day at her side in hospital, I hope that she did not experience the “gruesome, lonely, mechanical and dehumanized” aspects of dying in hospital (Palgi and Abramovitch 1984:403). My mother’s death was more precipitate and sudden than the rational efforts of her physicians to assess what was happening, that is, to construct a technical explanation (Chapple 2003:174) for the deterioration of her condition and, finally, the immediate cause of her death. I had been with her during that process and, if the doctors had not asked me to leave half an hour before her death, I could be more sure that my mother did not die a “wild” and “medicalised” but rather a “tame” death (Ariès 1989, 2004; Krakauer 1996). I feel a similar unease in connection with my father’s process of dying: my unsuccessful attempts that his pain be relieved bring into question the “tameness” of his death, although it certainly was so as regards all other characteristics.

My parents’ dying shows that they were both prepared for death towards the end of their lives. The diverse dynamics of their manner of preparation enables the assumption that we place our own deaths on the everyday horizon only when we become seriously ill. We do not dwell on it until then and it seems to be in the distant future which, because of the developments in medical science, will be postponed for a long time. The experiences described also indicate the conclusion that our modern, individualised and medicalised age need not necessarily imply a lonely death prolonged by technology in a corner of some “special hospital for chronic diseases” or a retirement home. I believe that my parents were exempted from the dominant manner of dying in Western Europe and America because they constructed the meaningfulness of their lives on the basis of an absence of

⁹ The bureaucratic nature of the hospital routine hid my mother’s death from me, leading to further widening of the gap between us (comp. Blauner, according to Palgi and Abramovitch 1984:406). That was completely contrary to my father’s death that took place at home. Since we ourselves dressed him and kept vigil beside him throughout the night, and were present with our closest kinfolk when his body was lain in the coffin and escorted from our house, I was able to say farewell to my father in a direct and intimate way. That moment of parting was much more important and moving in my experience of it, more authentic, than that of the funeral ceremony several days later. Such direct leave-taking was absent in the case of my mother.

selfishness and in giving of themselves to those closest to them (Elias in Rihtman-Auguštin 1988:182–183).¹⁰

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¹⁰ A longer version of this paper has been published under the title “Dva života i dvije smrti: Prilog antropologiji smrti i umiranja” [Two Lives and Two Deaths: A Contribution to the Anthropology of Death and Dying] In N. Ceribašić and Lj. Marks, eds. 2009. *Izazov tradicijske kulture: Svečani zbornik za Zoricu Vitez*. Zagreb: Institut za etnologiju i folkloristiku, 147–170.

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“SMRT PRIMARNO PRIPADA UMIRUĆIMA”: PRILOG ANTROPOLOGIJI SMRTI I UMIRANJA

SAŽETAK

U radu se etnografijom pojedinačnog – analizom iskustva umirućih roditelja i vlastita iskustva proživljenoga tijekom njihova umiranja – otvaraju neka pitanja suvremenog odnosa prema bolesti, smrti, liječenju i brizi za bolesnike. U okrilju antropološke, povijesne i psihološke literature autorica promišlja kulturno konstruirane percepcije, predloške i emocije vezane uz neke bolesti (karcinom) i pitanje bolesnika kao bliskog Drugog unutar obitelji, ali otvara i neka relevantna pitanja iz sfere medicinskoga, pa i općedruštvenoga tretmana bolesnika i umirućih ljudi, primjerice o primatu kurativne nad palijativnom medicinom, o nedostatku holističkoga sagledavanja pacijenta i njegove bolesti, te nadasve važno pitanje komunikacije i odnosa pacijenta i liječnika, odnosno pacijentove obitelji i liječnika.

Ključne riječi: antropologija smrti, umiranje, bolesnik/pacijent, liječnik