

Chapter 12

On the Sacred Character of Human Life and Death: General Discussion and Conclusion of Part II

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12.1 Introduction

It is my task to briefly look back on the discussions and reflections in this book concerning the topic of justice, luck and responsibility in health care, and in particular on the second part with end-of-life care issues such as our individual and social duties regarding end-of-life care for the elderly, especially for people suffering from dementia. It was not difficult to discover two different methodological approaches to the topic.

In the first approach, the theoretical endeavour is predominant, particularly the attempt to justify existing, real-life practices and the ethical intuitions involved. Some theories seem able to do this better than others. Of course, theorization is here a dialectical process: practices and intuitions may require changes in the theory, or the adoption of a better theory; but theorization seems to imply the possibility and even the necessity to change practices and/or intuitions.

The second approach starts from very concrete and particular situations, involving sometimes difficult, tragic and complex problems that occur in everyday health care. In such cases, we have to provide answers to these situations, or to the problem at hand.

I will very briefly discuss these two approaches as they appear in the various contributions to this volume and formulate some questions that seem to deserve additional attention if we want to reflect on the relationship between justice, luck and responsibility in health care, in particular on matters related to the ethics of end-of-life-care.

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12.2 Starting from Concrete Situations

Other authors proceed quite differently. Instead of constructing or further developing a theory capable of providing certain answers to particular problems, they start from concrete difficulties, intuitions and pre-reflexive understandings encountered in the context of end-of-life care itself.

When looking at the contributions of John Hardwig, Govert den Hartogh and Thomas Nys, we see that they all start from everyday questions like: Do I have a right or a duty to die? What should we think about assisted suicide? Should our children care for us indefinitely? What should the doctor, or our family members, do with the advance directive in our wallet? And what exactly do we fear when we are afraid of Alzheimer's disease? In these contributions, common sense reflections and understandings, human experiences and worries occupy central stage.

In the course of reflection on these concrete issues, certain notions or distinctions (like the right to die) and certain ethical principles (like respect for autonomy) are being appealed to or developed. The question here seems to be: are they sufficient or adequate to solve the problem or difficulty; and, even more fundamentally, do we really understand these notions and distinctions well? Do we really know what we mean by 'justice' and 'autonomy', by 'the self', by the distinction made between the 'then self' and the 'now self', etc.? These are very important questions, since a major objective of this book supposedly is the clarification of fundamental concepts like justice, luck and responsibility.

One could add that this clarification should include many more notions, especially concepts which belong to what Elisabeth Anscombe called 'philosophical psychology'. According to Anscombe in her famous paper entitled 'Modern Moral Philosophy' (Anscombe 1958), we should refrain from doing moral philosophy until we have an adequate philosophy of (moral) psychology. I agree with Anscombe that, in addition to the fundamental reflections presented in this book, more inquiry is needed on elementary notions we may take to be unproblematic, but which we perhaps do not understand properly, especially not when we are doing philosophy, and which therefore may steer our discussion in directions that are misleading.

In any case, the discussions and reflections in this book demonstrated to me the need for additional and deeper reflection on certain fundamental concepts and questions, more or less related to moral psychology. Let me give some illustrations.

12.3 What Is a Human Life?

Many of the discussions in the second part of this book involve the question: What is a truly human life? What gives it its worth or value? Does it consist in having had a certain amount of life-years of a certain quality? Is a good life about having had a certain number of experiences of a certain kind? Or is a truly human life better to be judged holistically, in accordance with the fulfilment of overarching ends or purposes? If so, doesn't this mean that its value can only be determined in the context

of recognition by others? And what do we mean exactly when we are saying that human beings are relational beings? Judging a human life's worth in terms of the number of QALY's (quality adjusted life years), as is being suggested in some lines of reasoning, may be evident in one perspective (e.g. in consequentialist reasoning), but utter nonsense in another (e.g. in a holistic consideration of the significance and value of a human life). Both perspectives cannot be right at the same time?

Involved in this discussion are the even more fundamental questions of the relation between life and time, self and other. These relationships (for example between *Dasein* and *Zeit*, between *Dasein* and *Mitsein*) have been the subject of deep thought in continental philosophy. Insights related to the notion of *life world* (*Lebenswelt*), have already been taken up also in analytic philosophy (cf. the work of authors like Peter Strawson, Bernard Williams, Stuart Hampshire, Richard Rorty, and many others) and could be made use of to refine our discussions. One can look upon people as atomistic individuals standing in purely contractual relationships with each other, for whom time is a succession of more or less agreeable or painful experiences, and on life as a space for self-management. Philosophers of the *life world* have put forward a completely different view of human beings, of their relation towards other human beings and towards themselves, of the way they experience and 'live' time while aiming at a human life, which is not directed at the fulfilment of needs, but rather at the pursuit of desires with respect to overarching values.

12.4 Theory as Central Preoccupation

Some contributors are interested in developing the consequences of theories of justice or equality with respect to end-of-life care issues, and vice versa. In the first part of the book, this is particularly the case with the contributions of Daniel Hausman and others. Hausman discusses the comparative merits of certain theories with respect to the justification of equality in health care or of the acceptability of specific inequalities; Shlomi Segall focuses on the merits of luck egalitarianism in relation to affirmative action in health; and Yvonne Denier inquires into the consequences of luck egalitarianism with regard to people's decisions in matters of reproduction.

From the second part of the book, we learn that a theoretical discussion can be helpful in providing answers to specific and concrete questions, like whether or not there is such a thing as 'a duty to die', or at least a responsibility not to extend 'futile' care. From Martin Gunderson's analysis, we learn that there might indeed be good reasons for not wanting to extend one's life indefinitely, but that individual freedom to decide what should be done at the end of one's life prevails over the duty to die. In his analysis, Elisabeth Anderson's theory of democratic equality serves as a corner stone. Another theory we meet in the second part of the book is the one defended in the contribution of Chris Gastmans, *viz.* the ethical theory of Louvain Personalism, which is based on the notion of respect for the dignity of the human person in his or her various dimensions. This theory is used in the discussion of the need for dignity-enhancing care for people with dementia.

In general, one can ask several questions as to the necessity of theorization in ethics. For instance, do we have to have a *theoretical* justification for ethical *practice*? And is that even possible? Furthermore, there also seems to be a problem with respect to the relationship between theory and fundamental ethical concepts. Are the concepts first? Or is their meaning ultimately determined by the theory? These are fundamental issues with respect to our ethical reflection. As is evident from these proceedings, the discussion between theories will continue; and it seems unlikely we will easily reach final conclusions in this domain.

12.5 What Is Autonomy in Relation to My Life?

Another problematic notion, explicitly or implicitly present in discussions in the second part of the book, is that of autonomy as related to my life as a whole. Sometimes autonomy is understood as the autonomy of a pure subject standing in a relation of ownership vis-à-vis its own body, a subject which through its own pure will can mould its own character and acquire competences in function of its self-chosen ends. The life of such a subject is considered as a kind of investment area to be filled with as many ‘worthwhile’ experiences as possible through self-management.

This is the ideology behind a lot of talk about autonomy today. Can real autonomy, as being lived in the *life world* ever mean anything like this? When I judge my life, can I do this objectively (as if it were the life of someone else)? Or is it the case that I am always already attached to it in an attachment, which precedes any conscious identification in such a way that even when I have a particular wish (even when I want to end my life, for instance), it is on the very basis of this ineradicable attachment (“*I cannot go on like this*”).?

In a discussion on genetic enhancement, Michael Sandel used Hannah Arendt’s notion of *natality* (which reminds one of Heidegger’s *Geworfenheit*) (Sandel 2007) in order to express the fact that human beings are born, not made (certainly not by themselves). Life is a (sometimes terrible) gift. It is only in the context of giftedness, as Sandel stresses, that a notion like autonomy can and must be given its proper meaning.

12.6 What Is the Relation of a Person to Another?

We have responsibilities toward other people, and *special* responsibilities toward particular others, like friends and family members. Again, with respect to these responsibilities, what looks perhaps straightforward at first, is less straightforward when thinking things through.

For instance, when we care about a family member, what exactly is it that we care about? When I care about my child, I care not simply because of its present or future interesting qualities or dimensions. Or put in stronger terms: when a pregnant

parent cares for her unborn baby, she cares for it even before she knows what interesting qualities it has or will have. She cares for it because of its singularity and the singularity of the (family) relationship: because it is *her* child. What is behind this care is the appeal on us of the *symbolic* meaning attached to family relationships. The term 'symbolic' does not refer to that which is 'merely' symbolic, as opposed to *the real thing*. Blood relationship is symbolic in the sense that the material or causal tie is over-determined by culturally established meanings and values, whereby the tie is not the justification, but only the 'incarnation' of these meanings and values. This also means that the vicissitudes of the material tie have implications for these meanings and values; e. g. the death of a child means an *irreparable* loss. The importance of the symbolic tie linking one person to another person, one human body to another has been discussed by some of my colleagues here in Leuven (Breur and Burms 2008; Burms 2001, 2008).

In all human societies blood relationship automatically has symbolic meaning, with special ethical consequences related to it. Some human relationships are of course a matter of choice. But even then, as for instance in marriage or adoption, they are symbolically over-determined which is noticeable from the symbols and rituals attached to their inauguration (adoption often or usually requires obtaining a new (family) name, making the child into *our* child, even though not in the sense related to biological offspring). The symbolic nature of family relationships implies that what interests us in the other person transcends all interesting qualities, the combination of which could also be found in someone else. The essence of family relationship is that it points to the importance for me of *this* person and *this* body as my next of kin, in whatever state he or she may be, whether handicapped, or old or depressed. Even dead, the person remains of extreme importance to the family. That is why we treat the deceased with care, and approach them in a respectful, even hallowed way. We do not want the dead body to be mishandled; even though the dead cannot possibly be the subject of harm (except symbolic harm).

It seems then that we cannot deny the fact that the relationship between human beings cannot be solely understood in terms of the useful or interesting qualities they have for each other. Indeed, not only family relationship is deeply symbolic, the same is true of our relationship with human beings in general. And again, this relationship has to do with the 'incarnation' of human beings in their body. The distress and horror people feel with respect to the violation of the human body, especially the female body or the body of children, and with respect to the desecration of dead bodies and graves, is not an irrational remnant of taboo mentality, but something central to human relationships as essentially mediated by the human body. Instead of an anomaly, it is something, which should be at the centre of our understanding of ethical behaviour vis-à-vis human beings. Again, this topic is not completely absent from analytic philosophy (see Diamond 1995). The conception of the 'sacredness' of the human body and of the human person is not the prerogative of religious thought. It is and should be a central topic in secular ethical thinking as well. Not only continental thinkers like Martin Heidegger, Hannah Arendt or Simone Weil, but also some analytic authors; some of whom, like David Wiggins (2009) or Stuart Hampshire (1983), have explicitly used this notion of sacredness in their reflections on ethics. 'Sacred'

here means that which is *'hors commerce'*, which cannot be merchandised, which has no price. It is also that, which is set apart and cannot be violated. It is a concept, which has meaning also outside the strictly religious context.

12.7 Sacrifice and Piety

The symbolic union of family relationship can sometimes (rightly or wrongly) be the origin of great sacrifice. A well-known version of extreme sacrifice in the context of family relationships is to be found in Greek Thought where Antigone, the subject of Sophocles' tragedy, attempts to secure a respectable burial for her brother Polynices, even though he was a traitor to Thebes and the law forbade mourning for him, on pain of death. Antigone wants to bury her brother, because he is her brother, and because it is the will of the gods. For doing this, she willingly and knowingly risks and sacrifices her life.

In this book, we have learned from John Hardwig that voluntary family care for an elderly family member can be extremely demanding, even self-sacrificing. From Yvonne Denier's contribution, we have learned that pregnant couples can decide to continue the pregnancy of a seriously handicapped baby in the full knowledge that their lives will be very complicated and demanding. However, it is not only in such extreme cases, that we discover the sacrifices that come with family relationships. We also notice them in our daily lives. Having a family, being a family member, being a husband or a wife, a brother or a sister, having children or being a child oneself, bring with them all sorts of duty and obligation, and small or great sacrifices. Fortunately, the symbolic order in which we live, normally helps us to deal with the 'cost' of living in such relationships, like for instance the rites of burial or cremation help us to mourn the loss and to resume the ordinary course of life. We also should not forget that everyday family life is replete with its well-known, fixed moments of small rites, like having breakfast or dinner together, reading a bed-time story, the traditional Sunday-morning family walk, or afternoon-tea with the grandparents. It would be wrong to divorce all this completely from ethics.

Taking into account the symbolic context of human life and particularly of family life, it seems very odd to understand the quality of family relationships in terms of their usefulness, or on their output determined by a careful cost-benefit-analysis in terms of quality-adjusted life years (QALY's). To conceive of responsibility in family relationships in terms of measurement of QALY's seems to equate them with business-like relationship. To me, this seems to demonstrate a complete alienation from the perspective of *piety*, which is very closely related to the symbolic character of family relationships. George Santayana defined piety as follows: "Piety is the spirit's acknowledgment of its incarnation" (Santayana 1905, p. 184). In view of this definition, and in view of the nature of family relationships, it is not surprising that piety is so deeply involved in the incarnational ties between family members.

If this is the truth behind family relationships, how could I – as some lines of reasoning in the second part of this book seem to suggest – enter into a discussion with my mother or father, weighing the comparative weight of a little less QALY's for them

vis-à-vis extensive financial benefits for me? What can more QALY's for me mean in comparison to the incredible lack of loyalty and piety betrayed by the very thought of such a discussion? The problem in real family relations is not about justice with respect to benefits and burdens measured in terms of QALY's, the problem is primarily about piety, love, guilt, shame, disgrace, atonement, etc. It is not surprising then – by the way – that ethics and ethical reflection are deeply narrative in nature. Movies like Wim Wenders' *Paris, Texas* (1984), or novels like J.M. Coetzee's *Disgrace* (1999), or Ian McEwan's *Atonement* (McEwan 2001) can show us a great deal of what it means to be part of a family and what it means to be ethical in this context. When this narrative background is not taken into account, ethics becomes an abstraction or, worse, an insensitive meddling with human affairs of great importance.

By pointing at all this, I do not wish to deny that there can be conflicts between the demands of filial piety and the financial survival of the family. However, these conflicts cannot be solved in a way which completely disregards the symbolic nature of family relationships. What is certainly needed here, are common institutions and common rituals telling us how to proceed. The need for institutions and rituals is, for instance, expressed in a dramatic way in the Japanese movie *The Ballad of Narayama* (1983). The movie is set in a small rural village in Northern Japan in the nineteenth century and pictures the tradition of a tribe living in very harsh conditions. To guarantee survival of the family, old people who have reached the age of 70 are carried to the top of the mountain Narayama at the beginning of winter, to leave them there to die, a practice known as *ubasute*. By custom, this task is assigned to the oldest son. What makes the movie so interesting, is that it demonstrates that it is only possible for the son to carry out this terrible task because it is a practice, which is steeped in tradition and rite.

It is not premeditated and orchestrated death per se which is ethically abominable; it is a death which is not part of meaningful human relationships determined by symbols and expressed in some form of ritual.

12.8 Notion of Personal Identity – The Sacredness of Each and Every Human Being

One last example of crucial notions and related questions to be much more thoroughly investigated in the context of our discussion of justice, luck and responsibility in end-of-life care is the notion of Self and the problem of personal identity. Certain notions of the Self make it impossible to understand the fear of disintegration of one's self, or of losing everything which has been important in one's life. Compare the opposition between the 'critical' self caring about disintegration and the purely experiential self, as has been discussed in the contributions of Chris Gastmans, Govert den Hartogh and Thomas Nys.

What exactly is the relationship between personal identity as referring to "a living organism of the human species in which houses *up to a point* a subject of experience", and a personal Self which in its constitution and self-awareness "is conditioned by its being-for-others"? As Hume has already demonstrated, it is impossible to find the

ground for personal identity in the individual's self-awareness. But it seems equally unsatisfactory to let personal identity depend simply on the (re)cognition of others? Perhaps the identity of the body is what is the real basis of personal identity (which is not to say that inter-subjectivity plays no role at all)? (Breur and Burms 2008).

Understanding the nature of care equally seems to suppose a close link between Self, Body, and Other. Suppose one is a living organism of the human species *without* a controlling subject (having a will, and long term projects). *Why* should this organism still be an object of care and piety, perhaps even overriding the advance directives of the 'earlier' subject? That this living organism no longer has normal physical, psychological, let alone relational or moral capacities (it no longer cares about anything), does this matter at all for care? If it doesn't, if simply *being a human body* (born from a woman) is sufficient for entitlement to care, what then is the basis of this entitlement? What is the basis for the special dignity of the human body?

It cannot be the special status of the human body from a neutral point of view, because from this perspective, it is only gradually different from other (complex) bodies (like those of animals). Again it must be the symbolic meaning and value attached to something material: *human* bodies (as in the case of the basis of care for family members, which is the symbolic meaning and value linked to family relationship). This time, special meaning and value is bestowed upon *any body* that stands in a certain causal-symbolic relationship with other human bodies. Belonging to the same (biological) species is given special moral significance here, not because of the objective difference with other bodies, but because *we see them as* 'untouchable' within our attitude of piety towards persons and the bodies they are incarnated in (De Dijn 1999). The attitude is not based on the objective difference. The objective difference is given special meaning, is symbolically over-determined in and by the attitude.

As such, and contrary to the thesis of George Kateb (2011), I defend the idea that there is no *external* justification for the idea of the special dignity of the human person or the human body. Human dignity has to do with the special meaning or significance with which each and every human body spontaneously appears to us (Wiggins 2009). The justification for our care can only be *internal*; it can only be grasped by someone who is seeing human bodies *as* persons. So if we want to ask *why* we should treat severely demented patients with respect (for instance why we cannot simply lock them out of our lives, or why we still have to respect their privacy when they are being washed, even when they are no longer aware of what we are doing), then the answer is simple. It is because they are human in this fundamental symbolic sense, which we express with terms like 'human dignity', 'sacredness', etc.

12.9 Concluding Reflection

If we want to reach our objective, which is the clarification of central notions like justice, equality, luck and responsibility, and their application to ethical discussions in end-of-life care issues, it seems unavoidable also to reflect on other, related, fundamental notions. It therefore seems to me insufficient to concentrate simply on the

relative merits of certain theories presupposing an already adequate insight into our fundamental notions. On the contrary, more preliminary work in the field of ‘moral anthropology’ is indispensable, as well as more reflection on what we are doing in real life (the life of the *life world*) and on the expressions of this in narratives of all kind. If this means that streamlined philosophical management of ethical discussions is (indefinitely) postponed, perhaps it is not so unwelcome a result for people’s ethical behaviour after all?

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