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Veselin L. Mitrović *Editors*

# Theories of the Self and Autonomy in Medical Ethics

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Michael Kühler · Veselin L. Mitrović  
Editors

# Theories of the Self and Autonomy in Medical Ethics

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# Preface

This volume is the result of a longstanding cooperation between the editors and some of the contributors. Starting with a workshop on “Issues in Theoretical and Applied Ethics,” organized by Gunnar Scott Reinbacher and Jörg Zeller in 2011 in Klitgaard, Denmark, the central topic of our shared discussion since then had quickly been found, namely, the controversial relation between debates and arguments in theoretical ethics and metaethics, on the one hand, and applied ethics, esp. medical ethics, on the other hand. Since then an edited volume based on this first workshop followed (Zeller, Jörg/Riis, Ole Preben/Nykänen, Hannes (eds.): *Issues in Theoretical and Applied Ethics*, Aalborg: Aalborg University Press) as well as two further workshops: “Applied Ethics and Applying Ethics,” organized by Michael Kühler and Jörg Zeller in 2013 in Münster, Germany, and “Theories of the Self and Respect for Autonomy in Palliative Care and End-of-Life Decisions,” organized by Veselin Mitrović and Michael Kühler in 2016 in Belgrade, Serbia. The latter workshop has been the starting point for the current volume, which contains a number of revised contributions to this workshop but also a number of additional contributions by other colleagues, thus joining our ongoing discussion.

As with all such volumes, they are the result of many people’s contributions and help. First of all, we would like to express our utmost gratitude to all contributors for putting in so much hard work to provide this volume with so many excellent and thought-provoking chapters. Furthermore, we would like to say a special “thank you” to Cecil Joselin Simon, Christopher Wilby, Floor Oosting, and Cynthia Kroonen at Springer for their tremendous support and truly admirable patience when it came to putting this volume together. Last but certainly not least, we are very grateful to Lucie White and Rachel Fedock for their invaluable help in proofreading and language editing. We cannot stress enough how much we appreciate their support.

Belgrade, Serbia  
Enschede, The Netherlands  
June 2020

Veselin L. Mitrović  
Michael Kühler

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**Michael Kühler** is Assistant Professor at the University of Twente, Netherlands and “Privatdozent” (roughly equaling Associate Professor) at Münster University, Germany. His research interests include ethics, medical ethics, metaethics, and political philosophy. His recent publications include “Technological Moral Luck,” in: Beck, Birgit/Kühler, Michael (eds.): *Technology, Anthropology, and Dimensions of Responsibility*, Techno:Phil 1, Stuttgart: Metzler, 2020, 115–132, [https://doi.org/10.1007/978-3-476-04896-7\\_9](https://doi.org/10.1007/978-3-476-04896-7_9), “Romantische Liebe und die Freiheit zu gehen,” in: Dietz, Simone/Foth, Hannes/Wiertz, Svenja (eds.): *Die Freiheit zu gehen. Ausstiegsoptionen in politischen, sozialen und existenziellen Kontexten*, Wiesbaden: Springer, 2019, 195–222, “*Modus Vivendi* and Toleration,” in: Horton, John/Westphal, Manon/Willems, Ulrich (eds.): *The Political Theory of Modus Vivendi*, Dordrecht: Springer, 2019, 235–253, “Toleranz und/oder Paternalismus im engeren sozialen Nahbereich?,” in: *Zeitschrift für Praktische Philosophie* 4, 2017, 63–86; and “What if I Cannot Do What I Have to Do? Notions of Personal Practical Necessity and the Principle ‘Ought Implies Can’,” in: Bauer, Katharina/Mieth, Corinna/Varga, Somogy (eds.): *Dimensions of Practical Necessity. “Here I Stand. I Can Do No Other,”* Houndmills: Palgrave Macmillan, 2017, 87–107.

**Veselin L. Mitrović** is a senior research associate at the Institute of Social Sciences at the University of Belgrade. His research activities feature topics in Bioethics, Disaster Study, Sociology of Culture and Social Action in different strata (from marginal to elite). His recent publications include “Ethics and Floods: A Systematic Review,” *Disaster Medicine and Public Health Preparedness* 13/4, 2019, 817–828. “Parent’s Religious and Secular Perspectives on IVF Planning in Serbia,” *Journal for the Study of Religions and Ideologies* 15/43, Spring 2016, 48–81; “From Global Bioethics to Neuroethics,” *TEME* XL/4, 2016, 1457–1475 (Serbian); “Resilience: detecting vulnerability in marginal groups,” *Disaster Prevention and Management* 24/2, 2015, 185–200; “The Contingency of the ‘Enhancement’ Arguments: The Possible Transition From Ethical Debate to Social and Political Programs,” *Journal for the Study of Religions and Ideologies* 13/37, Spring 2014, 93–124; “Ethos of the Elite and Future of Serbia,” *Balkanske sinteze* 1/1, 2014, 167–189 (Serbian); “Nanotechnologies and Global Survival,” *Sociologija* LIV/1, 2012, 37–54 (Serbian);

“The Myth of Moral Enhancement: Back to the Future?,” *Filozofija i društvo* XXIII/2, 2012, 111–123 (Serbian); “Human Enhancement: Toward the Creation of Patterns of Injustice?” Zeller, Jörg/Riis, Ole Preben/Nykänen, Hannes (eds.): *Issues in Theoretical and Applied Ethics*, Aalborg: Aalborg University Press, 2013; “Study,” *Sociology in Serbia 1959–2009, Institutional Development*, 59–107, (ed.) Marija Bogdanović, (Beograd: Službeni glasnik i Filozofski fakultet Univerzitet u Beogradu, 2009) (Serbian). He is also author of the following books written in Serbian: *Apathetic Society* (2015); *The Stride of Bioethics, New Bio-Technologies and Social Aspects of the “Enhancement” of the Healthy* (2012) and *Jazz as Socio-Cultural Improvisation – A Qualitative Research of Social Mobility* (2012).

# Chapter 1

## Introduction



Michael Kühler and Veselin Mitrović

### 1.1 Autonomy and the Self in Recent Medical Ethics

For the last few decades, the principle of respecting patients' autonomy has been of major importance in medical ethics, notably in terms of the requirement of gaining patients' informed consent for any treatment to be considered legitimate.<sup>1</sup> However, there is still an ongoing debate about its exact understanding and implications. It is not only a matter of dispute how to analyze the concept of personal autonomy in general,<sup>2</sup> but also whether and to what degree resulting specific conceptions of autonomy are suitable for being used in medical ethics in particular.<sup>3</sup>

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<sup>1</sup>Cf., for example, Eyal (2012) and Article 5, "Autonomy and individual responsibility," of the *Universal Declaration on Bioethics and Human Rights*: "The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests" (UNESCO 2005, 77).

<sup>2</sup>See, for example the contributions in Mackenzie and Stoljar (2000), Christman and Anderson (2005), Taylor (2005); and Kühler and Jelinek (2013a). For current overviews of the debate, see Buss (2013), Christman (2015), and Stoljar (2015).

<sup>3</sup>See, for example Maclean (2009).

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In this regard, Tom Beauchamp and James Childress, in their highly influential *Principles of Biomedical Ethics*,<sup>4</sup> start their analysis of autonomy intentionally with a rather generic and in part negatively defined notion of autonomy: “We analyze autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action.”<sup>5</sup> One of the reasons for doing so is to acknowledge and accommodate various different and competing conceptions of autonomy. Yet, while they indeed explicitly acknowledge the importance of relational accounts of autonomy in this regard, they miss to discuss them in more detail, especially when it comes to addressing their competing implications in comparison to strictly individualistic accounts, like the resulting analysis and assessment of the influence of friends and family on a patient’s decision-making process.<sup>6</sup> Moreover, given that autonomy essentially refers to the idea and capacity of *self-determination* and, thus, includes an *authenticity criterion* to ensure that it is actually the agent him- or herself determining his or her decisions and actions, this raises the question of how to spell out this authenticity criterion and, consequently, the notion of the agent’s self in more or less relational or individualistic terms as well.<sup>7</sup>

Accordingly, one of the driving motivations behind putting together this volume is to address and discuss critically the implications of theories of the self and of personal autonomy for medical ethics and practice, especially for the principle of respect for autonomy, and vice versa. Certain hard cases in medical ethics prove to be exceptionally well suited to accomplish this, not only because of their challenging circumstances in general, but also because they specifically bring to the forefront contested implications of the respective underlying account of autonomy. Given the range of new possibilities in assisted reproductive technologies, such questions already have to be raised at the very beginning of life, i.e. what impact these technologies might have on the constitution of the future person’s authenticity and autonomy. On the other hand, in cases of palliative care and end-of-life decisions, e.g. physician-assisted suicide, patients usually have only little control left over how they live their remaining life. Their autonomy, especially their capacity for carrying out their autonomous decisions, including bringing about their own death, may be drastically diminished or may even no longer exist at all. Moreover, finding out whether, or ensuring that, a patient’s decision is actually autonomous poses major

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<sup>4</sup>Beauchamp and Childress (2013). For helpful introductions to medical ethics more generally, see Schramme (2002), Schöne-Seifert (2007), Have and Gordijn (2013), Wiesemann and Simon (2013), Sturma and Heinrichs (2015), and Hope and Dunn (2018).

<sup>5</sup>Beauchamp and Childress (2013), 104.

<sup>6</sup>Cf. Beauchamp and Childress (2013), 106. It should be noted that Beauchamp and Childress address such issues partially in the context of their three other principles, i.e. nonmaleficence, beneficence, and justice. However, this already characterizes these issues as external to a person’s autonomy, while relational accounts of autonomy typically aim at depicting social relations as internal characteristics of autonomy. Hence, Beauchamp and Childress essentially still presuppose an individualistic conception of autonomy.

<sup>7</sup>See in this regard, for example, the contributions in Kühler and Jelinek (2013a) and, for an overview, the volume’s introduction, Kühler and Jelinek (2013b).

epistemic, normative, and practical problems. What (epistemic) conditions should be fulfilled in order to conclude that it is really the patient's autonomous and authentic will to die? What (normative) reasons are or should be considered decisive when it comes to determining what may be regarded as sufficiently autonomous in such cases in the first place, i.e. why should some preference or decision be regarded as autonomous and be respected? How can respect for and support of autonomy be ensured in medical practice in general if the patient is no longer able or drastically impaired in his or her capacity to utter what he or she wants, e.g. in certain cases of palliative care or in case of a comatose patient?<sup>8</sup>

At this point, underlying theories of the self and of personal autonomy are obviously of crucial importance because they have a fundamental impact on what kind of answers to such epistemic, normative, and practical questions may be regarded as promising or plausible. For example, could a narrative approach to the constitution of the self and to personal autonomy give decisive (epistemic and/or normative) reasons to interpret and assess as (in-)authentic and (non-)autonomous what an unconscious, comatose, or otherwise incompetent patient would want, depending on how well it fits the patient's constitutive story of his or her self? A story might, for example, explicitly include a certain personal evaluative outlook on 'death,' which could guide the (narrative) assessment of the patient's intention to die. Alternatively, based on relational accounts of personal autonomy and the self, especially friends and family seem to be able to play a crucial role in determining a patient's autonomous will, as they are already considered being partially constitutive for the patient's autonomy in general. In contrast, individualistic accounts usually dismiss external social influences when it comes to the constitution of autonomy and the self. At most, such influences are regarded as posing a threat to autonomy. Consequently, supporting and respecting a patient's autonomous preferences would have to play out quite differently in practice.

In any case, given that our personality and preferences are likely to change over time, at least to some degree, what about the normative standing and binding force of patients' advance directives to ensure long-term respect for their autonomy? On the one hand, advance directives are explicitly intended to secure respect for autonomy even if a patient is no longer able or severely impaired to make autonomous decisions. Referring to the patient's advance directive apparently provides an easy and decisive way of determining what the patient autonomously wants in the situation at hand. However, it is still a matter of debate what epistemic and normative bearing past decisions should have on current situations, especially in cases of conflict. Why

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<sup>8</sup>As one reviewer of this volume helpfully remarked, it should be noted that some hard cases nowadays pose a flip sided challenge. In these cases, the patient explicitly wants to continue treatment, e.g. due to the patient's advance directive including that "everything be done," while physicians and other caregivers would prefer to cease treatment due to it being clearly futile. This indeed raises the familiar issue discussed in this volume, i.e. whether the patient's wish that "everything be done" may be considered sufficiently autonomous. However, given the assumed futility of further treatment, the more pressing ethical questions presumably concern matters of justice in access to specific and likely expensive health care while assuming that health care resources are scarce and need to be distributed effectively, efficiently, and fairly—questions that go beyond the scope of this volume.

exactly should an advance directive have priority over a patient's current, conflicting preference, or vice versa, e.g. in cases of dementia and major changes in the patient's personality? Moreover, substantial changes in personality, e.g. again in cases of severe dementia, raise critical questions about whether these patients can even still plausibly be held responsible for their past actions. This poses a major challenge in criminal law and for the penal system when dealing with inmates suffering from dementia. And even if such inmates are still considered responsible for their past crimes, how should their special needs for appropriate treatment be acknowledged best, especially when assuming that prisons are usually not well-equipped to handle such cases? In general, how should we, as individuals as well as society, address such challenges? Despite the complexity of these issues as a whole, keeping in mind the implications of competing theories of autonomy and the self for medical ethics and law-making at least seems to be a promising starting point.

However, respect for autonomy is not the only principle to be adhered to. For the purpose of this volume, in particular beneficence and nonmaleficence play an important role as well, again especially in hard cases such as palliative care and end-of-life decision-making. In palliative care, attempts at reducing a patient's pain and suffering through suitable medical drugs often include the unwanted side effect of diminishing the patient's capacity for autonomy (even more) or of diminishing his or her remaining life expectancy, with the latter blurring the line between treatment and physician assisted suicide in case the patient wants to die.<sup>9</sup>

In addition to such cases located literally at the end of life, we also often talk figuratively about someone's life having come to an end, namely in cases in which a person has not only reached a low point in life, but in which there is, apparently, also no longer any, or only very little, hope that his or her well-being will improve again.<sup>10</sup> This holds, for example, for people suffering from certain permanent diseases or poor health conditions, as is often the case when living—or rather only surviving—at the margins of society, like homeless people. Assuming that patients in such dire circumstances are especially vulnerable,<sup>11</sup> it appears to be an extra challenge when it comes to respecting their autonomy and trying to improve their well-being. Put more generally, how should we analyze the relation between autonomy and vulnerability, and what ethical consequences should be drawn from this analysis?<sup>12</sup> Ultimately, such cases pose not only major challenges to medical ethics in particular, but to ethics, politics, and law-making in general.

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<sup>9</sup>In this regard, the doctrine of double effect may also play an important role. See McIntyre (2014).

<sup>10</sup>Article 8, "Respect for human vulnerability and personal integrity," of the *Universal Declaration on Bioethics and Human Rights* pays special attention to such individuals and groups: "In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected" (UNESCO 2005, 77). Still, no specific guidelines are mentioned that define the manner in which such persons have to be protected, especially when it comes to the relation between vulnerability and autonomy.

<sup>11</sup>Another example of such vulnerable positions would be embryos created in IVF (in vitro fertilization).

<sup>12</sup>For a discussion of some practical implications of such cases, see Mitrović (2015).

## 1.2 Contributions

The papers of this volume are grouped into two sections. In the first section, specific theories of the self and of autonomy are used as starting points in order to flesh out and discuss critically their implications for how to deal with hard cases in medical ethics. The contributions in the second section take the other way around and discuss crucial issues in medical ethics in order to make explicit and discuss critically their implications for formulating adequate positions in theoretical ethics or law. It should also be noted that a number of contributions explicitly consider specific German or Serbian points of view in terms of idiosyncratic social norms or laws, while other contributions aim at a more universal perspective when discussing their topic.<sup>13</sup>

### 1.2.1 *Section 1: From Theories of the Self and Autonomy to Medical Ethics*

In her contribution “What Is Autonomy Anyway?,” Milijana Djerić takes respect for autonomy in palliative care and end-of-life decision-making usually to imply a patient’s right to choose or refuse a life sustaining treatment. It is, however, close only to one sense of this notion, namely to autonomy as individual or personal liberty. This sense of autonomy is derived from Mill’s work *On Liberty*, and it is important for the context of end-of-life decision-making because it provides the classical grounds for the moral obligation of a physician not to proceed without the patient’s consent. It highlights the importance of the absence of external constraints and rules out the possibility of medical paternalism. However, there is another sense of autonomy, namely autonomy as rationality. This notion highlights the importance of the absence of internal constraints and refers to autonomy as decision-making capacity. It implies the absence of cognitive and psychological limitations in decision-making. Therefore, it seems that true autonomy implies that the person is free from internal as well as from external constraints. The aim of Djerić’s contribution is to point out these two different notions of autonomy, to explore the role and mutual relations of these notions in the context of end-of-life decision-making, and to address the question of whether and, if so, how terminally ill patients may still be able to achieve true autonomy in this sense.

In her contribution “Personal Identity and Self-Regarding Choice in Medical Ethics,” Lucie White argues that when talking about personal identity in the context of medical ethics, ethicists tend to borrow haphazardly from different philosophical notions of personal identity, or to abjure these abstract metaphysical concerns as having nothing to do with practical questions in medical ethics. In fact, as she points out, part of the moral authority for respecting a patient’s self-regarding decisions can only be made sense of if we make certain assumptions that are central to a particular,

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<sup>13</sup>For an instructive overview of different cultural perspectives on medical ethics and bioethics more generally, see Have and Gordijn (2013), section III.

psychological picture of personal identity, namely, that patients will remain psychologically connected to a certain degree with their future selves. White draws this out in detail, shows important problems with approaches in medical ethics based on alternate theories of personal identity that do not recognize this, and explores some important implications.

In his contribution “Personal Identity and the Validity of Advance Directives,” Karsten Witt addresses the fundamental role of personal identity within medical ethics and especially its role and importance for certain kinds of future-directed medical decisions, namely decisions enshrined in oral or written advance directives. While it is not always clear in what sense the term *personal identity* is used in respective debates, part of the discussion is about our numerical identity through time and, at first sight, its importance seems indisputable. When we declare that a certain patient should under such-and-such future circumstances receive such-and-such medical treatment or, more frequently, that she should not receive a given treatment, whether we are that patient appears to make a crucial difference. According to conventional bioethical wisdom, medical decision-making for others is much more problematic, and in need of a different kind of justification, than deciding for ourselves. And whether the decision is self-regarding or other-regarding seems to turn on personal identity in the strict philosophical sense. While this intuitively plausible claim about personal identity’s importance is widely shared, it has recently been criticized by various bioethicists for its seemingly troubling consequences for advance directives when combined with a psychological-continuity account of personal identity: the signer of an advance directive might not be numerically identical with her severely demented or permanently comatose ‘biological successor’, possibly depriving the directive of its moral authority. Still, Witt defends the initial claim and mainly argues that many objections against it are variations of the idea that what is crucial for the validity of advance directives is not whether signer and patient *are* numerically identical, but whether certain people in the patient’s environment *believe* that they are. Yet, this idea is problematically vague, Witt argues, as it borders on incoherence, and has troubling ethical consequences. Critics of the initial claim, therefore, have two options left: they might save part of their critique by embracing conventionalism about personal identity or they might claim that advance directives are not about self-determination but can still play an important part in decisions about the patient’s best interests.

In his contribution “Narratives in Flux. Why Patients’ Life Stories Do Not Provide Decisive Instructions in Cases of Surrogate Decision-Making,” Michael Kühler critically discusses the role narrative accounts of the self might play in surrogate decision-making. Medical cases in which patients are not or no longer able to express their interests and also have not given a prior account of them present us with the question of how to respect their autonomy, i.e. how the patient would probably want to be treated, were he or she able to decide for him- or herself. In such situations it seems natural to refer to a notion of the person’s identity or self, for based on this we might extrapolate how the person would decide in an authentic manner. In this regard, narrative theories of the self seem to be able to provide a reasonable answer. Knowing a person’s life story seems to suggest a simple and convincing way to



determine her authentic interests based on how her story, i.e. her narrative identity, would continue in a plausible and coherent way. Kühler, however, argues that narrative accounts of the self inherently fail to provide a simple and convincing answer in such cases. After distinguishing between mere expressive narrative accounts and constitutive narrative accounts, he argues that expressive narrative accounts do not present an independent analysis of the constitution of the self to begin with and are at best a helpful epistemic tool to find out what the patient's autonomous preference likely would be. Yet, even this only holds under the contestable assumption that the patient's self remains stable. Constitutive narrative accounts, on the other hand, while indeed presenting an independent account of the constitution of the self, either revert back to an expressive narrative account if the idea of one's free authorship of one's life story is rejected, or they fail to provide any reason for why one should choose a certain version of the patient's life story as the newly to be constructed one. Instead, Kühler concludes that a person's life story remains in a constant state of flux, which is why also constitutive narrative accounts are unable to provide surrogate decision makers with a well-justified answer which treatment option to choose in order to respect the patient's autonomy based on who he or she is.

In her contribution "The ART of Authenticity," Birgit Beck starts off with the fact that recent progress in biomedical research in the fields of stem cell technology and genome editing has entailed a revival of ethical concerns regarding the autonomy and authenticity of future persons who might be created by prospective novel means of assisted reproductive technologies (ART) on the basis of, e.g. in vitro gametogenesis or germline interventions. In this regard, critical authors refer to the Habermasean concern that persons who are "made" by technological means instead of coming into existence in a "natural" way could be deprived of forming a self-concept of being autonomous and authentic "authors of their life histories". The notion of being the "author" of one's life history appears to relate to the idea that we can—somehow and within certain limits—actively influence who we are. It is hard to see why this idea could not include the possibility of integrating the circumstances of one's coming into existence—be they "artificial" or "natural"—in an authenticity-preserving way. Given that (future) persons are aware of those circumstances, Beck argues that they should be able to adapt their life history accordingly. Assuming a relational structure of autonomy and authenticity in general, it appears plausible that no person's life narrative and self-concept are constituted and maintained in an isolated and individualistic manner. Quite the contrary, Beck argues, (self-)ascriptions of autonomy and authenticity require adequate social relationships in the first place. From this assumption, it follows that, should (future) persons conceived by means of novel ART be deprived of a confident self-concept and feel "objectified" by their "creators", this would be due to prejudice rather than actual lack of essentialist authenticity. For Beck, the Habermasean concern can thus be regarded as revealing a structural social problem rather than one raised by biotechnology per se, and it can be smoothed out by Habermas' own conceptual conditions for the development of personal identity, authenticity, and autonomy.

In the final contribution to the first section, "Remainders of the Self: Consciousness as a Problem for Neuroethics," Marco Stier firstly notes that neuroscience has

made great progress in recent years in detecting mental processes using electrophysiological and imaging techniques. One of the major breakthroughs in this regard has been the detection of residual consciousness in persons diagnosed with a vegetative state. However, Stier argues that this very success gives rise to a number of theoretically as well as ethically crucial follow-up questions. What neuroimaging can provide are highly artificial, mathematically processed images and not direct information about the patient's mind. Therefore, it is far from clear whether and to what degree behaviorally unresponsive patients are indeed conscious. This is all the more so since we are confronted with a double mediation: one between the person's mind and the image of the brain and the second between the image and something that we interpret as a meaningful answer of the patient to a question of the physician. For the patient in question it is of vital importance that his ability for consciousness is neither over- nor underrated since both can lead to significant suffering. Above that, residual consciousness or remainders of the person's self—even if reduced and fragmented—have to be taken into account for treatment or end of life decisions. Unfortunately, as Stier points out, there is no consensus in neuroscience about what “consciousness” and “being conscious” really means. To be sure, there is a long tradition regarding notions like these in philosophy. However, philosophical insight does not find its way into neuroscience easily. Against this background, Stier's contribution aims at connecting philosophical and neuroscientific understandings of consciousness in order to better understand what may go on inside an otherwise unresponsive patient. The notion of a “self” that might be preserved even if the person in question is not fully conscious or only has some basic form of consciousness will serve as a working concept for this problem. As Stier emphasizes, neuroethics has to solve the conceptual problem of consciousness in order to be able to solve the clinical problem of consciousness and with it the ethical problem of autonomy and the self.

### ***1.2.2 Section 2: From Medical Ethics to Theories of the Self and Autonomy***

In the first contribution to section 2, “Ethical Issues Concerning Patient Autonomy in Clinical Practice,” Alfred Simon takes up the perspective of clinical practice and discusses the importance of respect for patients' autonomy from this angle. He starts by mentioning that, until a few decades ago, physicians and nurses involved in ethical decision-making primarily considered the principles of beneficence and nonmaleficence. Respect for the patient's autonomy clearly played a subordinate role. In traditional ethical codes such as the Hippocratic Oath or the Declaration of Geneva of the World Medical Association of 1948, no reference is made to the patient's wishes. This has changed radically: In line with the shift in values towards greater individuality and personal responsibility observed in the Western world in the second half of the twentieth century, patient self-determination became more and more important. Legal decisions and modern medical ethics emphasize that patient autonomy overrides what physicians and nurses consider best for the well-being of

the patient. Informed consent is now a widely acknowledged normative standard in medical ethics, and patient autonomy finds its concrete expression in clinical practice in this concept of informed consent. Simon introduces the concept and discusses central issues concerning patient autonomy in clinical practice: What can health care professionals do to encourage patient autonomy? What are possible limits to patient autonomy? How can a patient's capacity to consent be assessed? How should health care professionals deal with patients who have temporarily or completely lost their capacity to consent? What is the importance of advance directives? What are possible problems concerning advance directives in clinical practice, and how can they be solved?

By comparing articles from Serbian legislation, Hajrija Mujovic analyzes in her contribution "Patients' Rights to Refuse Medical Treatment Through the Act of Advance Directives" the (im)possibility of patients' rights to refuse medical treatment through the act of advance directives. Serbia's legislation on patients' rights mostly adheres to contemporary standards. But the practice of implementation shows some misunderstandings when it comes to the question of whether the rights stipulated in the Patients' Right Act (2013) completely apply to the persons in need of palliative care or in end-of-life care. Besides, there are issues particularly important for terminally ill patients, including the form of possible advance directives (Article 16) and passive euthanasia (Article 28), which still need to be discussed and revised. In fact, Serbian legislation treats so-called "active euthanasia" simply as "euthanasia" in general. Therefore, passive euthanasia, which implies withholding life-saving treatment from a patient at the patient's will, does not count as euthanasia. Following Serbian law, it will be shown that this creates a problem in terms of the patient's right to refuse medical treatment. A dying patient also exercises basic rights and human dignity in all these cases, which are to be respected as well. One of these rights is the right to provide an advance directive, which should be recommended to be revised and fully accepted in Serbian law.

Taking up the issue of advance directives, Oliver Hallich, in his contribution "Prolonged Autonomy? The Principle of Precedent Autonomy and the Binding Force of Advance Directives in Dementia," takes as starting point the fact that dementia has become a central problem of health care in modern societies. Currently, 47.5 million people worldwide suffer from some or other form of dementia, and it is projected that 75.6 million people will have it in 2030. Against this background, the question of the binding force of advance directives in dementia will be of growing importance in future years. Defenders of the view that dementia advance directives should be seen as binding often invoke the principle of precedent autonomy to support their view. According to this principle, it is the right of a competent individual to make decisions for a later time once competence has been lost. However, Hallich criticizes this principle of precedent autonomy and argues that it cannot be upheld because there are some cases in which it is morally legitimate to act against the will of the competent patient that is expressed in an advance directive pertaining to a later life stage in which competence has been lost. First, he paves the way for a criticism of the principle of precedent autonomy by laying bare its fundamental premise, namely the "dominance thesis," according to which critical interests dominate experiential interests in cases of

conflict between these two kinds of interests. He then distinguishes between various ways in which critical and experiential interests may relate to each other and argues that the dominance thesis holds true only with regard to some but not all of these constellations. In focusing on a specific scenario with regard to which the dominance thesis turns out to be false, he argues that in some cases of a conflict between critical and experiential interests the latter ones negate the normative authority of the former. Based on a rebuttal of two objections to this view, he concludes that we should answer the normative question of whether advance directives in dementia should be seen as binding with a qualified “no.”

In their contribution “Individual and Collective Decision-Making in Palliative and End-of-Life Care,” Zoran Todorović and Dragana Protić start with the assumption that the distinction between individual and collective decision-making strongly influences the bioethical foundations and perspectives of palliative and end-of-life care. Kemp and Rendtorff<sup>14</sup> promoted an integrated approach to basic ethical principles and discussed that autonomy implies the capacity to make your own decisions about your own life. However, such a decision depends on the interaction or collaboration with others, including their values. In addition, autonomy is interconnected with vulnerability, and individuals are not always able to judge the treatment process and understand and weigh different perspectives and possibilities. Against this background, Todorović and Protić explore the corresponding interplay between individual and collective decision-making in palliative and end-of-life care from the point of view of medical practice.

In her contribution “Who Should Take Care of Offenders with Dementia: Some Thoughts on Fading Selves and the Challenge of Responsibility Interpretations,” Annette Dufner investigates the way in which our understanding of a dementia patient’s self holds relevance to issues of punishment and responsibility. This topic is motivated by the fact that some countries with particularly large prison populations—such as the United States—are starting to build specialized prison tracts for inmates with dementia. In other countries that do not have such specialized facilities, authorities are trying to find the least badly equipped facility for such patients, and they are turning to ordinary retirement homes, forensic hospitals as well as ordinary psychiatric and geriatric hospital wards. The problem is expected to become increasingly urgent as the population ages and the number of dementia patients increases. Dufner analyzes the way in which justifications of legal (or private) punishment for offenders with dementia can depend on an account of relevant psychological features of the self. As she argues, especially retributivist and expressivist justifications of punishment require the offender’s ability to comprehend that he or she is being punished for a particular action in the past, and that it was him- or herself who committed this action. In the second part of the paper, Dufner distinguishes between different accounts of responsibility and argues that accounts of relevant features of the self are also needed here to answer the question of whether offenders with dementia are still responsible for past or current inappropriate behavior. In the final part of the paper, Dufner argues that certain puzzles of responsibility interpretation as well

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<sup>14</sup>See Rendtorff (2002) and Kemp and Rendtorff (2008).

as potentially existing private punishment intuitions among caretakers can make it plausible to relieve certain caretakers from primary responsibility for offenders with dementia, especially caretakers who belong to a relevant former victim group of the offender.

In the final contribution to the volume, “Understanding ‘Euthanasia’ Across Various Medical Practices,” Veselin Mitrović takes as starting point that end-of-life decisions and assisted suicide are often equated with ‘euthanasia.’ In everyday parlance of social actors, the term euthanasia is understood rather broadly, even lumped together with other medical procedures. Still, Mitrović argues that ‘intended merciful death,’ whether we like the definition or not, ought not to be equated with other practices. Although all of these medical procedures result in the destruction of potential or actual life, the reasons behind such actions could be quite different from empathy or mercy, making the acceptance and advocacy of a problematic definition and understanding of euthanasia the subject of ethical and social debates and analyses. When considering the Universal Declaration on Bioethics and Human Rights (from the 33rd session of the General Conference of UNESCO, (2005)),<sup>15</sup> specifically the principle of human dignity and rights (article 3), the principle of benefit and harm (article 4) as well as the principle of autonomy (article 5), the debate stretches out to include also vulnerable groups in general, which in the contemporary context range from homeless persons and other marginalized groups to embryos created during IVF (in vitro fertilization). In his article, Mitrović presents two case studies, chosen from ten personal stories of former and current IVF procedure patients. In all ten narratives, interlocutors equate abortion with embryo reduction, and both of those with euthanasia. Mitrović analyzes their perspective to embryos that were not implanted, as well as similarities and differences in their views regarding the activities in the cases of implanted embryos (twin and triplet pregnancies).

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<sup>15</sup>See UNESCO (2005).

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