Chapter 14
Concluding Remarks

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Although advance directives have been widely discussed since the 1980s, their ethical basis still remains a matter of heated debate: What makes an advance directive valid, placing others under a moral obligation to follow its instructions? Where should we set ethical boundaries for the scope and binding force of advance directives? What effects do advance directives have on relations with family, loved ones and professionals, and are these effects desirable from a moral point of view? What ethical opportunities and risks are associated with advance directives, given their prerequisites, limitations and effects? No definitive, or even satisfactory, answers have been given to these essential questions. But, especially in view of the increasing prevalence of advance directives in Europe, these questions need to be resolved if advance directives are to be justified as an ethically compelling tool for realizing patient self-determination—a tool worthy of social, political and medical support.

The present volume seeks to contribute to the ongoing debate by integrating fundamental ethical issues with practical matters concerning the implementation of advance directives. The authors highlight cultural, national and professional differences not just in laws and regulations, but also in how advance directives are understood by healthcare professionals and by patients. These views do not necessarily reflect the ways in which advance directives are actually implemented in clinical practice. Revealing such differences and even identifying inconsistencies between conceptions, legal regulations and clinical practice can set the stage for one of the future challenges—tackling the question of whether it is (culturally and politically) practicable and (ethically) required to try and reach a more substantial agreement on advance directives beyond the minimal consensus formulated in

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Article 9 of the 1997 Convention on Human Rights and Biomedicine: "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."

Whatever the legal status of advance directives may be, the authors are convinced that advance directives are ethically valuable because they give a voice to patients at a time when their decision-making capacity has been lost. Granting such a voice is essential, given that the process of dying can be prolonged as a result of advanced medical technologies. In order to provide good end-of-life care and a satisfactory "quality of dying", individual preferences have to be taken into account. Advance directives also enable patients to express their wishes in non-terminal (e.g. psychiatric) conditions. In such cases, benevolence may involve respecting patients' autonomy by acting in accordance with their individual preferences and wishes, especially regarding refusal of treatment.

As demonstrated in several chapters of this volume, advance directives have a significant impact on the patient-healthcare professional relationship and can foster a more patient-centred medicine. This impact is independent of the number of patients who possess an advance directive. Even if the historical advance directive movement has missed its goal—since only a minority of patients make use of advance directives—these documents have been successful in shifting the focus from the healthcare professional to the patient when medical decisions are made.

Regarding advance directives as a way of promoting patient autonomy and well-being—and accepting such an endeavour as a political goal—is compatible with both individually oriented and family-/community-oriented cultures. In embracing a relational conception of autonomy, advance directives are not incompatible with placing a high value on relations with family members or other close persons. This is particularly the case when advance directives are used to designate a proxy for future medical decisions. In fact, a surrogate decision-maker is appointed in the majority of advance directives.

Since advance directives give instructions for future situations of decision-making incapacity, patients are essentially dependent on healthcare providers to act on their wishes. However, advance directives are not always clearly formulated and have to be interpreted in the light of the specific medical situation. From the perspective of the third parties, a significant limitation of advance directives is the inherent uncertainty as to whether the advance directive is actually applicable in the given situation. As research shows, third parties often have difficulty in correctly judging patients' wishes and preferences. Their perspectives always remain external to the patient, while the advance directive at least expresses the patient's perspective.

In order to ease the potential tension between the perspectives of the patient and healthcare providers and to facilitate anticipation of future medical situations, it would be helpful to place advance directives in the broader context of advance care planning, in which communication with healthcare professionals is supported and decision-making is shifted towards a patient-oriented process. Advance directives themselves can then function as an accepted tool for communication between the

parties concerned both at the drafting and the implementation stage. This strengthens the validity and binding force of advance directives from the perspective of third parties—which is crucial, as they are responsible for implementation. It has also been shown empirically that advance care planning serves to improve end-of-life care.

The use of advance directives also involves certain risks. Some patients fear that if they write an advance directive, they will not be treated by the same standards as those who do not—i.e. they might experience a limitation of treatment, not reflecting their previously expressed wishes. Some healthcare institutions might indeed be tempted to require a care-limiting advance directive before admitting patients. Such fears could be fuelled by discussions about the impact of advance directives on cutting healthcare costs. Although reducing expenses is economically necessary even in affluent countries—especially in view of the high costs of end-of-life treatment—it would clearly be an abuse if advance directives were employed against patients' wishes for financial reasons.

In order to make advance directives an effective tool for self-determination and to prevent misuse, two issues need to be resolved. Firstly, as regards the binding force of advance directives, it is essential that there should be legal safeguards in case the patient's representative or medical staff do not act in accordance with the patient's wishes. Moral appeals to respect the patient's wishes are not sufficient to guarantee patient autonomy in clinical practice. In this respect, further elaboration of the European Convention on Human Rights and Biomedicine is to be recommended; amendments are also required where no provision is made in national legislation for a patient, proxy or loved ones to appeal if they are convinced that the patient's wishes are not being respected. The availability of legal recourse would in itself have a positive effect on clinical practice, giving healthcare staff such as nurses the courage to express their moral concerns when care-related conflicts arise.

Secondly, the decision to declare a patient incompetent is crucial for the patient's involvement in the medical decision-making process. The declaration of incompetence is the trigger for implementation of an advance directive. However, standard tools for assessing decision-making capacity need to be further refined and, especially, harmonized and consistently implemented in clinical practice. The elaboration and use of such tools must also be guided by ethical considerations.

Improving our understanding of when advance directives should take effect and ensuring that they are appropriately managed would be an important step towards a healthcare system in which patient-oriented outcomes are taken seriously, even at times when it is difficult to ascertain what is in the patient's interest.