

**Veröffentlichungen des Instituts für Deutsches,  
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Gesundheitsrecht und Bioethik der  
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Editors

# Advance Care Decision Making in Germany and Italy

A Comparative, European and International  
Law Perspective

 Springer

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ISSN 1617-1497

ISBN 978-3-642-40554-9

ISBN 978-3-642-40555-6 (eBook)

DOI 10.1007/978-3-642-40555-6

Springer Heidelberg New York Dordrecht London

Library of Congress Control Number: 2013955003

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Printed on acid-free paper

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# Foreword

This book presents the results of a 2-year interdisciplinary research project on the subject “Legal and ethical questions raised by advance care decision making in Germany and Italy: a comparative, European and international law perspective”, which was approved and financed by the German Academic Exchange Service (DAAD) and the Italian Ministry for Education, University and Research (MIUR) in the framework of the Vigoni Program 2010. This joint endeavour was an initiative of Prof. Dr. Stefania Negri, director of the Observatory on Human Rights: Bioethics, Health, Environment of the University of Salerno. Prof. Dr. Jochen Taupitz, managing director of the Institute for German, European and International Medical Law, Public Health Law and Bioethics (IMGB) of the Universities of Heidelberg and Mannheim, gladly accepted her invitation to join the project.

The project brought together German and Italian academics from different fields and backgrounds and was conceived in a period when the debate on end-of-life care and advance directives regulation was particularly lively across Europe and exceptionally topical both in Germany and in Italy. In fact, acceptability and regulation of end-of-life decisions and permissibility of different forms of euthanasia have recently experienced an increasing attention from the scientific community in many European countries. An animated discussion on these topics has thus taken shape in ethical and legal literature, as well as in medical practice. This has also triggered a very emotional reflection on the patients’ right to refuse or discontinue life-sustaining or life-prolonging efforts as part of their right to informed consent and self-determination (including the highly controversial right to die with dignity). In this context, several countries have passed legislation aimed at regulating individual choices by way of health care advance directives.

Germany was the last European country that enacted a law on living wills strengthening the principle of patient autonomy. During the 1990s and early 2000s, a Criminal Panel of the German Federal Court of Justice (Bundesgerichtshof) and the German Constitutional Court (Bundesverfassungsgericht) established a general hierarchy of decision-guiding criteria for cases concerning patients who are unable to give or refuse consent to medical treatment, acknowledging the legal validity of advance directives and the primacy of patient autonomy.

However, in a controversial decision of 2003, a Civil Panel of the BGH considerably differed from these judgments, holding a contradictory position on the power to refuse life-sustaining treatment when the patient is not suffering from a terminal disease that is “irreversibly leading to death”, thus considerably restricting the right of self-determination. This decision triggered an intense debate that diminished in 2009, when the German Parliament passed the “3rd Act Changing the Custodianship Law” (3. Gesetz zur Änderung des Betreuungsrechts), entered into force on 1 September 2009, by which the German legislator broadened the scope of applicability of advance directives.

In the same year, Italy was confronted with the well-known Englaro case, which lit the spotlight on Italy’s lack of an organic legislation on advance directives. This case heated the social and political debate on end-of-life choices and divided the public opinion, as well as the major institutional organs of the State, including the judiciary. It hence prompted the submission to the Italian Parliament of several bills aimed to intervene in this field with an endeavour to regulate the patient–physician relationship, informed consent, and advance directives. As a result of the acceleration impressed on the parliamentary debate, the Senate of the Republic approved on 26 March 2009 Draft Bill 10, also known as Calabrò Bill, which was transmitted to the Chamber of Deputies and discussed in Commission XII as Draft Bill 2350 (Disposizioni in materia di alleanza terapeutica, di consenso informato e di dichiarazioni anticipate di trattamento). The Bill was approved with amendments on 12 July 2011 and sent back to the Senate for final approval of the amended text, but the legislative process was interrupted by the dissolution of the Italian Parliament in December 2012, and so the Bill was never enacted as law. In its substance, the Italian Bill mainly went into a substantially different direction as compared to German law, stating that advance directives are not binding and even strictly prohibiting refusal of artificially provided nutrition and hydration. For its paternalistic approach to patient autonomy, it was the object of harsh criticism both in the political and the academic arenas.

Against this background, this book explores the most controversial ethico-legal questions concerning advance care planning and end-of-life issues, taking the German and Italian experiences as pilot examples to foster a broader reflection on the desirability and efficacy of a regulation by legislation of such a sensitive and complex field of individual decision-making. To this end, the various contributions portray and compare the current legal situation in both jurisdictions, using an interdisciplinary approach that takes into consideration the major legal and bioethical issues at stake, as well as the relevant economic aspects that are usually neglected in current researches on this topic. All topical issues are examined in the light of the responses provided by national legislators and courts, with reference both to domestic positive law (constitutional, private, and criminal) and to the relevant case law, which provides authoritative guidance on how critical problems are dealt with and solved in everyday practice.

Moreover, through contextualisation of the debate in the broader European and international legal frameworks, the book also aims to appeal to a transnational

scientific and political community, in the hope that the lessons drawn from the experiences of Germany and Italy may offer useful insights for other countries facing similar problems.

Salerno, Italy  
Mannheim, Germany  
June 2013

Stefania Negri  
Jochen Taupitz





# Contents

<b>Universal Human Rights and End-of-Life Care . . . . .</b>	<b>1</b>
Stefania Negri	
<b>Advance Health Care Directives Under European Law and European Biolaw . . . . .</b>	<b>39</b>
Angela Di Stasi and Rossana Palladino	
<b>Advance Directives Regulation in Italy: Between Consent and Legal Rules . . . . .</b>	<b>83</b>
Vitulia Ivone	
<b>Patient’s Autonomy According to German Law . . . . .</b>	<b>111</b>
Jochen Taupitz	
<b>“Killing Me Softly”: New Questions About Therapeutic Self-Determination in the Italian Society and Old Answers from the Criminal Code . . . . .</b>	<b>131</b>
Emanuele Corn	
<b>The German Law on Euthanasia: The Legal Basics and the Actual Debate . . . . .</b>	<b>151</b>
Anna Zwick	
<b>Access to Palliative Care in the Italian Legal System . . . . .</b>	<b>187</b>
Vitulia Ivone	
<b>Legal Rules on Palliative Care Under German Law . . . . .</b>	<b>201</b>
Amina Salkić	
<b>End-of-Life Care and the Economics of Living Wills . . . . .</b>	<b>235</b>
Marcus Oehlich	
<b>Appendix</b>	
<b>Constitution of the Italian Republic . . . . .</b>	<b>257</b>

**Italian Draft Bill: “Dispositions in Matter of Therapeutic Alliance,  
Informed Consent and Advance Treatment Directives” . . . . . 259**

**Italian Criminal Code . . . . . 265**

**Italian Civil Code . . . . . 267**

**Constitution of the Federal Republic of Germany . . . . . 269**

**German Criminal Code . . . . . 271**

**(Model) Professional Code for Physicians in Germany . . . . . 275**

**German Social Code . . . . . 277**