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## Book review

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*Families and End-of-Life Treatment Decisions: An International Perspective*, Brigitte Feuillet, Kristina Orfali, and Therese Callus (eds.) (Brussels: Belgium: Bruylant, 2013), ISBN 9782802740667, 346 pp., £70.99

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Before the last half century, death was usually a private spiritual or religious event involving family and friends. In more recent times, the way a person experiences death has changed drastically. Today, death is often a public matter with a technological dimension; we are now more likely to die in hospital as elderly patients suffering from serious illness after all the sophisticated interventions of modern medicine have failed. Difficult and emotional issues of varying complexity are at stake in this era of the technological dying process. An advance directive by a competent patient setting out his or her preferences at end of life will assist stakeholders when the patient becomes incompetent as his or her condition worsens. Unfortunately, such a clear directive may often be lacking. Consequently, there is an urgent need for a surrogate decision-maker to act on behalf of a patient who is now unable to exercise his or her right to self-determination directly.

It is common for family members to decide on behalf of a patient who has lost his or her capacity. The identity of a person's 'nearest and dearest' or 'loved ones', along with their roles and legitimacy, raises many difficult issues. In his foreword to *Families and End-of-Life Treatment Decisions: An International Perspective*, Siegler identifies four problems in this context.<sup>1</sup> First, patients sometimes do not have anyone to act as a surrogate decision-maker. Second, conflicts frequently emerge among surrogates about what is best for the patient. Third, conflicts can emerge between surrogates and the patient's clinical team. Finally, surrogate decision-makers may not have the same code of values as the dying person. These critical issues pertaining to end-of-life medical care have attracted a diverse range of legal and bioethical responses around the world. In its 21 chapters, the book offers a blend of legal, medical, philosophical, sociological and anthropological perspectives on end-of-life issues from 17 countries. The book

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1. M. Siegler, 'Foreword', in B. Feuillet, K. Orfali, and T. Callus, eds., *Families and End-of-Life Treatment Decisions: An International Perspective*. (Brussels: Bruylant, 2013), p. 12.

is a typical example of functional comparative health care law and an interdisciplinary study. Curiously, a third of the contributions (i.e. five chapters) focus on France; Germany, the United Kingdom, Switzerland, Spain, Greece, Hungary, Tunisia, Belgium, Tunisia, Senegal, Turkey, Brazil, Chile, the United States, Japan and Lebanon are each the focus of single contributions. Each contributor brings an interesting perspective to the theme.

In Chapter 1, Pierre Le Coz, a French philosopher, seeks to evaluate the deontological and utilitarian ethical arguments which relate to the role of loved ones in end-of-life care. Deontological thinkers consider that an attempt to construct a way of living with reference to the individual's right to pleasure is highly risky because it may result in the sacrifice of the individual on the altar of collective happiness. In order to avert this, deontological thinkers contend that the interests of family, close friends and society must be unconditionally subordinated to the respect for patient's dignity. Le Coz contends that it is inappropriate for any law to require a patient to nominate a trusted person to act as a surrogate decision-maker, confer power of attorney or issue an advance directive governing the manner of care to be given at the end-of-life stage. Such a law may unfairly compel a patient who does not wish to think about death to face that which he or she might prefer to avoid. If a patient chooses a non-family member as his or her trusted person, the doctor cannot ignore the family's objections without encountering a power struggle. Le Coz argues that family and friends are also affected emotionally by their loved one's end-of-life care and therefore deserve to be factored into the clinical team's decisions. This makes the utilitarian model relevant because 'it approaches humans through a prism of sensitivity and places them back into the fabric of inter subjective relations . . . It does not separate the individual's well-being from that of the group, the family's from the patient'.<sup>2</sup> In this regard, the suffering of the family as a group might become a priority; a gravely ill patient may therefore have his or her wish to die at home trumped by the preferences of his or her family. Le Coz concludes that the deontological and utilitarian ethical frameworks should not be treated as mutually exclusive where end-of-life decision-making is concerned. 'We can protect the patient when the values of autonomy and dignity are at stake, but give priority to the group if the distress caused by strict respect for the individual's will is too trying'.<sup>3</sup>

In Chapter 2, David Le Breton, a sociologist, explores the individual nature of death and society's failure to confront the profound issues of existence, death and dying. The breakdown of religion in France and many other European countries is responsible for society's inability to assist the individual to overcome his or her anxieties about death and dying. Consequently, the patient should have maximum autonomy during his or her final months. Le Breton notes that the patient's demands at this stage may be unreasonable or out of step with the law because he or she faces the emotional impact of an imminent private tragedy. Nevertheless, those demands must be respected.

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2. B. Feuillet, K. Orfali, and T. Callus, eds., *Families and End-of- Life Treatment Decisions: An International Perspective*. (Brussels: Bruylant, 2013), p. 21.
  3. Feuillet, et al., 'End-of-Life', p. 26.

A person's struggle with his or her fate is mitigated somewhat by the support which he or she draws from his or her loved ones. Irene Thery advocates for a relational approach to end of life in Chapter 3. She bemoans the medicalization of the dying process and its tacit endorsement by the law, which has marginalized the patient's family members and close friends. Drawing upon an empirical survey of patients with HIV, Thery highlights the important role played by family members and close friends in minimizing the pain and indignity associated with dying. She says that until there has been 'a better understanding and deeper respect for the approach of death as a moment that is deeply and intensely relational', there will continue to be a lack of proper respect for the role of the patient's spouse, children and close friends. Relational theory is grounded in the core belief that the object or subject of attention should be understood in relation to others.<sup>4</sup>

The last two French contributors to the debate expose the law's insensitivity where the selection of proxy decision-makers is concerned. Jean-Marc La Piana, Medical Director at the Palliative Care Centre, draws upon his experience in practice to conclude that 'laws do not capture the complexities of what is going on at the bedside of a dying person'. La Piana contends that the legal requirement for proxy or nominated trusted persons does not serve its intended purpose because family members tend to be more active in the care management of a dying patient than a person with legal status. He criticizes the fact that 'laws adopted to address these painful questions result from political issues, while the priority should be the person who is dying'.<sup>5</sup> In Chapter 5, Francis Kernaleguen asks whether end-of-life matters shape and define 'family'. This question is timely due to the way in which the construction of the traditional family has changed in recent years. Kernaleguen notes that the current trend in France suggests that without an express nomination by an end-of-life patient of a trusted person or proxy, the law will look to his or her family to identify someone to take decisions on his or her behalf. However, the selection from a family is not merely based on kinship but also on affective ties or closeness with the patient. Apart from Chapter 22, which is an editorial synthesis of the key findings from the various contributors, the remaining chapters comprise contributions relating to 16 other countries.

In Chapter 6, Françoise Furkel, a German law professor, explores 'the Central Role in Germany of the "Angehörige" in Enhancing Patient Autonomy at the End of Life'. Furkel praises German law for making more progress in the legal regulation of end-of-life care than many other European countries. In particular, he notes that even where the patient has not made any advance directive or nominated a legal representative, German law still safeguards the patient's self-determination through indirect participation of the patient's family and loved ones in the treatment decisions.<sup>6</sup> He argues that despite Germany's non-ratification of Article 9 of the Convention on Human Rights and

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4. J. Downie and J. Llewellyn, 'Relational Theory, Health Law and Policy', *Health Law Journal* 194 (2008), p. 195.

5. Feuillet, et al., 'End-of- Life', p. 62.

6. Feuillet, et al., 'End-of- Life', p. 100.

Biomedicine, which requires respect for the previously expressed wishes of a patient, the German national law goes much further by imposing on the patient's family and friends a duty to monitor compliance with his or her wishes.

In Chapter 7, Dominique Manai explores 'the Preeminence of Relationships in the Legal Recognition of the Rights of the Patient's Loved Ones in Switzerland'. Manai surveys the state of Swiss law before a recent revision of the civil code and decries the unsatisfactory position of loved ones of the patient in the context of end-of-life care. The author notes that since the old law was silent on the role of loved ones, their involvement in the end-of-life care was managed pragmatically. The loved ones were consulted by doctors as *de facto* stakeholders in the therapeutic relationship when the patient lacked capacity. The limitation of this pragmatic arrangement was that 'it was sometimes difficult for healthcare professionals to identify who should represent the patient among those close to the patient, particularly if there was a conflict between them'. Manai welcomes the recent revision of the Swiss civil code, which has clarified the role of the patient's loved ones by placing greater emphasis on family solidarity. The law now identifies the person(s) who will be able to speak to the doctor on behalf of the patient. Manai notes that the formal legal recognition of these rights restricts the role of adult guardianship and the decision-making powers of doctors to emergency situations. This highlights the importance of those close to the patient as real partners in therapeutic partnership. To this extent, Manai advocates for the inclusion of loved ones 'in all communication and to build a relationship with them in an end-of-life situation'.

Therese Callus brings English law into perspective in Chapter 8 by advocating for at least a limited role for loved ones in end-of-life treatment in order to enhance patient autonomy. Callus notes that the common law did not recognize the role of loved ones in the end-of-care situation prior to the Mental Capacity Act 2005 (MCA). Doctors had the discretion to make critical decisions in the best interests of a patient lacking capacity. If the patient was unable to express his or her wishes and the doctor's recommendation was opposed by loved ones, the doctor had to apply to the Court of Protection to decide what is in the best interests of the patient. The Lasting Power of Attorney (LPA) introduced by the MCA allows a patient to designate a third party to represent his or her interests in decision-making. The document executed as LPA must clearly articulate the donor's (i.e. patient) precise wishes in specified circumstances before it will be given any weight in end-of-life decisions. Although Callus welcomes the introduction of this subjective element to complement the traditional objective test in assessing the best interests of a patient lacking capacity, she says that the new law still denies patients' loved ones a formal status.

Like Callus, Geneviève Schamps in Chapter 9 argues for a role for loved ones to promote patient autonomy at the end of life, although this time in the Belgian context. Belgian law does not provide a specific coherent legal regime to govern end-of-life medical care. Nevertheless, there are disparate provisions that provide legal guidance on the matter. A thread which runs through all of these provisions is respect for the patient's right to self-determination in accordance with his dignity at the end of life. Schamps worries that there is a lack of consistency in the various statutes regarding the meaning of 'loved ones'. Another layer of complexity is that different designations – such as 'nominated trusted person', the 'proxy' or the 'representative' – are used to denote the concept of

loved one. Schamps argues for legislative reform to ensure better protection of the patient's privacy after death.

In Chapter 10, Veronica San Julian explores 'the broad definition of "relatives" in end-of-life care in Spain'. San Julian notes that despite the modest progress made by Spanish law since 2002, the current efforts to legislate on end-of-life and palliative care need to focus on the useful lessons from the autonomous region of Andalusia. She lauds the efforts made in Andalusia to clarify the hierarchy of individuals who may act on behalf of a patient when he or she is unable to take decisions on his or her own behalf. On the other hand, Silvia Brandani and Gianluca Navone criticize Italian law in Chapter 11 for being riddled with contradictions which permit the unhealthy appropriation of end-of-life matters by physicians. They point out that under Italian law a physician has the power to exclude relatives and loved ones from the decision-making process if by doing so he or she respects the individual's best interests.

Penelope Agallopoulou in Chapter 12 describes the Greek Code of Medical Ethics, which contains legal rules governing end-of-life care, as unsatisfactory for two reasons. First, the law does not rank the priority of family members and loved ones despite the frequency of disagreement between them. Second, the Greek law makes no provision for the making of advance directives or appointment of trusted proxy decision-makers. These Greek problems are not evident in Hungary. In Chapter 13, Judit Sandor points out that Hungarian law allows a competent patient to designate a person to refuse or consent to end-of-life treatment on his or her behalf. However, in the absence of any such designation, the law refers to a list of persons in a hierarchical order of priority who can make treatment decisions on behalf of an incapacitated patient. Sandor concedes that the future of the legal status of dying persons and that of their relatives is uncertain because Hungary has recently introduced a new fundamental law to replace its constitution. For that reason, the eventual answer will come from the constitutional court.

Religious and cultural factors are quite prominent in shaping the legal approaches to end-of-life decision-making. For example, in Chapter 14, Amel Aouij-Mrad explains that in Tunisia, Islamic law prohibits a person from taking decisions concerning a patient's end-of-life care. Similarly, in Chapter 15, Mamadou Badji contends that 'it is always the doctors' ethics which prevail, irrespective of the convictions that underlie the decision-making power of the patient, his family and loved ones, and the doctor's power to provide care'. Dina El Maoula laments the fact that Lebanon has no concept of palliative care and lags behind the world where end-of-life matters are concerned. In Chapter 16, she calls for urgent action to address this problem in Lebanon. Another jurisdiction with similar religious and cultural influences is Turkey. In Chapter 17, Saibe Oktay and Basak Baysal note that Turkish law does not recognize a patient's right to consent to or to refuse treatment in end-of-life situations. The authors contend that because any medical procedure interferes with a patient's bodily integrity, Turkish law is inconsistent with human rights standards for end-of-life care. Maria-Claudia Crespo-Brauner and Anderson Orestes Lobato express similar concerns in Chapter 18 in their exploration of patient autonomy in the context of end-of-life medical care in Brazil.

The remaining three substantive chapters demonstrate that the law recognizes the role of loved ones in end-of-life matters in Chile (Chapter 19), the United States (Chapter 20) and Japan (Chapter 21). The editors synthesize the key themes and findings of each

discrete contribution in Chapter 21. Essentially, they conclude that in all of the countries examined, family and loved ones do play a role in the end-of-life decision-making when the patient is no longer able to consent for himself or herself, irrespective of the legal frameworks that apply.

This edited volume is very impressive in its global scope and offers key insights into the universal challenges of end-of-life decision-making. This suggests that countries can learn lessons from one another and thereby harmonize the global legal responses to the role that the family can play in end-of-life care and treatment decisions. The book is a good work in comparative health care law and bioethics. It can serve as a compendium for a survey of the legal and sociocultural trends extant in different countries around the globe concerning the extent of recognition accorded the families and close friends of patients. Its interdisciplinary perspectives ensure that the book will have a broad audience ranging from students to experts in medical law, bioethics, sociology, clinical psychology and anthropology. However, readers expecting a uniform and erudite presentation of arguments in the book may need to adjust their expectations; each contributor writes according to his or her own style and eschews strict templates. Chapter 21 brings these discrete contributions together in distilling the key themes and arguments into a single editorial chapter. The editors of the book are to be commended in that regard.

### **Acknowledgement**

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