Moving towards European Convergence in Classical Individual Patients' Rights

Valorisation Addendum

This legal dissertation focuses on the protection of classical individual patients' rights within the European Union (hereinafter 'EU'). It approaches the issue of national divergence between the EU Member States in the protection of classical individual patients' rights from the perspective of a fictional Dutch woman, Bella, who, with a so-called negative advance directive, considers travelling to Germany or Hungary for receiving planned healthcare. This story is created in order to demonstrate the main practical and legal difficulties that arise with regard to the portability and legal validity of a negative advance directive to, and in, another EU Member State than the home Member State that includes Bella's wishes regarding the refusal of her informed consent for life-sustaining resuscitation in case she has a heart attack after a recommended surgery.[1]

The aim of this dissertation is to examine the added value of the Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare (hereinafter 'Directive 2011/24/EU' or 'the Directive') in opening up to new regulatory mechanisms to manage national divergence between the EU Member States in the protection of classical individual patients' rights. For the purposes of this dissertation, the strength of Directive 2011/24/EU lies in the introduction of the new individual patients' rights to information on 'patients' rights' under Article 6(3). According to Article 6(3) of the Directive, the Member State of treatment has to ensure that incoming patients from other EU Member States, like Bella, will receive, on request, information on 'patients' rights' according to the legislation of that Member State, through their National Contact Point (hereinafter 'NCP') for cross-border healthcare. The view taken in this dissertation is that Article 6(3) has a special meaning in that the concept of 'patients' rights' refers to the protection of classical individual patients' rights in the legislation of the Member State of treatment. From that perspective, the new individual patients' rights to information under Article 6(3) of Directive 2011/24/EU could be applied to provide clarity to an individual about the level of legal protection of her or his classical individual patients' rights and, more specifically, to define the legal validity of a negative advance directive in cross-border healthcare within the EU.

Added Value for Patients: Improving the Legal Position of Patients within the EU

Far from being purely academic, Bella's fictitious story can happen in the daily routine of cross-border healthcare practice within the EU, e.g. when delays encourage people

[1] Compare Pickersgill 2013, p. 323. See also Smits 2011, p. 6; Bonner et al. 2009, p. 1230.

to travel or when people living in border-regions avail themselves of the opportunities cross-border healthcare offers.[2] Despite the fact that the absolute numbers of people within the EU seeking planned healthcare in other Member States remain relatively small, for the few EU citizens who do exercise their rights to free movement, apart from practical difficulties, there are legal challenges resulting from national divergence between the Member States in the protection of classical individual patients' rights. Therefore, in creating Bella's fictitious journey, this dissertation casts fresh light on the challenges that an individual patient still encounters when travelling with a negative advance directive to, and applying it in, another EU Member State, and in that way it contributes to improving the legal position of patients within the EU.

Directive 2011/24/EU highlights the tendency that an individual patient, as a EU citizen, is expected to fulfil a variety of roles, being able to look for the essential information in order to make an informed choice regarding cross-border healthcare within the EU. However, previous research identified a general lack of awareness amongst EU citizens of the existence of Directive 2011/24/EU. A vast majority of EU citizens has not even heard about the existence of the NCPs for cross-border healthcare in the Member States to help them exercise their rights under the Directive.[3] In addition, Bella's fictitious journey for cross-border healthcare, in this dissertation, shows that none of the three EU Member States studied publishes the existence of their NCP for cross-border healthcare widely. In contrast to the view the European Commission had expressed in their information leaflet entitled ''The Top Ten Mistakes Patients make in Cross-border Healthcare'',[4] Bella's fictitious journey shows that the idea that patients across the EU are well-informed and capable of understanding their new individual rights to information is highly problematic. To take full advantage of the new individual patients' rights to information under Article 6(3) of Directive 2011/24/EU, an individual, like Bella, first needs to know that s/he has them.[5] One of the most important challenges of Directive 2011/24/EU, therefore, is to ensure in daily practice that an individual is informed about the Directive and about the existence of the NCPs for cross-border healthcare in the Member States in order to help her/him to benefit from the opportunities in Article 6(3). In fact, the new individual patients' rights to information under Article 6(3)

[2] Compare Andorno 2012, p. 73-85.
[3] See, e.g.: European Court of Auditors 2019.
[4] European Commission 2018, p. 2.
[5] 'More efforts needed to implement the Cross-border Healthcare Directive to its full potential', Interview with Françoise Grossetête, in: Health-EU Newsletter 203 - Focus, 2017, via https://ec.europa.eu/health/health-eu-newsletter-203-focus_ga.

of Directive 2011/24/EU cannot contribute very much if EU citizens are not even familiar with the existence of the NCPs for cross-border healthcare.[6]

This dissertation exposes the need for the EU and its Member States, as the Directive's addressees, to improve the general awareness across the EU of Directive 2011/24/EU and to invest more in the information provision to individuals on their new individual patients' rights to information under Article 6(3). The comparative legal study of three domestic laws on the classical individual patient's right to refuse, in advance, a medical treatment by signing a negative advance directive shows that it is essential for individual patients to know in advance where to go to for information on the applicable domestic laws in the Member State of treatment. In addition, they should know, in advance, what level of legal protection those applicable laws contain, and also, whether, and to what extent, they diverge from the laws applicable in the situation where the patient would receive medical treatment in the Member State s/he is affiliated to. Those EU citizens who do organise their cross-border travel for healthcare are first of all human beings and therefore fundamental human rights holders.[7] Bella's fictitious story warns against the potential unintended interferences with the fundamental human right to respect for private and family life for an individual patient seeking to receive cross-border healthcare. It also warns against the risks for other actors involved, such as the health professionals in the Member State of treatment, since the burden is put on them, to consider the legal validity of any negative advance directive that they receive.[8]

Added Value for the EU: Insights into the EU-wide Acceptance of Negative Advance Directives[9]

The overall aim of Directive 2011/24/EU is to facilitate the access to safe and high-quality cross-border healthcare within the EU. It obviously does not go so far as accepting that the classical individual patients' rights, intended to protect individuals against arbitrary interferences with private and family life,[10] are threatened. In order to overcome threats for the protection of classical individual patients' rights in cross-border healthcare situations, the European Commission is recommended to reassess its answer in January 2006 to the Parliamentary question on the 'Europe-wide acceptance of

[6] Compare Hall et al. 2018.
[7] Pace 2009, p. 5. See also Claes 2018, p. 97-130.
[8] Bonner et al. 2009, p. 1234.
[9] Written question by Daniel Caspary (PPE-DE) to the Commission, Europe-wide acceptance of advance directives, Parliamentary Questions 12 December 2005, OJ C 327, 30/12/2006.
[10] Council of Europe/European Court of Human Rights 2020, p. 8.

advance directives'.[11] In an era in which the access to safe and high-quality cross-border healthcare within the EU is facilitated, Bella's fictitious story shows that the legal validity of a negative advance directive is questionable in situations of cross-border healthcare, as its legal status, if any, and regulation, differs by EU Member State.[12]

Few research results are known so far about how the new individual patients' rights to information under Article 6(3) of Directive 2011/24/EU have been implemented in domestic laws and policies across the EU, what kind of strategies have been followed for the interpretation of 'patients' rights' in practice, and how effective those were. Likewise, there is no EU-wide overview of Member States' compliance with Article 6(3) in the reality of cross-border healthcare practice and the difficulties encountered at that level. Bella's fictitious journey for cross-border healthcare within the EU has produced first insights in this regard and exposed weaknesses in the minimal interpretation and implementation of Article 6(3) by the three EU Member States studied.[13] The European Commission is therefore recommended to assess in its forthcoming evaluation report whether the Member States have discharged their responsibilities under Article 6(3) of Directive 2011/24/EU correctly.[14] Ensuring the effective application of Article 6(3) will increase the transparency of the levels of legal protection of classical individual patients' rights in domestic laws across the EU. As a result, Directive 2011/24/EU will highlight the national divergence in the levels of legal protection of classical individual patients' rights. The fact that classical individual patients' rights are legally better protected in one EU Member State than the other is likely to encourage a new debate about whether there should be a move towards greater European convergence in classical individual patients' rights and, if so, what it should include.

[11] Answer given by Mr. Kyprianou on behalf of the Commission, Parliamentary Questions 26 January 2006, OJ C 327, 30/12/2006.
[12] Porteri 2018, p. 2; Evans 2012, p. 277; Goffin 2012, p. 121; Nys and Goffin 2011, p. 202; Albers 2018, p. 458.
[13] Compare Roscam Abbing 2004, p. 10 and p. 12-13.
[14] Article 20(1) of Directive 2011/24/EU. See also Greer 2013, p. 415-421.