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**Law, public debates and professionals' attitudes:**
**A comparative study on the use of ADs in England, France and Germany.**

**Ruth Horn**

**Abstract:**

Advance directives to refuse treatment (ADs) are legally binding in many Western European countries. Yet, in practice ADs are only rarely used. This chapter explores the influence of different socio-cultural and legal contexts on the implementation of ADs in three European countries: England, Germany and France. More precisely, this chapter focuses on physicians' perspectives on the law and the reasons given by them for failing to implement it. It will show how physicians' sense of duty to respect ADs depends on: 1) the definition of the legal status of ADs in a country; 2) the way the law addresses physicians' concerns regarding the use of ADs (e.g. uncertainty about validity, respect for patient preferences); and 3) the way ADs are discussed in the public (or not). The findings presented are based on literature review and qualitative interviews.

## 1. Introduction

Respect for patient autonomy is an essential element of modern medical ethics (Beauchamp, Childress, 2008). But there are instances in which a patient is not able to communicate her will, such as when people are kept alive in chronic and at times critical condition. These kinds of cases raise difficult questions about how to respect people who cannot communicate. Since the 1980s, advance decisions to refuse treatment (ADs) have been discussed, first in the United States (US) and then in Europe, as one possible mechanism for enabling a person to communicate, prior to any loss of competence, her will regarding specific treatment refusals. Although criticism has been raised with regard to a persons' ability to know and articulate their treatment preferences in advance and the difficulty to interpret those wishes with regard to a specific situation (Fagerlin, Schneider, 2004), ADs are increasingly valued as decision support tools safeguarding respect for patient wishes.

In the last decade, following legislation in the US and recommendations of the Council of Europe (2009;2012), many Western European Countries have adopted legislation on advance decisions to refuse treatment (ADs) (Andorno et al., 2009). And yet, despite the shared acknowledgement of the importance to respect ADs, different countries accords different legal status to these directives.

Whereas countries with a strong emphasis on patient autonomy, such as England and Germany, have recognised the binding force of ADs for many years, countries that are less concerned with patient autonomy, such as France, struggled until recently to accord binding legal value to ADs (Veshi, Neitzke, 2015). These differences reflect the different values that are dominant in each country, and the different socio-political contexts (Horn, 2012).

Despite these differences, there are some similarities between the three countries in terms of the implementation of ADs. In none of the aforementioned countries are ADs always implemented in practice, nor do doctors always respect them. Each country's legislation

leaves scope for interpretation and ADs can easily be invalidated or ignored without consequences for the physician (Michalowski, 2005). As White et al. (2012) have shown, it is not law itself that motivates physicians to respect ADs. Rather, the doctors' compliance with law reflects whether their reasoning (e.g. respect for patient preferences) is in line with the law. (White, Willmott, 2016) By comparing the views of physicians from the three countries, this chapter shows how attitudes towards ADs depend on 1) the definition of the legal status of ADs; 2) the way the law addresses physicians' concerns regarding the use of ADs (e.g. uncertainty about validity, respect for patient preferences); and 3) the way ADs are discussed in the public (or not).

The findings presented below are based on qualitative interviews with physicians in England, Germany and France. The interviews explored physicians' perspectives on the law and the reasons given for failing to implement it. The analysis focuses particularly on the cultural, legal, and social context of each country. This comparative approach allows identifying general, as well as country specific, factors that impede the implementation of ADs. The chapter emphasises the importance of doctor-patient communication and shows how the implementation of ADs could be improved by making discussions about treatment preferences a legal requirement.

## 2. Methods

Based on 30 semi-structured face-to-face interviews, this paper explores physicians' perspectives on their duties to respect ADs, and their general attitudes towards these documents. In 2014, 8 English, 13 German and 7 French physicians and 2 French nurses were recruited from university hospitals (n=2 in England (within one Trust), n=3 in Germany, n=2 in France). The focus was on doctors working in services which take care of seriously or terminally ill patients such as, oncology, neurology (neuro-oncology, amyotrophic lateral sclerosis), and palliative care. This study builds on a previous study on this topic for which interviews were carried out in 2011 in England and France (Horn, 2014). Each interview lasted approximately 45 minutes, was audio recorded and transcribed.

The interviews covered a range of different topics related to physicians' experiences with ADs and, more broadly, with communication and decisions at the end of life. For the purpose of this paper, I focused on data reflecting physicians' views on benefits and challenges of ADs and their sense of duty to comply with and apply the law.

The interview data is supported by ethnographic observations carried out in each country during 2014-15 over a period of three to four months.

The analysis of data involved numerous readings of the transcribed interviews and field notes. This was followed by identifying and refining comparable recurrent themes and patterns that came out during the interviews, which describe the physicians' attitudes.

Ethical approval for the study was obtained in all three countries from the respective authorities.

Participants are identified according to their nationality (EDn; GerDn; FDn). Gender or medical speciality did not come up as a factor influencing doctors' compliance with the law; therefore, in order to maximise anonymity, age and gender are not reported here.

## 3. Results

### *3.1 England*

**3.1.1** The socio-cultural and legal background

England is a country with a strong liberal tradition supporting individual rights. This tradition goes back to the Magna Carta in 1215, and philosophers of Liberalism such as Mill (1859) and Locke (1690) who influenced England's political and legal system. Applied to the doctor-patient relationship the liberal model implies that a patient has the right, as Dickenson (1999) comments, to "pursue his or her own notion of well-being". This focus on autonomy and self-determination is furthermore in line with the Protestant influence in England, emphasising the individual's ability to make their own decisions (Durkheim, 1896). Thus, respect for patient autonomy is a dominant principle in English (and Welsh) law[1], and can outweigh medical decisions. In 1984, it was stated that patients can "reject [medical] advice for reasons which are rational, or irrational, or for no reason" (*Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985]). Following this trend, ADs have been legally binding under common law since the 1990s (*Re C (adult: refusal of treatment)* [1994], *Re AK (medical treatment: consent)* [2001], *Re B (adult: refusal of medical treatment)* [2002]) and since the Mental Capacity Act (MCA) 2005 came into force in 2007, ADs also have binding force under statutory law. According to the law, an AD is legally binding if it was issued voluntarily by a competent and sufficiently informed patient, and applies to the circumstances that have arisen. In the case where an AD concerns the withdrawal of life-sustaining treatment, the MCA additionally requires that the directive must be written, signed and witnessed, and it must clearly state that the decision is to apply even if life is at risk. In case of doubt or where the person has not anticipated their will, the Act is underpinned by the best interests standard. This standard requires that the physician or Lasting Power of Attorney, who make decisions on behalf of an incompetent person, must: permit and encourage the latter to participate, 'so far as reasonably practicable' in any decision regarding them; consider the person's past and present wishes, feelings, beliefs, values and any other factor the person would consider, if they were able to do so; and take into account the opinion of any other person that could contribute to determining what would be in the person's best interests (MCA, 2005, section 4). In case the decision concerns withdrawal of artificially assisted nutrition and hydration for patients in persistent vegetative state and no written AD exists, this decision has to be approved by the court.[2]

[1] England and Wales have both adopted the Mental Capacity Act 2005 providing the legal framework for ADs. In the following, because my data was gathered in England, I will only refer to the 'English' situation.

[2] As Kitzinger and Kitzinger (2016) show, this measure can lead to important delays in the decision-making which is often not in the best interest of the patient. This paper will however not focus on the particular case of patients in persistent vegetative state.

### 3.1.2 English Physician's concerns: "How can we be sure an AD expresses the patient's current wish?"

The MCA lists many conditions to be fulfilled for an AD to be valid. These precautionary measures seem to be reflected in English physicians' attitudes. In compliance with the law, the physicians interviewed in this study confirmed that ADs are very important documents helping them to make decisions for incompetent patients. While physicians considered ADs legally binding, they expressed reservations about the written document and its ability to express a patient's wish regarding a concrete situation.

Rather than taking ADs as the ultimate documentation of a patient's wish, English physicians considered them a "very useful tool […] to talk and know what a person wishes to do" (ED7).

> "It's a way of, at least, having the conversation or starting it, otherwise people might not find it that easy. It's this piece of paper but, you know, it's used as an opportunity to think about some things… I think it gives permission to everybody to talk about difficult things which one would talk about anyway, but it does ease it." (ED8)

> "I am ambivalent about actually the value in terms of the written document. […] I worry more about having the conversation than having the written document." (ED1)

Discussing end-of-life preferences and continuity of the relationship with the patient were considered as "more useful than a piece of paper". (ED7)

One of the physicians interviewed told me that staff does not need written ADs because;

> "We would always write down their [patients] wishes in the notes and clearly follow their wishes. So if we have a patient who says I absolutely want to go home to die, even if in normal circumstances they would be too ill to travel, we would do everything we can to get that patient to the right destination for their death. […] So, if we clearly have got wishes we will put those into action. I think we write them down on the notes." (ED4)

Indeed, during my observations, I observed that English doctors would write down the conversation they had with the patient. One copy was put in the patient file and one copy was sent to the patient for their own records.

Physicians also suggested that building a relationship where the patient can "trust [the doctor] to make a sensible decision on their behalf" (ED2) can be more important than filling in a form. One of the physicians explained the importance of a good doctor-patient relationship:

> "What the vast majority of people want is to know that they are going to be cared for, in the right way. […] what they really want is that we, us doctors or a team, will consider your best interests and do what's right for you, knowing you as we do. And then they sort of think, yes, that's what I want. That's what they really want. And

> that's ok because they know us and they know that we are a team who cares about them and that we are going to do the right thing." (ED8)

In order to build mutual trust and establish what patients want, English physicians commented that open communication about diagnosis and prognoses are very important. The physicians I observed during this study, demonstrated their openness when communicating diagnoses to their patients, for example, where patients wanted to know their prognosis, the doctors did not hesitate to explain the statistics. In response to my question about whether they worried that patients might misunderstand a given prognosis, one of the doctors replied:

> "Patients are not stupid, if you explain things well, they understand. They can find the statistics in the internet but I prefer they ask me, so that I can explain the numbers." (ED4)

Although English physicians value respect for patient preferences, they hesitate to encourage their patients to write an AD, partly because they are concerned that ADs may not always represent a patient's wish regarding a specific situation. This concern echoes the legal framework of ADs, which define the conditions under which these documents are valid or not. What counts for English physicians, when it comes to knowing or discerning their patients' treatment preferences, is communication. However, while, most physicians in this study considered that ADs can be useful tools to generate discussion about treatment preferences with the patient, another study has shown that this does not always work in practice (Horn, 2014). Physicians may delay such discussion because it means admitting the limits of medicine as well as of life. In his work on prognosis, Christakis (1997) has shown that this problem is inherent in medical profession. Since medical science has improved and doctors are progressively supposed to "eradicate disease", deterioration of the patient's health condition and death are seen as a failure "not just of the therapeutic armamentarium to achieve its objective, but also of the physician to fulfil his or her social role" (Christakis, 1997, p. 314). English physicians then seem to be torn between their wish to respect patient preferences, which is emphasised in law and professional guidelines (Mental Capacity Act, 2005; General Medical Council, 2008; 2010) and their unease about discussing patients' wishes at the end-of-life.

Several physicians interviewed mentioned that this is partly because they lack specific training for discussing end-of-life issues. Another reason for the lack of communication on ADs is that the public awareness of ADs is still low. In 2014, the House of Lords (2014) emphasised that better awareness among patients, families and health care professionals is needed to improve the implementation of ADs. HM Government (2014) shared this concern and made recommendation to raise awareness about ADs. Yet, Kitzinger and Kitzinger (2016) pointed out that there is still a long way to go until the wider population as well as professionals will be aware and use ADs. As we will see in the next section, the situation in Germany is in many aspects similar to that in England, yet with a clearer legal statement and broader public awareness.

### *3.2 Germany*

### **3.2.1** The socio-cultural and legal background

Like England, Germany is a country with a strong focus on respect for patient wishes. The priority given to respecting the patient's will points to the influence of Protestantism, a philosophical Kantian tradition according to which the autonomy of the individual's will is the fundamental principle of all moral laws, and to Germany's recent history. As the historian Maehle (2009) showed, self-determination assumed an important place in the legal debate during Imperial Germany from the 1890s on. At this time, the majority of lawyers associated a medical intervention without a patient's consent with infringement of physical integrity (§ 223 of the penal Code of 1871). However, doctors in this period were largely influenced by the paternalistic model and did not agree with this interpretation. Thus, the patient's right to self-determination principally remained a rhetorical right. It is only in the wake of the Nuremberg trials in 1946, that physicians in Germany tried to re-establish trust into medical interventions and medical professionals by invoking patients' wishes as the principal justification for medical decisions. In light of the crimes committed by doctors under National Socialism, euthanasia could not be considered as a means to guarantee autonomy at the end of life and so the debate in Germany focused on ADs relatively early on. Since the 1980s, there has been an extensive public debate raising awareness about ADs and about each citizen's responsibility to think about their treatment preferences in the event of incapacity. German law has been emphasising respect for the patients' wishes for many years (Horn, 2011). In numerous cases regarding treatment withdrawal decisions for incompetent patients, the court's decisions were based on the previous or presumed patient wishes (*BGH*. 1StR 357/94. 13.9.1994; *OLG* Frankfurt a.M.. 20 W 224/98. 5.8.1998; *BGH*. XII ZB 2/03. 17.03.2003). A law, passed in 2009, recognised the binding force of ADs also under statutory law (*Drittes Gesetz zur Änderung des Betreuungsrechts vom 29.07.2009*. BGBI. I: 2286). This law specifies the doctors' obligations to respect ADs regardless of whether the patient has a terminal illness or not. In order to be valid, the AD has to be concrete and take into account specific situations (BGH. XII ZB 61/16. 06.07.2016). In case of ambiguity or absence of a written AD, the physician, together with the surrogate, has to establish the presumed wish of the patient based on previous statements and general values (Wiesing et al. 2010). Unlike in English Law where court approval has to be sought in case of withdrawal of life sustaining treatment in the absence of a clear AD, German law requires such approval only in case of conflict between the physician and the surrogate or family. Failure to respect a valid AD violates the patient's right to physical integrity and can be punished under paragraph 223 of the criminal law.

### **3.2.2** German Physician's views: "Always challenging ADs undermines the whole idea"

As I have shown also elsewhere, German physicians aim constantly to rely on the patient's will in order to justify their practices and decisions (Horn, 2011). This certainly reflects the weight of the history, but also the force of juridical rules and a Germanic understanding of the concept of autonomy that relies on the Kantian idea that the self-determining individual takes control over the moral value of their action. In line with the law, the physicians

interviewed confirmed that ADs are completely binding for them and cannot be ignored. They considered ADs as very important tools that allow for the enactment of patients' wishes, even when the patient has lost capacity. Unlike their English colleagues, the German doctors rarely challenged the validity of anticipated decisions. In 2008, Jox (et al.) found that there were over 200 official AD-forms available. Most forms pre-define concrete situations and also include an empty page where patients can explain general beliefs and wishes in order to facilitate the interpretation of the AD. Referring to this dual process (precise decisions and general values), as well as to the law, German doctors believed that ADs are valid instruments to express treatment preferences and should not be questioned:

> "[…] the new law clearly states that the patient will has to be respected. […] you need a very good reason not to implement the patient will." (GerP4)

During my observations and an informal discussion, one doctor explained:

> "Why should I question my patients' wishes only because they were made in advance? They know what they want, and ADs are legally binding, so why should I question what they want?" (GerP2)

Another physician explained:

> "I find it difficult when doctors say that they don't know if an AD really applies to a concrete situation, it's kind of paternalistic. If we think like this, ADs make no sense at all. I always explain to my patients that there is a risk that they may see things differently in a particular situation. But this is the patient's decision. […] Challenging every AD […] undermines the whole idea of ADs. [...] I find it extremely dangerous to constantly question the validity of ADs and not taking them seriously." (GerP12)

Also another physician thought that ADs always entail some risks, specifically the

> "…risk of withdrawing treatment too early. That's possible. Yet, it's important to carefully consider if this is really worse than suddenly being in a situation you never wanted to be in." (GerP7)

One doctor explained that there are some physicians who find it difficult to respect an AD that goes against their medical opinion.

> "In those cases, you really need to teach them [physicians] like in school: 'Guys, you have to respect this. This is your job! It is your professional duty to respect this!'" (GerP2)

Like their English colleagues, German doctors explained, that ADs should never be written without also having an in-depth discussion with the patient: "so that it's clear what the patient wants" (GerP7). Indeed, a study by Lang-Welzenbach et al. (2008) has shown that German physicians consider discussion about ADs as more valuable than a signed document.

Several physicians also mentioned potential conflicts with or between family-members and emphasised the importance of having end-of-life discussions with all parties so that everyone has a chance to hear and learn what the patient wants (GerP2; GerP4; GerP5; GerP7).

> "It's important that the family is there when the patient writes their AD so that everyone knows what the patient wants, and we can refer to this later." (GerP5)
>
> "Clearly, if I discuss those things with the patient, and I note and record this, I cannot be attacked."(GerP7)

It was argued that discussing end-of-life decisions helps to validate ADs and aid decisions about unexpected situations that are not covered in a written document.

> "When you discuss those things with the patient, you get to know their thoughts and can understand their wishes much better. Also things you wouldn't think of discussing can be sorted or misconceptions about what could happen can be clarified with the patient and the family." (GerP9)

Despite a strong sense of duty to respect ADs, aided by the clarity of the new law and wide media coverage, physicians said that they do not always ask patients if they have written an AD. Several physicians explained that they believe that the palliative care teams will hold such conversations (GerP11; GerP10; GerP2). Other physicians said that they prefer to wait until the patient starts the discussion.

> "Some people want to get it off their chest that they have an AD, some people find it very important. So some patients start talking and others don't start talking but are relieved when we ask and they say, 'yes, I've got one and it is very important for me. I've got it at home and will bring it next time.' We then make a copy and put it in the patient file. That's how we do it." (GerP8)

Also another physician confirmed that when he asks his patients whether they have written an AD, almost all patients say they did, and those who have not done it yet are thinking of doing so.

> "I think patients don't always know when they should tell us, and we don't know when we should ask." (GerP9)

Despite the strong sense of duty to comply with the law on ADs, the lack of communication not only leads to physicians not knowing if someone has written an AD but also not knowing whether someone has thought about writing one. As highlighted in a study, German physicians are reluctant to discuss ADs as they are afraid to put psychological burden on the patient when discussing ADs, which entails an inevitable discussion of the condition's terminal stage (Evans et al., 2012). Yet, as another study (Voltz et al. 1998) as well as my interviews show, patients in Germany strongly rely on their physicians to initiate those discussions. The potential impact of the reluctance to help patients setting up an AD becomes particularly important when considering recent statistics which show that 93% of the German population knows about ADs and 45% are planning to write one, but only 28% have actually written one (Institut fuer Demoskopie Allensbach, 2014). The statistics suggest that Germany is the country in Europe with the highest level of awareness of ADs. Among other reasons, this is due to the strong media coverage of ADs since the 1990s.

### *3.3 France*

#### **3.3.1** The socio-cultural and legal background

In contrast to the English and German approach, the French healthcare only recently shifted towards a more patient-centred approach. For a long time, the medical profession has defended a physician-centred approach focusing on physicians' responsibilities to guarantee that individual choices are in accord with socially accepted values. Patients were seen as vulnerable persons that ought to be protected by physicians who represent societal values, and, therefore, are legitimised to make decisions on behalf of the patient (CCNE, 2000). This understanding of the individual as embedded within society refers to Rousseau's social contract and the continuing influence of Catholic values in secular France (Horn, 2013). Although today patient preferences are seen as increasingly important, it has taken a long time for ADs to become legally binding.

In 2005, a 'law on patients' rights and the end of life' (Loi n° 2005-370) mentioned ADs for the first time in France. This law clearly states that physicians should not insist on futile treatment and that they must respect a competent patient's refusal of treatment, even where that refusal concerns clinically assisted hydration or nutrition. The law also stated that the 'patient can write an AD' and that the 'physician can take them into account.' Nevertheless, they are not obliged to respect them (L. 1111-11 Public Health Code). Since the adoption of this law in 2005, then, decisions for incompetent patients should be made among medical colleagues (*décision collégiale*), meaning that the physician has to discuss such a decision with another doctor. The 'collegial decision' is a procedure required by the medical code of conduct in order to guarantee medically sound decisions and was introduced into the law in 2005.[3] Prior to the collegial decision, the physician has to 'consult' a representative (*personne de confiance*), a relative or, where it exists, the AD of the concerned person without those statements having obligatory value. The law of 2005 saw ADs as "indications" of wishes, but not as legally binding statements (Feuillet, 2011). Furthermore, unlike in England and in Germany, there were no court decisions about treatment withdrawals for incompetent patients in France until the Lambert case in 2013 (Begouin, Clavreul, 2014). Following the huge media coverage around this case, and regarding previous end-of-life cases (e.g. Chantal Sebire, Herve Pierra), a law on 'new rights for patients and terminally ill persons' was voted in 2016 (Loi n° 2016-87). Amongst other things, this law now recognises the binding value of ADs. However, it also allows for the physician to question the 'appropriateness and applicability of the ADs to the medical situation', stating that in such instances the physician should make a *décision collégiale*. In other words, the law does not always require the physician to base the decision on the patient's previous or presumed wishes and beliefs.

[3] As Thouvenin (2011) points out, the 'law on patients' rights and the end of life' (Loi n° 2005-370) in 2005 relies on medical standards in order to regulate the doctor-patient relationship.

**3.3.2** French Physicians' views: "If they don't ask they don't want to know or make decisions"

Treatment builds an essential part of the doctor-patient relationship in France, and physicians equate withdrawing treatment as a failure on a professional, as well as on a personal, level (Horn, 2011; 2014). Several French physicians interviewed confirmed how difficult it is for them to decide to withdraw treatment. As one of them explained,

> "It is difficult because our natural tendency is to treat. Telling someone who is competent that we stop treatment is a failure. It means that we have to accept a medical failure, and to break bad news. This is not gratifying. It is easier when the patient is not competent anymore because they don't realise what we do." (FD3)

Rather than discussing patients' preferences with regard to treatment withdrawal, the physicians interviewed explained that they prefer not to tackle these issues unless the patient explicitly asks to discuss this.

> "If they don't ask, I suppose they're ok with my treatment. I don't give treatment I don't have any hope in, but if I have the slightest hope to improve the patient's condition or to gain a little bit of time, I propose the treatment." (FD5)

The definition of the 'slightest hope' largely varies among doctors and gives scope for interpretation, and my observations suggested that French physicians do not hesitate to give treatment that has no effect or that is futile (Horn, 2011). French doctors favoured for many years active treatment even at the end of life and the law of 2005 did not change this well-entrenched attitude. My previous study showed that treating a patient has moral significance for French physicians who compare withdrawing treatment with judging the value of life. French doctors confirmed that although the law states that physicians must not insist on "unreasonable" treatment, the persisting problem in France is that "most physicians still maintain a curative perspective and always want to go further in order to avoid death" (Horn, 2014).

Nevertheless, the law seems to have some impact on French physicians, at least on their discourses. They agreed that they

> "have to tell the truth […] and give the patient essential information such as that they won't recover anymore" (FD9).

Yet, the physicians also seemed to be fairly protective and aimed to reassure the patient rather than raise concerns about the future. Thus, as long as the patients do not ask questions, the doctors concluded that they do not want to know and explained that they do not want to 'impose' bad news on them (FD3; FD 5; FD7). If "patients really want to know, they will get the information", explained one of the doctors (FD1).

Not all French physicians agreed with this view, and one of the physicians interviewed explained that it is important for him to honestly answer patients' questions. Yet, when he does so, he also wants to

> "reassure them [the patients] at the same time, explain that the question comes too early, and that we [staff] will do everything to ease the patient's suffering". (FD8)

Several of the physicians interviewed said that they do not want to "frighten people" with bad news and possible future scenarios.

> "You know, I have been thinking a lot about this, and then I thought, 'what gives me the right', even if you know the statistics, and the prognostic is grim, even as a professional, 'do I have the right to say 'listen, in 1 or 2 years, you won't be here anymore'? I don't think I have the right to say that. […] I am not in favour of brutal announcements […] we are humans." (FD2)

In an environment where physicians hesitate to confront patients with 'bad news' about prognoses, it is difficult to implement ADs, the creation of which implies knowledge of possible outcomes on the part of patients. As my interviews with the German physicians show, patients need to be encouraged to discuss these issues with their consultant but rarely tackle these issues when they are not asked. Indeed, in 2014, when I did the interviews in France, physicians told me that they hardly see any written ADs. Even though one of the wards I observed had started mentioning ADs and offering forms to complete and sign during the initial consultation, physicians said that patients hardly ever return these documents (FD1; FD2; FD3). My previous study has shown that many French physicians see ADs as 'American inventions' that do not have their place in a country with 'social' values protecting the vulnerable individual (Horn, 2014).

One physician said that even if patients would return the signed document, he is not certain that it should be respected because decisions should evolve "naturally" over time and cannot be made in advance (FD3). Another doctor explained that he is worried that ADs are only a "box ticking exercise" and thought that these decisions should be negotiated and discussed with the patient over time, and depending on the evolution of the illness. He admitted that "ideally it would be important to discuss things with the patient". Yet, because such discussions could be "malicious" for the patient, he thought that these decisions are better made among colleagues (FD9).

Although the law of 2005 did not recognise the binding force of ADs, several French physicians interviewed in 2014 mentioned that the law made it easier for them to speak about ADs with their patients (FD3; FD5; FD7).

> "In fact, the law made us talk to the patients. I think ADs are useful tools to initiate discussion about end-of-life decisions. […] However, to be honest I didn't have good experiences with it; patients didn't react well to these discussions." (FD4)

Another physician considered:

> "If there weren't ADs there wouldn't be any discussions. […] If we didn't have the law, nothing would move at all." (FD7)

Physicians referred to the potential force of the law and valued the idea of ADs at least as a means to facilitate discussion about difficult end-of-life decisions. As we have seen, French

physicians find it difficult to tackle end-of-life discussions and prefer to protect patients from bad news. Unsurprisingly, well-entrenched attitudes were not immediately changed by the alteration of the law in 2005 (Horn, 2011; Pennec et al. 2012), my observations have shown that it had an impact on physicians' perceptions of their duties to share information with patients. Since 2005, the discourse among physicians became increasingly critical towards medical decisions that do not respect patient wishes to refuse treatment. Furthermore, awareness of ADs has been raised since the 'National Campaign on Information about the end of life' has been launched (Ministere des Solidarites et de la Sante, 2016). Between December 2016 and March 2017, adverts on the national television, internet websites and social media along with public events across the country have been organised. According to a study conducted by the National Centre of Palliative Care and the End of Life, the number of phone calls inquiring about the use and legal status of ADs has risen significantly since the beginning of the campaign.[4] It is to be expected that the public discussions in daily press and media will lead to increased confrontation of physicians with ADs in their practice and stimulate wider reflection about these documents.

## 4. Discussion

The interviews with physicians and the observations in England, Germany and France suggest a reciprocal influence between the legislation on ADs, the public debate and physicians' attitudes. One cannot, as White and Willmott (2106) suggest, infer from the fact that physicians do not always implement ADs that the law lacks influence. Other factors such as the wording, the rigidity and the appropriateness of the law as well as awareness of its content seem to play a role.

In England, a country with a strong liberal tradition, both law and physicians value patient preferences. The emphasis on the patient's authentic wishes raises concerns about the possibility to express valid wishes in advance. In order to avoid uncertainty about the validity of an anticipatory decision, English physicians emphasised the importance of good communication when the patient is competent. Yet, although they did not hesitate to give patients open information about their situation as required by law, they hesitated to discuss ADs. It is this lack of communication that is the reason for the weak implementation of written ADs in England. English physicians complied with legal requirements such as sharing information with patients or respecting ADs, but they did not always implement professional guidelines inviting them to discuss treatment preferences with the patient (GMC, 2010). The existing correlation between the law and physicians' attitudes suggests that a legal framework focusing less on criteria that limit the validity of ADs and more on physicians' duty to discuss anticipatory treatment decisions together with the patient, could improve doctor-patient discussions on treatment preferences and ease physicians' doubts about the authenticity of ADs. The problem of professionals omitting to make patients aware of the provisions of the MCA as well as the lack of awareness among the public more broadly was highlighted by

[4] This study has not been published yet. The information relies on informal discussions with members of the National Centre for Palliative Care and the End of Life.

HM Government in 2014. Long-term strategies will need to be in place to change professionals' attitudes and raise broader awareness on patients' rights.

In Germany, physicians demonstrated a strong sense of duty to respect patient wishes and to comply with the law on ADs. The almost unconditional acceptance of ADs can be explained 1) by the existing awareness of ADs raised by intensive public debates since the 1990s; 2) by the clear position of the law on ADs and 3) by the dual process promoted by the official AD-forms that take into account wishes regarding precise situations as well as general believes and values. The law hardly focuses on conditions determining the validity of ADs other than the requirement that the AD must comprise reflection about concrete situations as well as general values and believes (BMJV, 2016). Although the law requires the physician to establish the presumed patient wishes through discussion with the surrogate and/or family, it does not explicitly require the physician to have those discussions with the patient. Indeed, although most German physicians agreed on the importance of open discussions, in practice, they acknowledge that they do not always initiate such discussions. Consequently many physicians do not know whether a patient has written or thought about an AD (Evans et al., 2012). Considering the German physicians' adherence to law, a legal requirement to routinely discuss ADs with patients could also improve the implementation of these documents.

In France, physicians seemed to believe that patients want to only know as much as they ask and that bad news does not always have to be shared with the patient (Fainzang, 2006). In such a context, ADs have long been considered as 'foreign ideas' and were largely ignored in the clinical setting and by the media. According to a national survey of 2012, only 2,5% of patients at the end of life had completed an AD (Monnier et al., 2012). Another study conducted among elderly persons in France has shown that 90% of the participants have never heard of ADs and even after having been informed, 83% did not wish to write an AD. At least in part, this was because they believed that physicians would do what they want and ADs would have no impact on their care (Fournier et al., 2013). The debate and attitudes in France is, however, changing. My observations have shown that junior doctors often value honest information but lack role models and communication skills training. Having laws and regulations they can refer to when trying to implement more patient-centred care and decision-making appeared to be of benefit. The above mentioned impact of the previous law of 2005 on public discourses and physicians' perceptions suggest a positive effect, also of the new law of 2016 confirming the binding value of ADs. In view of its ambiguity regarding the interpretation of ADs and its remaining focus on medical decisions, the law will however not resolve French physicians' difficulty to discuss patients' preference at the end of life; a revision of the law should consider explicit emphasis on physicians' obligation to discuss treatment preferences with patients. Furthermore, efforts such as the national campaign of information on ADs launched in 2017 will raise awareness among the general population as well as professionals. Current evidence shows the positive effect of this campaign.

The data from the three countries suggests that open communication about patients' treatment preferences is essential in order to respect patients' wishes and that this communication needs to be improved. Such improvement could be achieved by introducing public debates and legislation that requires physicians to encourage discussions. A useful model for a

'communications approach' is Advance Care Planning (ACP), a process "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions." (Singer et al., 1996) A number of studies have shown the positive impact of ACP on the implementation of ADs (Sabatino, 2013).

## 5. Conclusion

In all three countries, legislation concerning ADs reflects relevant societal debates and national contexts. This comparative study shows how the socio-cultural context, public debates and the way the law is formulated impacts on physicians' attitudes with regard to the implementation of ADs. The lack of communication about anticipatory treatment decisions and patients' values appears to be the main factor hindering the implementation of ADs in practice. Depending on the country, various factors lead to these communication problems. These include: the lack of public awareness of ADs, the lack of a patient-centred approach, lack of clarity of the law, and the lack of specific communication skills training. In contrast to the conclusions drawn by White and Willmott (2016), this study shows the influence of the law on physicians' attitudes. Although ADs are legally binding in England, France and Germany, there is no legal requirement to discuss ADs with patients in any of these jurisdictions. The introduction and revision of professional guidelines regarding management and implementation of ADs in each country may encourage these discussions and have a positive impact on the uptake of those directives by patients. In view of the influence of the law on physicians' attitudes, a legal requirement to discuss treatment preferences is likely to persuade more physicians to develop care plans together with their patients. In the same way, laws that clearly state the value of ADs without defining limiting conditions under which these documents can be invalidated can allow physicians to overcome their hesitation to implement ADs. Tight laws combined with a legal requirement to engage in discussion and the provision of communication skill training will allow for increased respect of patient wishes and preferences based on joint reflection between physicians and patients. Additionally, broad public debates on ADs are necessary to raise awareness among the population and encourage more professionals to discuss ADs with patients.

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