

The near-failure of advance directives: why they should not be abandoned altogether, but their role radically reconsidered

Marta Spranzi^{1,2} · Véronique Fournier²

Published online: 5 May 2016
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Abstract Advance directives (ADs) have been hailed for two decades as the best way to safeguard patients' autonomy when they are totally or partially incompetent. In many national contexts they are written into law and they are mostly associated with end-of-life decisions. Although advocates and critics of ADs exchange relevant empirical and theoretical arguments, the debate is inconclusive. We argue that this is so for good reasons: the ADs' project is fraught with tensions, and this is the reason why they are both important and deeply problematic. We outline six such tensions, and conclude with some positive suggestions about how to better promote patients' autonomy in end-of-life decision. We argue that ADs should continue to be an option but they cannot be the panacea that they are expected to be.

Keywords Advance directives · Near-failure · Tensions · End-of-life decisions · Patient's autonomy

Introduction

Advance directives (ADs) have been promoted in connection with patients' rights for a number of years. They were conceived as a tool for respecting patients' autonomy by

allowing their preferences about medical procedures to be taken into account, when they will be incompetent or only partially competent.¹ In the United States, they are a major provision of the 1990 Patients' Self-determination Act. In Europe, they are gradually being integrated into current practice. In France, they were voted into law in 2005, as a tool for giving doctors indications as to patients' wishes, although they were not binding.² Ten years later, they have finally been made compulsory for doctors to follow as in the German approach (Evans et al. 2012; Wiesing and Jox 2010). In all countries, they are associated either with the place that patients legitimately deserve in dealing with life and death decisions, or with the respect of patients' rights in cases of incompetence. For the last 20 years, they have been hailed everywhere as THE solution to deal with intractable end-of-life decisions such as withdrawing or withholding treatment, as well as in cases of conflict between doctors and proxies. Countless proposals for their best format have been discussed, implemented and evaluated.

However, despite consistent efforts of information, education and research as well as the development of various legal provisions, it does not seem that the consistently low number of ADs written by actual and potential patients is bound to increase in the near future, and for

✉ Véronique Fournier
veronique.fournier@aphp.fr

Marta Spranzi
marta.spranzi@club.fr

¹ University of Versailles-St-Quentin-en-Yvelines (UVSQ), Versailles, France

² Centre d'éthique clinique, Hôpital Cochin, Assistance Publique-Hôpitaux de Paris, Paris, France

¹ In this paper, we shall only be concerned with treatment-specific ADs, to the exclusion of more generally conceived living wills and power of attorneys to name healthcare proxies.

² The End-of life act, n. 2005-370 of April 22nd, 2005. The revised version of the law has been approved on February 2nd 2016. Article L. 1111-11 deals with advance directives and establishes that they are binding for doctors provided that the patient's actual medical condition corresponds to what has been described in the ADs. (https://www.legifrance.gouv.fr/affichCodeArticle.do?sessionId=BCA0AF498C6201146692DFD582E635BE.tpdila18v_3?idArticle=LEGLIARTI000031972302&cidTexte=LEGITEXT000006072665&categorieLien=id&dateTexte=).

good reasons, as we shall see. The figure of about one in five who actually writes ADs remains remarkably constant across cultures as different as England, France, and the United States.³ While some scholars hold on to the tool as the only and last resort, and insist that they have to be encouraged at all costs, others openly advocate their abandonment, because of the existence of too many obstacles, that make it difficult for ADs to be easily filled out and to be really useful in clinical decision making. “The failure to devise workable forms (of ADs) is not a failure of effort or intelligence. It is a consequence of attempting the impossible” (Fagerlin and Schneider 2004).

The authors eloquently conclude: “Persistence in error is but the triumph of dogma over inquiry and hope over experience” (Fagerlin and Schneider 2004).

The difficulties surrounding ADs are not surprising. The apparently simple idea behind the project—making a patient decide in advance for the situations when she is partially or completely incompetent—hides inextricably difficulties, both conceptual and practical, as Schneider and Fagerlin discussed at length. Controversial issues concern the nature of patients’ preferences, the status of personal identity and the continuity between the former and the present selves, as well as the role and reliability of family members or proxies in the decision-making process, whenever they have been designated in the ADs as surrogates. Other more empirical difficulties concern the fact that patients’ preferences change over time, that ADs have to be interpreted, that the medical conditions tend to be ever more complex and, even more to the point, the fact that people have an inherent psychological difficulty in thinking, let alone talking, about death. Each of these issues has been the object of careful studies, even though such collective efforts have failed to produce any clear-cut solution. Moreover, although the analyses that have been offered to explain the so-called “failure of living wills” are all relevant and correct, they tend to encourage the belief that it suffices to answer those objections, either theoretically or practically, in order to reaffirm the ethical legitimacy and the usefulness of ADs. Proponents of ADs remain convinced that more time and creative efforts will vanquish all resistances and that finally a large majority of people will be convinced, as they themselves are, of the importance of ADs, and will write them.

Our modest proposal in this paper is to offer a different diagnosis, one that will account for the inconclusive state of the present debate. We would like to suggest that the qualified success—or the “near-failure”, as we shall call it—of ADs does not result from a number of serious obstacles, but from the fact that the concept involves a series of inner

structural tensions that could never be completely overcome. It is precisely because ADs enclose several such tensions, that they are both interesting—and thus difficult to dismiss out of hand—and hopelessly difficult to implement. The main elements of our analysis have been suggested to us by old people which we have met in the course of a qualitative clinical ethics study we have carried out in 2009–2010 in France, about the perception of ADs in a population older than 75. During this study, we have met 186 people (106 female, 80 male, mean age: 82.7 years old), with different health and/or disability status, also including some still very healthy and active people, with whom we have conducted long, narrative and qualitative interviews.

The results of the study have already been published.⁴ Here, we shall only refer to them in a piecemeal fashion and quote some participants’ eloquent views in order to illustrate our argument.

In this paper, we shall focus on six specific structural tensions, involved in the concept of ADs, that in our view explain both why they cannot work better than they do, and the reasons why most people do not want to write them. In other words, these six tensions are enough for us to infer what we have called the “near failure” of ADs. However, we shall not advocate that ADs should be abandoned altogether. We still consider that they do play an important role when they are written, even if this concerns a minority of people. Moreover, we shall insist that the question ADs were meant to address remains crucial, namely: How are doctors to make complex decisions in a way that does not leave out the patient entirely? In the conclusion, we shall not offer an outright solution but we hope, some novel ways of thinking about the issue. We shall argue that the fact that the ADs continue to exist and to be a legal possibility could play an important role for letting people know that it is crucial for them to express something about end-of-life issues, and for the society to develop different, more informal, and dialogical approaches in order to fill that need.

Tension 1: ADs are meant to enhance respect for patients’ autonomy, but they also limit their freedom

The first tension amounts to a paradox: ADs are considered as a tool for allowing one’s autonomy to be respected, and at the same time they are often viewed as a threat to one’s future freedom. As we have already mentioned, ADs have been hailed as a fundamental tool for respecting patients’

³ For a useful and up-to-date review of data concerning the writing of AD, see Aulisio (2014) and Perkins (2007). For a comparative European perspective see Horn (2014).

⁴ The main results of our clinical ethics study are reported and discussed in: Fournier et al. (2013). More detailed results are available in: Spranzi and Favereau (2013) (<http://www.ethique-clinique.com>).

autonomy and allowing her to virtually participate in the medical decision when she is unable to express herself. Personal autonomy, however, is a complex “umbrella” notion. The concept of autonomy as a value worth pursuing involves not only control over, and fidelity to, one’s true self, but also freedom, as I. Berlin’s metaphor of the “inner citadel” indicates (Berlin 1969).

It may come as a surprise, therefore, that people perceive the fact of putting their preferences in writing as a threat to their own freedom. An elderly man living in a nursing home that we met during our study gave us a hint as to why this might be the case. Asked why he had refused to write his ADs, he answered: “ADs can be tyrannical, as one’s own will always is; man is a creature of imagination and not of will”. Indeed, an important philosophical tradition associates freedom to contingency, which allows for unforeseen deviations from the rigorous paths created by one’s will and structured life-plans. It is what Leibniz called “freedom of indifference” (Leibniz 1952) as the ancient atomists held, there is no freedom in the universe without chance. Patients, it would seem, fear necessity more than contingency, and value the precious little room allowed by the occurrence of unexpected events, as improbable as they might be. This is the reason why, although they value autonomy, they fear ADs. As another patient told us: “These precautions are an obstacle to life, it is not interesting to anticipate”. They resent the fact of being nailed down to their former selves and they are wary of restricting in advance future possibilities, by embracing a kind self-made “reasonable servitude”.

One of the main results of our study is that the desire to write ADs seems to be very “personality-dependent”: only a minority of people (about 15 %) are interested in the concept of ADs and might choose to write them, thus accepting to restrict their own future choices, and among those most of them (70 %) are female, at least in our cohort. Furthermore, they all share the same personality: they are people who value being able to foresee and control the events that affect their life, and are ready to renounce part of their freedom in order to achieve that end. As an elderly lady who had written ADs said: “I want to write them myself because I refuse to defer my decisions to a third party, and I accept that my cognitively impaired future self be bound by what I state today”.

Tension 2: The validity of ADs presupposes the continuity of personal identity, but people doubt that they will still be the same person when ADs will be needed

The relationship between ADs and personal identity also reveals a tension: the validity of ADs presupposes a certain continuity between the persons signing them and the

person for which they are used (Buchanan 1988; Buford 2008). However, ADs are needed precisely when a patient has become totally or partially incompetent, and in these states one may well wonder whether she is really the same person anymore. For example, when we asked people in our study if they would be interested in writing ADs for the case they might become demented, they surprisingly stated that ADs were not relevant in such a situation. They felt that if that happened they would not be the same person anymore and therefore they would be relatively unconcerned by the medical decisions that will be made on their behalf. Moreover, in a subgroup of our study cohort, who was constituted by people who had just been diagnosed with Alzheimer disease, none were interested in writing ADs: “No, I don’t fear Alzheimer disease, it will be hard for my loved-ones, but not for me; I will not be aware of my state. And I may still enjoy life!” (Spranzi and Favereau 2013).

Nevertheless, those who choose to write ADs might do so *precisely because* they suspect that in certain circumstances they might become a different person: by writing ADs they intend to privilege the person that they are now and to accept the fact that they will impose their own views on to a different later “self”. They presuppose that there exists a hierarchy of persons, the previous more competent one having the right to ‘enslave’ a later, more diminished, person (Shaw 2012).

This second tension, therefore, suggests that efforts to demonstrate the continuity of personal identity through important life changes in order to prove the validity of ADs are unnecessary. Contrary to what might be expected, people who are interested in writing ADs perceive them as perfectly compatible with the discontinuity of personal identity, even though, discontinuity does not serve the cause of autonomy, which lies at the foundation of ADs’ original project. Although it is conceptually different, this second tension is related to the first one, as far as its consequences are concerned. Indeed, it is not surprising that the minority of people who wish to subjugate their future self to their present one is the same as the one that, by writing their ADs, accepts to renounce their own future freedom, in the name of their present autonomy.

Tension 3: ADs are supposed to reduce the need for deliberation in end-of-life medical decisions, but good medical decisions in such circumstances often result from a complex deliberation process

ADs are supposed to represent the person who has written them when she is not “present” anymore, and to do so in a direct and straightforward way. In the relevant circumstances, they are supposed to cut short hesitations and

controversies among all concerned parties—doctors, loved ones, family members, proxies, as the case may be. In our study however, we frequently heard from people we met, that a good end of life decision is likely to be the result of lively exchanges and a thoughtful dialogue among all caring people—be they proxies and doctors alike—at the precise moment when a decision has to be made (Nolan et al. 2005; Sulmasy et al. 2007). As one person says: “I will trust life and people around me, including my doctor” (Seymour et al. 2004; Berger 2008). Actually, both potential and actual patients often see doctors as a crucial voice in the deliberation process. This is why a mere “family covenant”, as some authors suggest is not enough (Doukas and Hardwig 2003).

By contrast, the people who told us that they were inclined to actually write ADs do so for two different reasons. Some of them think they are useful precisely in order to relieve third parties from the psychological burden of the decision and their feeling of guilt should treatment be withdrawn. Others envisaged writing them because they wanted their own voice to silence others’: very often, they were people who either lived alone, were in situations of potential conflict with family members and other loved ones, or were deeply mistrustful of medicine. One of them told us: “The ultimate decisions should not belong to doctors, they are strangers. That is the reason why I wrote ADs; and I did so because I am alone, there is nobody around anymore” (Fournier et al. 2013).

Tension 4: People are more interested in speaking about the conditions of a life worth living than about the precise conditions of their dying process, and yet ADs are meant precisely to plan about a good death

ADs are associated with death and planning for it; they are meant to tell something about how people conceive of their ideal death—and what they might want to tell doctors about it. Most authors who want to explain the “failure of living wills” argue, quite plausibly, that they don’t work because patients have a difficult time thinking—let alone talking—about death (Emanuel 2000). And that, understandably, doctors themselves are reluctant to introduce the topic of ADs, fearing that the very fact of bringing it up will undermine hope, cause moral suffering and even precipitate death by encouraging patients to give up on the healing process (Quill 2000). Some people we met in the course of our study had precisely this kind of reaction, the same that has been described in other empirical studies (Nishimura et al. 2007). For example, in the subgroup of patients suffering from advanced cancer, the more they were near death, the less they were able to speak about it as

well as about ADs, as if they were denying the severity of their health condition. One of these very sick people told us: “ADs are indeed useful for planning about death; they are interesting for very sick persons; I am not there yet, I’ll think about it when the time comes”.

However, we frequently heard something else in the interviews we carried out. We discovered that most people knew all too well that they have to die, but they were more interested in positively evoking the ways they wished to spend the time which was left to them rather than planning for the precise conditions of their death. When asked what they would write in their ADs, they focused on what they viewed as the limits of an acceptable life for them: still being able to listen to music, to feed their cat, to walk or talk, to communicate with their loved ones. Also, they often expressed interest in some close, and as yet unrealized project: to go for the holidays they have planned for a long time, to be able to attend an important special event, to wait for the birth of a grandchild, etc. Indeed, what they all said is that they would not want to “outlive” themselves (Cohen 2014) that is live beyond what is not a life anymore at least according to their own particular outlook, situation and history. In fact, they spoke about their real and immediate concerns and expected doctors to translate their views into appropriate medical decisions. Thus, some patients wished to let their doctors know that they would not want to live as tetraplegics, but were unable, and unwilling, to tell their doctors what exactly should be withdrawn or withheld, and at which stage, in order for them to avoid that kind of life. ADs, however, are not suited for having these sorts of conversations about what still matters in life. And they are not supposed to let doctors freely interpret their patients’ loosely expressed life wishes.

Tension 5: At end of life, patients often seem interested to talk about their own values, but ADs are not suitable for value histories

Most ADs forms focus on a variety of medical procedures: future or actual patients are supposed to determine whether they would want resuscitation, assisted ventilation, feeding tubes, etc., for how long and in which precise medical conditions. However, all the technical details that would help doctors make a decision in case of a patient’s incompetence are hard to imagine especially for relatively healthy people who have not had any experience with them.

More importantly, our study suggests that patients who accept to speak about their dying conditions are not keen on concentrating on issues as trivial detailing which medical actions or treatments they would be ready to accept or not. The ones we met during our study often wished to

share their preferences with respect to their religious and spiritual convictions, or to discuss their general attitude towards actively hastening death or letting it occur naturally at its own pace. For them, such end-of-life conversations might be fruitful for telling something about their own values and history, in order to help them achieving a death resembling, so to speak, the person behind the medical chart.

Sensitive to this problem, some have discussed or introduced value-based Ads (Levi and Green 2010; Doukas and McCullough 1991). But while value histories are certainly welcome, they need, as do conversations about what still matters in life do, a large amount of translation, adjustment and interpretation for doctors to be able to use them in making their own medical decisions. As we already said, this defeats, so to speak, the initial purpose of ADs, which have been conceived as a direct operational tool, something that they definitely cannot be.

Tension 6: ADs that have been conceived as a tool for promoting patients' rights are mostly valued by doctors when they favor their own choices

We already said that ADs have been introduced everywhere in order to further a better respect for patients' autonomy. However, it would seem that it is doctors rather than patients who are more likely to value ADs and profit from their existence. Here, our argument does not refer to the results of the study about ADs that we have quoted in the previous sections of this paper, but to the experience we have had for more than 10 years as a CESS in hospital.

Indeed, according to what we see daily in the clinical setting, doctors have several substantial reasons to view ADs as a useful tool in their own decision-making process (Bond and Lowton 2011).

First of all, in situations of uncertainty and doubt, where no unique medical decision is the "good" decision, they are happy to use them, insofar as they bring whatever relevant considerations may complement their technical reasoning alone. Indeed, when difficult decisions are at stake—decisions involving important risks, end-of-life situations and authentic dilemmas—doctors are extremely reassured when they can have a clear indication of their patient's preferences and when the latter confirms what they think should be done.

Secondly, doctors value ADs because they help them get a direct hint of the patient's personality and history, rather than having to rely on what family members and other loved ones have to say about it. They usually don't trust so much what the latter say, wondering if they really speak in the patient's name and best interest or merely for themselves.

But there is a third argument that shows, to a greater extent than the previous ones, that it is doctors rather than patients that benefit from the existence of ADs. Indeed, even though a patient might sometimes indirectly profit from ADs—by seeing her chances increase that doctors' decision respect them as persons—this is not the *reason why* doctors value ADs in the first place. This is shown by the fact that if the decision indicated by the patient in her ADs is different from what doctors themselves recommend, they can easily find a way around ADs and ultimately refrain from applying them (Bonner et al. 2009; Stone 1994). This constitutes a major misappropriation of ADs. In such cases, they don't serve anymore as a means to better respect patients' autonomy, but as a tool to facilitate doctors' own work. Whether existing ADs actually help them solve an intractable situation is different question and a moot point—there are good reasons to think that they do not. This makes the tension between ADs' original purpose and the way they are actually used all the more relevant.

Conclusions

The six tensions we have outlined in this paper—and there may well be others—are inherent and constitutive of the ADs concept. They show that if ADs do not work as well as they were supposed to, it is not only because of the practical difficulties they raise. Rather, what we tried to show is that they cannot work more than they do now because they involve too many contradictory presuppositions and values. This is the reason why the chances that more people will ever write them in the future are slim. Indeed, it is remarkable that patients themselves intuitively perceive all the contradictions and tensions, embedded in the concept. This is probably why most of them vote with their feet and do not write ADs. Nevertheless, the crucial idea that patient's autonomy needs to be respected at the end of life should not be abandoned. ADs, and the countless efforts made to promote them, have served at least the important purpose of highlighting this issue.

We would like to suggest another way to serve the cause of patient's autonomy at the end of life, for the majority of people who do not want to write ADs. That is to invite doctors—possibly with the help of a third party as for example a clinical ethics consultant or a palliative care specialist—to engage in frequent subtle, free and open-ended conversations with patients in order to help them clarify their own values and life options, unshackled by the technicalities of ADs (Tulsky 2005). People should be encouraged to engage in a dialogue about what they consider to be the main conditions that would make life worth living for them, and share them with proxies and/or loved ones, as well as with their attending physician. We are

aware that even though these narratives and value histories can be useful, they will not be easily translated into technical medical choices. However, we think that there is no other option: a medical translation of patient's values, wishes and preferences is unavoidable, and it necessarily involves a subjective dimension that must be endorsed as such. In order to minimize its arbitrary nature, this translation should be discussed during an ad hoc meeting, where the different members of the healthcare team, the patient's surrogate(s), and, if necessary, a third neutral party, engage in a thorough deliberation process.

In conclusion, we would like to insist on the necessity for ADs to continue being a possibility, systematically offered to everyone, in spite of the insurmountable inner tensions that the concept involves and that we have described. We hold that this should be the case for two reasons. First, for everybody, and especially for doctors, they serve as a reminder of the important fact that patients should not be left out of the crucial decisions that must be made on their behalf at the end of life. These decisions should be decisions which they would have agreed to. In the majority of cases, this purpose can be better achieved through an open-ended dialogue among patients, loved ones, and doctors. Secondly, if ADs are not the universal tool they were meant to be, they may nonetheless correspond to the needs of a minority of people. In this respect, we would like to stress the fact that whenever people choose to write them, ADs should be made binding for doctors—although they are not directly operational and need some uneasy medical translation—rather than optional as they too often are now. Indeed, those who have decided to consign their precise wishes in writing have clearly signified that they are ready to sacrifice other values—freedom, dialogue, and trust—in order to achieve better control over their own future. The least society owes to them, is to respect such hard-won choices.

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