



In the main population, what are the problems lead by the binding law of advance directives? A thematic analysis based on a systematic literature review

Énora Krurien

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In the main population, what are the problems lead by the binding law of advance directives?
A thematic analysis based on a systematic literature review.

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Résumé : Dans la population générale, quels sont les problèmes posés par la loi opposable des directives anticipées ? Une analyse thématique basée sur une revue systématique de la littérature

Introduction : Les directives anticipées (ADs) sont peu utilisées. Leur caractère contraignant pose des problèmes éthiques. L'objectif de cette étude est de comprendre ces problèmes vis à vis de la population générale.

Méthode : Une revue systématique de la littérature a été réalisée selon le guide PRISMA, dans les bases de données suivantes : Pubmed et Psychinfo. L'équation de recherche était : « directives anticipées » et « éthique ».

Critères d'exclusion : ADs non objets de l'article, communauté non objet de l'article, éthique non objet de l'article et résumé non disponible.

Critères d'inclusion : articles centrés sur le caractère opposable de la loi, les ADs, et la population générale, langue française ou anglaise, article accessible, et format adapté.

Un processus « boule de neige » a été effectué, utilisant le même protocole. Une analyse thématique suivant un processus de codage en double aveugle a été réalisée. L'analyse a ensuite été comparée à la littérature actuelle et à une analyse parallèle réalisée dans la littérature grise par le Dr Zambonino (1), dans le cadre du groupe de recherche brestois.

Résultats : Documents extraits : 484 (Pubmed) + 586 (Psychinfo). 28 doublons. 1042 résumés soumis à analyse, 921 exclus. 121 articles soumis à éligibilité, 17 ont été inclus, 2 non trouvés.

Boule de neige : 436 références. 41 doublons. 395 résumés soumis à analyse. 377 exclus. 18 articles soumis à éligibilité. 6 articles inclus. 23 articles ont été intégrées.

Analyse thématique : 156 codes axiaux, 23 codes théoriques regroupés en 10 thèmes : sphère individuelle, entourage, sphère soignante, société, la Cour, principes de bioéthique, élaboration du document, temporalité, communication, interprétation.

Conclusion : Plusieurs problèmes ont été identifiés, pouvant expliquer le faible taux d'achèvement des ADs. Leur connaissance peut améliorer la pratique en fin de vie.

Mots clés : directives anticipées, éthique, population générale, loi d'opposabilité, problèmes

Abstract : In the main population, what are the problems lead by the binding law of advance directives ? A thematic analysis based on a systematic review of the literature

Introduction: Advance directives (ADs) are little used in the French population. Their binding nature raises ethical problems. The objective of this study is to understand these problems with regard to the general population.

Method: A systematic literature review was performed according to the PRISMA guide, in following databases : Pubmed and Psychinfo. Search queries were: “advance directives” and “ethic” (MESH terms).

Exclusion criteria : “not about the ADs”, “not about community”, “not about ethic” and “no availability of the abstract”.

Inclusion criteria : “about the binding nature of the law”, “about the ADs”, “about the general population”, “available language”, “accessibility of the article”, “adapted format of the article”.

A snowballing was performed, using the same protocol. A thematic analysis was compared to the current literature and the results of a parallel analysis made in the grey literature by Dr Zambonino (1).

Results: Documents extracted: 484 (Pubmed) + 586 (Psychinfo). 28 duplicates. 1042 abstracts submitted for analysis, 921 excluded. 121 articles submitted for eligibility, 17 were included, 2 not found.

Snowballing : 436 references. 41 duplicates. 395 summaries submitted for analysis. 377 excluded. 18 articles subject to eligibility. 6 items included. 23 articles have been integrated.

Thematic analysis : 156 axial codes, 23 selective codes grouped in 10 themes: individual sphere, entourage, caring sphere, society, the Court, the principles of bioethics, elaboration of the document, temporality, communication, interpretation.

Conclusion: Several problems have been identified, which may explain the low completion rate of ADs. Knowledge can improve end-of-life practice.

Keys words: advance directives, ethic, general population, binding law, problems

Title: In the main population, what are the problems lead by the binding law of advance directives? A thematic analysis based on a systematic review of the literature

I - Introduction:

“Advance directives (ADs) are documents which encompass preferences, values, and anticipated situations for end of life situations. They centre on defining a « good death »”(2). “The instrument of « advance directive » - or « living will » as this document was originally named made its first introduction in 1969 in America”(3).

“Overtreating will obviously not help dying people to escape death. The question of "medically futile" interventions and excessive life-prolonging treatment has been raised several times.” “Making an advance directive is one of the options for facing near-death situations, and probably a sophisticated way to cope with the death as a notion”(4).

“In France, a first law concerning the rights of patients at the end of life, called « the Leonetti law » allows since April 2005 the limitation or discontinuation of treatment and sedation for a symptom that has remained refractory until death. “

“On the February 2, 2016, after the re-examination of questions related to the accompaniment of patients at the end of life by a parliamentary commission, the French Government proclaimed a law called the Claeys-Leonetti law. This law recognizes the wishes expressed by patients and establishes the right to deep and continuous sedation, consisting of sedative and analgesic treatment leading to a profound and continuous change of vigilance to death if the patient is likely to suffer pain, associated with the cessation of all life-sustaining treatments including artificial nutrition and hydration”(5).

“The law obliges clinicians to abide by any ADs regarding treatment and investigation, except in cases where they are « obviously inappropriate » in a given medical situation, or in cases of emergency, in order to allow medical staff to take time to assess the patient’s situation“(6).

However, ADs are not available to all patients because some countries have not legalized them. Even in countries where such instruments are available, the percentage of patients who execute them is relatively low (7,8).

“It is known that ADs pose serious practical and ethical problems related to, among other things, continuity, liability, completeness, interpretation and the relationship between rejected and demanded medical treatment”(2). “The most important legal requirement is

the acknowledgement of patient autonomy” (9). But this concept of autonomy brings many reflections and uncertainties. A better understanding of the problems associated with ADs allows them to be better resolved.

These ideological problems sometimes divide society. They raise new ethical questions that enrich the end-of-life debate.

Why is the execution of ADs so low? What problems can a person encounter when writing their directives? What are the obstacles to their achievement? What problems can a professional encounter when applying them? Through a thematic analysis based on a systematic review of the literature, the aim of this report is to investigate the problems lead by the binding law of ADs in the main population.

II - Method:

A. Protocol:

A research group, made of GPs, was built in Brest (France) to explore the various issues related advance directives.

A systematic literature review (SRL) centered on the problems in the main population induced by the binding law of advance directives was performed. The PRISMA guidelines were followed at each step of the study, (10) in order to ensure the reproducibility of the study.

Pubmed (the world’s largest indexed database), and Psycinfo (International documentary database produced by the American Psychological Association, and specialized in psychology in the broad sense) were used to extract records. The search query should not be restrictive in order to extract a broad selection.

The first research query « Advance directives » [MeSH Terms] AND « Community health services » [MeSH Terms] founded not enough results. After consensus group, this search query: « Advance Directives » [MeSH Major Topic] AND « ethic » [MeSH Major Topic] was used.

The research was restricted in the time from the past until march 2018 (start of research into the databases). Studies selected may occur all around the world.

Mendeley bibliographic management software was used to reference the different sources found.

Exclusion and inclusion criteria of each step of the PRISMA process were selected in focus group, in accordance with the quality criteria of the international scientific writing (IMRAD format and bibliographical substantiation of the argument) and the objectives of the research problematic.

B.Screening:

After exclusion of duplicates, these exclusion criteria were applied on abstracts:

- **No availability of the abstracts (I)**, writing format: scientific (IMRAD), legal or humanities; Articles not in a peer-reviewed journal were systematically excluded
- **Not about the Advance Directives (II)**, as the main subject of the article, articles about psychiatric advance directives or euthanasia were excluded.
- **Not about Community (III)**, for example, references referring specifically to a part of the population such as dialysis patients or hospitalized were excluded, in order to collect opinions concerning the population as a whole
- **Not about ethic (IV)**, because ethics is at a main topic of this research.

This phase was carried out in a double-blind manner by a second investigator. After comparing the selection, in case of disagreement on a reference, it was selected.

C.Eligibility criteria:

The full-articles related to abstracts were found using the Brest Library University Access on the internet and by asking the Brest Library University for international import if not found on the internet. The full-articles were submitted at eligibility process using the following inclusion's criteria:

Major inclusion's criteria:

- **About the binding nature of the law (I)**, in order to be in accordance with the Claeys-Leonetti french law, which changed the relationship with the ADs.
- **About the Advance directives (II)**, what is the main topic
- **About the general population (III)**, the case reports were not included, as the articles about hospitalized, institutionalized or sick patients; in order to reflect the population as a whole, without the influence of the state of health.

Minor inclusion's criteria:

- **Available language** (IV), languages used were French and English so that the articles would be fully understood by the investigators
- **Accessibility of the article** (V), in order to have a proper thematic analysis
- **Adapted format of the article** (VI), the books, chapters, comments or editorials were not included. The majority of the articles found were not in IMRAD format.

Two blinded investigators at the screening step performed the eligibility process. Disagreements were resolved by consensus or by consulting with external researchers.

D.Snowballing:

In order to be exhaustive, a snowballing was applied to bibliography of full-articles included using the same PRISMA statement and exclusion/inclusion criteria respective at each respective step. The new full-articles included were added to those already included for narrative analysis.

E.Thematic analysis:

The following step was performed according quality criteria of the qualitative research.(11,12)

Excerpts from text related to the research question were extracted from the included articles, then grouped and discussed. These text extracts have been transcribed and conceptualized to give open codes. Open codes have been grouped into stable fundamental concepts: axial codes.

The next phase was hermeneutics: that is a stable and consistent interpretation and explanation of the texts. It was thematic hermeneutics because it went through the prism of the research question. To do this, the axial codes have been grouped into different conceptual fields: selective codes (or sub-themes), themselves grouped into focus codes (or themes).

In order to give more coherence to the research work of the Brest group, the thematic analysis has been harmonized with that of a thesis of the same group published earlier, of Dr Zambonino(1). The subject of this thesis was the search for factors that hindered

the achievement of AD for the community since the Claeys-Leonetti law, a systematic review of gray literature.

To view the coding and compare their data, the coders used an Excel spreadsheet. The hermeneutical themes extracted allowed a targeted analysis of the themes and sub-themes.

To understand this hermeneutics quickly, intuitively and globally, a heuristic diagram was then produced, in order to understand the interaction between the themes.

III - Results:

A. Study selection:

1. Exclusion phase

In databases, 484 records (Pubmed) and 586 records (psycinfo) were extracted. 28 duplicates were removed. 921 were excluded. There was a disagreement for 34 abstracts' exclusion. They were selected to be fully read. After consensus 121 full-text articles were assessed for eligibility. Results are shown in table 1 and figure 1.

Table 1: Exclusion of abstracts

<i>Exclusion criteria</i>	Abstract not available	N=250
	Not about Advance Directives	N=203
	Not about the Community	N=569
	Not about ethic	N=263

2. Eligibility phase

After eligibility process, 17 full articles were included. 2 full articles were not found. The inclusion criteria "Ethic" was first applied, but it was not relevant and deleted.

When one of the three minor inclusion criteria were not met, the full text were not read. Results are shown in table 2 and figure 1.

Table 2: Inclusion of articles

Major inclusion criteria	About general population	N=23
	About binding law	N=51
	About advance directives	N=4
Minor inclusion criteria	Available language	N=22
	Accessibility of the article	N=2
	Format of the article	N=32

3. Snowballing

New records were extracted, using the bibliography of the 17 included articles. They were submitted to the same PRISMA process. Results are shown in table 3, table 4 and figure 2.

Table 3: Exclusion of abstracts (snowballing)

Exclusion criteria	Abstract not available	N=142
	Not about Advance Directives	N=162
	Not about the Community	N=159
	Not about ethic	N=152

Table 4: Inclusion of articles (snowballing)

Major inclusion criteria	About general population	N=0
	About binding law	N=8
	About advance directives	N=1
Minor inclusion criteria	Available language	N=0
	Accessibility of the article	N=0
	Format of the article	N=4

Figure 1 : Prisma Flow Diagram

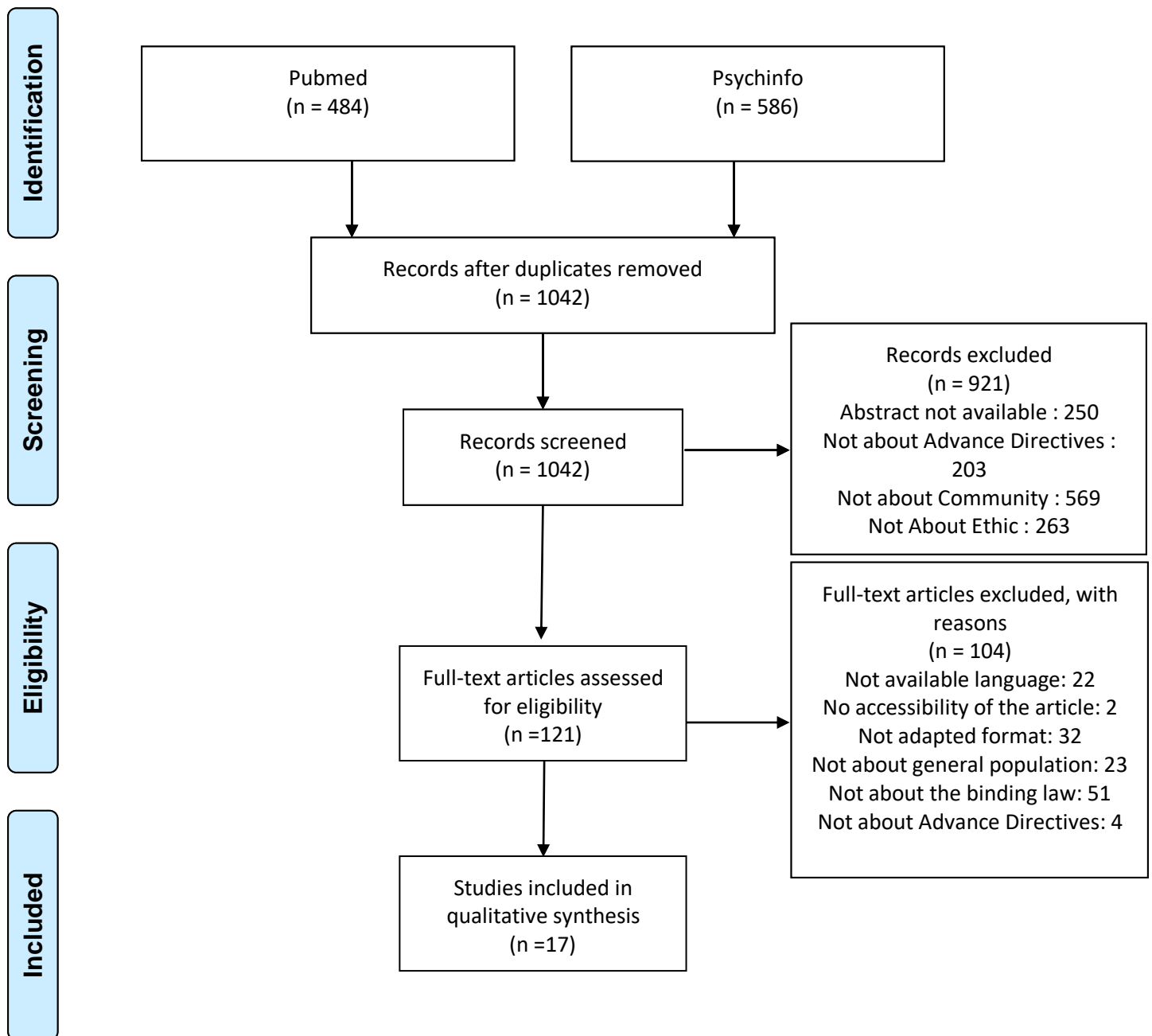
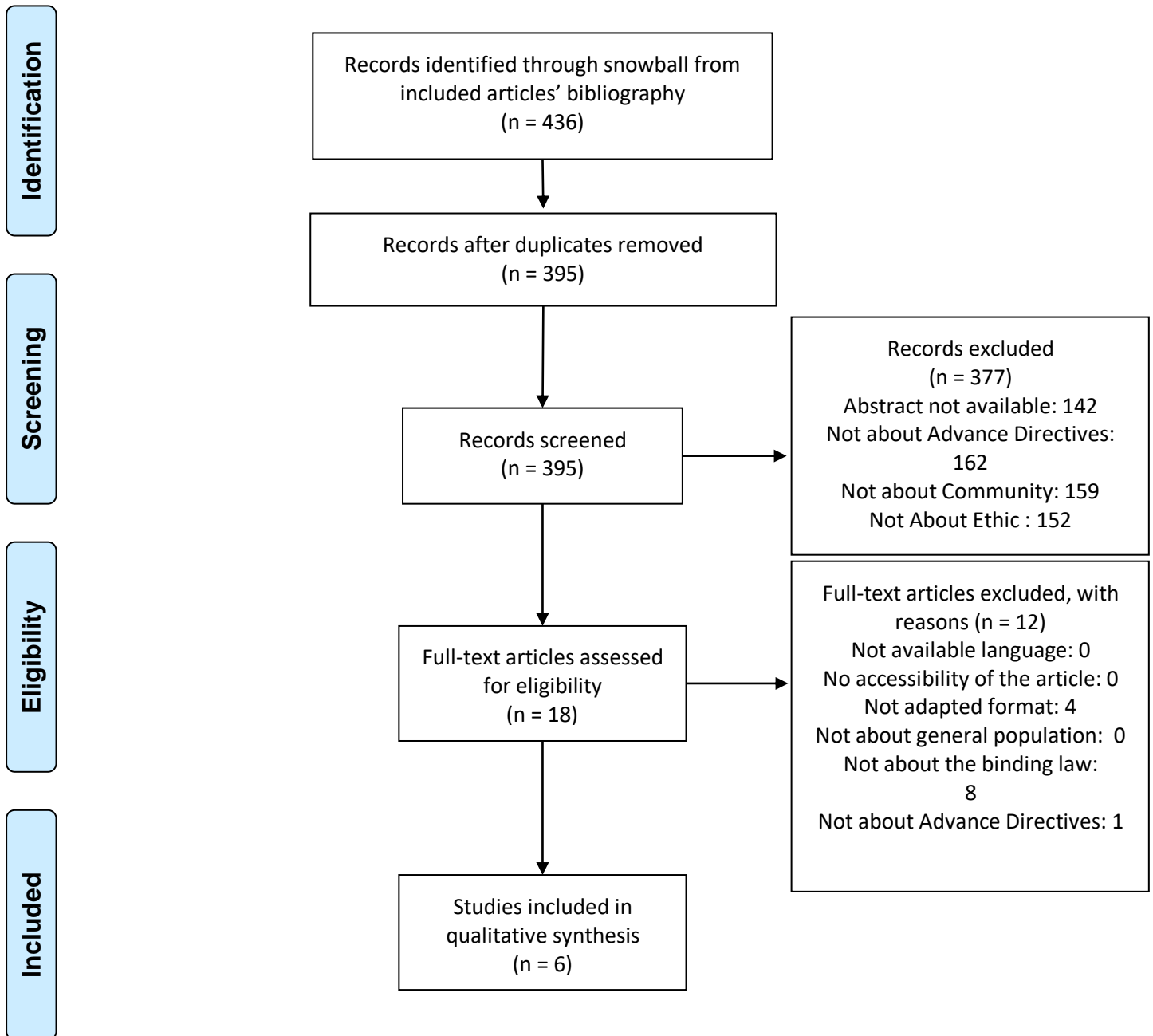


Figure 2: Prisma Flow Diagram (snowballing)



23 studies were included for the thematic analysis, after both processes PRISMA were completed.

B. Study characteristics

All eligible articles were narrative reviews. A third of the articles were less than 10 years old, and two-thirds of the articles were published after 2005. All were never more than 30 years old. 7 were from USA, 6 from England, 4 from Germany, 3 from Australia, 1 from New Zealand, 1 from Italy and 1 from Netherlands. The older articles were from USA and England.

Table 5: Included studies

Title	Source	Year	Author	Country	Type of ad	Type of article
The Patient Self-Determination Act: not now.	Hastings Center Report	1990	Alexander Morgan Capron	USA	Living wills, Advance directives, advance planning,	Narrative review
The values history. The evaluation of the patient's values and advance directives.	Journal of Family Practice	1991	David J, Doukas, and Laurence B, McCullough	USA	Advance Directives, Living Wills	Narrative review
Living wills: Anticipatory decisions and advance directives.	Reviews in Clinical Gerontology	1994	Charles A. Erin, John Harris	England	Advance directives	Narrative review
Advance directives in the UK: legal, ethical, and practical considerations for doctors.	British journal of general practice	1998	Anthony S. Kessel, J. Meran	England	Advance Directives, Living Wills	Narrative review
Biomedical ethics and the withdrawal of advanced life support.	Annual Review of Medicine	2001	Noreen R. Henig, John L. Faul, Thomas A. Raffin	USA	Advance directives	Narrative review
Advance directives and Living Wills.	NeuroRehabilitation	2004	Laura Palazzani	Italy	Advance Directives, Living Wills	Narrative review
Enough: the failure of the living will	Hastings Center Report	2004	Angela Fagerlin, Carl E. Schneider	USA	Living Wills	Narrative review
Advance refusals of life-sustaining medical treatment: The relativity of an absolute right.	The Modern Law Review	2005	Sabine Michalowski	England	Advance directives	Narrative review
Advance Directives, Future Selves and Decision-Making	Medical Law Review	2006	Alsdair R. Maclean	England	Advance directives	Narrative review

Medical treatment of dementia patients at the end of life: can the law accommodate the personal identity and welfare problems?	European Journal of Health Law	2006	Penney Lewis	Netherlands	Advance directives	Narrative review
Legitimate advance directive in Germany.	Journal of Public Health	2008	Angela Seifert	Germany	Advance Directives, Living Wills	Narrative review
Substitute decision-making in medicine: comparative analysis of ethico-legal discourse in England and Germany.	Medicine, Health Care and Philosophy	2008	Ralf J. Jox, Sabine Michalowski, Jorn Lorenz, Jan Schildmann	Germany	Advance directives, living wills, substitute decision making	Narrative review
Advance directives and the rocky waters of anticipatory decision-making	Medical Law Review	2008	Alsdair R. Maclean	England	Advance Directives, Living Wills	Narrative review
Advance Directives Refusing Treatment as an Expression of Autonomy: Do the Courts Practise What They Preach?	Common Law World Review	2009	Lindy Willmott	Australia	Advance directives	Narrative review
Interpreting advance directives: Ethical considerations of the interplay between personal and cultural identity.	Health care analysis	2009	Silke Schicktanz	Germany	Advance directives	Narrative review
A new law on advance directives in Germany.	Journal of medical ethics	2010	Urban Wiesing, R.J. Jox, H.J. Heßler, G.D. Borasio	Germany	Advance directives	Narrative review
Vague Oviedo: Autonomy, culture and the case of previously competent patients.	Bioethics	2010	Assya Pascalev, Takis Vidalis	USA	Advance directives	Narrative review
Resolving ethical dilemmas, part 2: Ethical and cultural relativism and other issues in decision-making.	Directions in Psychiatry	2010	Edmund G. Howe	USA	Advance directives, Do Not Resuscitate orders	Narrative review
Law, autonomy and advance	Journal of law and	2010	Lindy Willmott, Ben	Australia	Advance	Narrative review

directives.	medicine		White and Ben Mathews		directives	
Advance directives and the promotion of autonomy: a comparative Australian statutory analysis.	Journal of law and medicine	2010	Lindy Willmott	Australia	Advance directives	Narrative review
Advance directives and older people: Ethical challenges in the promotion of advance directives in New Zealand.	Journal of medical ethics	2011	Phillipa J. Malpas	New Zealand	Advance directives	Narrative review
Advance directives in English and French law: Different concepts, different values, different societies.	Health care analysis	2012	Ruth Judith Horn	England	Advance directives	Narrative review
Advance consent, critical interests and dementia research.	Journal of medical ethics	2015	Tom Buller	USA	Advance directives	Narrative review

C. Thematic analysis

156 axial codes were gathered *in* 23 selective codes (or sub-themes), themselves grouped into 10 focus codes (or themes). Hermeneutics are shown in the table 6. And the links between the different focus codes and selective codes are shown in figure 3.

Table 6. Thematic analysis

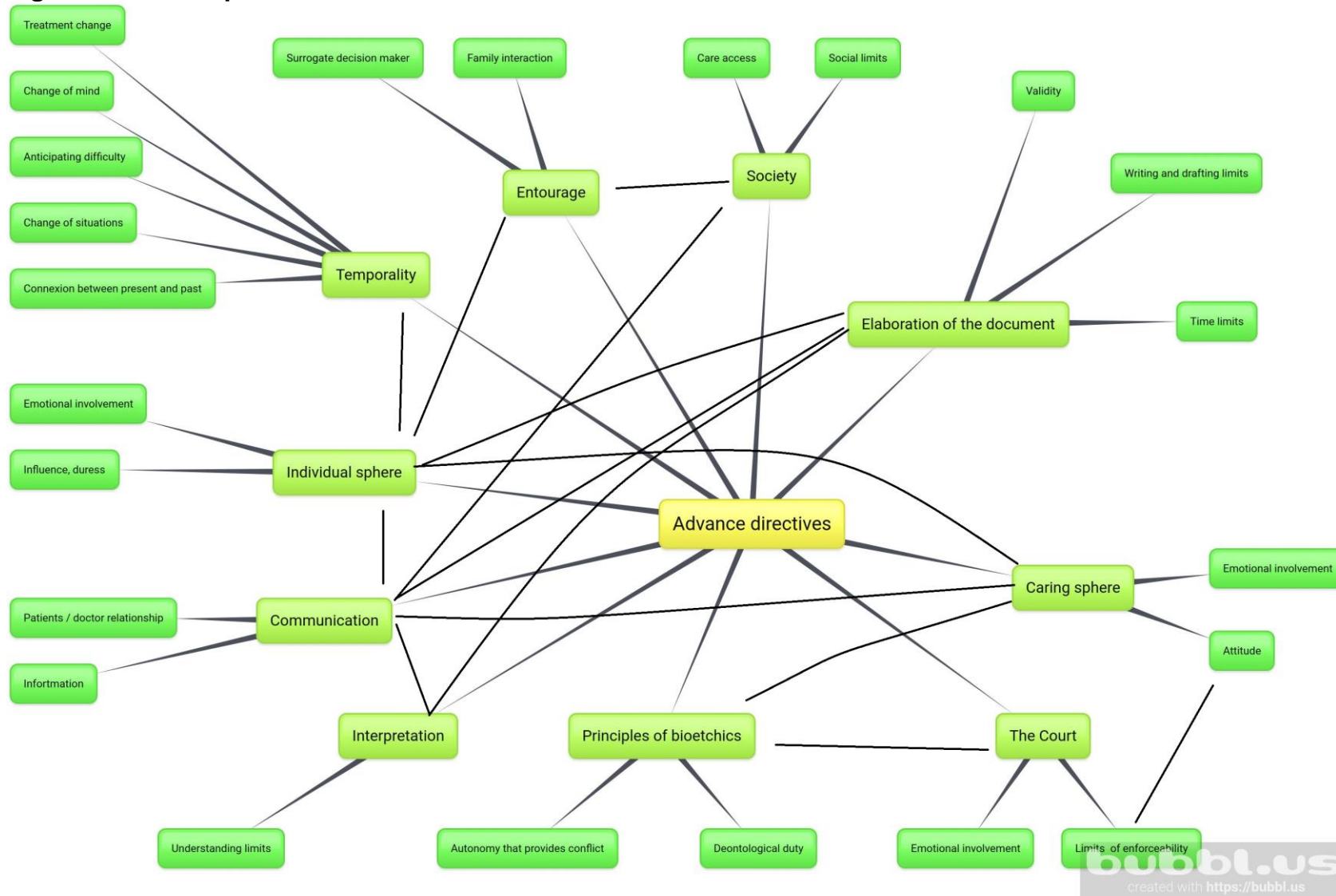
Focus Codes (= Themes)	Selective Codes (= Sub themes)	Axial Codes
Individual sphere	Emotional involvement	<ul style="list-style-type: none"> -Feeling of risk -Feeling « affected » -Fear of abuse -Suspicion and scepticism -Distrust of the caregiver -Fear of worsening of care -Emotions and the social embeddedness -Death as an unpleasant subject -Difficulty to speak about AD -Hesitation to broach the topic -Daunted by the decisions' difficulty -Decision based on panic
	Influence	<ul style="list-style-type: none"> -Depression -Choice under pressure -Culture -Surrounding -Ageism -Values of the others -Economic impact -Prevent financial hardship -Personal experience -Influencing information -Duress not easy to define
Entourage	Family interaction	<ul style="list-style-type: none"> -Conflict of interest with the family -Disagreement of the family -Patient's relative's idea of the best interests Risk to lose the sense of responsibility
	Surrogate decision maker	<ul style="list-style-type: none"> -Prediction errors of overtreatment -Predictions of patient preferences are poor -To fail to follow the patient's prior autonomous directives. -Conflict between the prior wishes of a patient and the views of the legal representative -Not a true extension of patient's autonomy
Caring sphere	Attitude	<ul style="list-style-type: none"> -No more master of their moral conscience -Indifference of physicians towards patients -Paternalism -Attitude ingrained -Ageism -Procrastination to invoke the AD

	Emotional involvement	<ul style="list-style-type: none"> -Physician fear of liability, -Reluctance -Resentment -Concerns about validity -Lack of confidence in AD -Discomfort -Disagreement -Difficulty accepting an unusual practice -Issues are too painful -Difficulty to speak about death
Society	Care access	<ul style="list-style-type: none"> -No care unit if an AD exists -Not a private agreement -Financial limits: Costs of illness
	Social limits	<ul style="list-style-type: none"> -Human psychology and social organization -Social expectation of suicide -Unaware about the existence of the directive -Believe that living wills are hard to execute
The Court	Limits of the enforceability	<ul style="list-style-type: none"> -Values of the judge: personal bias in favour of life -Church disagreement -Doubts -The court can override the directives -Judges perception of autonomy -Capacity : not a static concept -Finding incompetent -An irrational choice should be accepted -No sufficient information -Physician's judgement : legal consequences -Practical and ethical problem -Validity is conditional
	Emotional involvement	<ul style="list-style-type: none"> -Anxiety of judges -Emotional reluctance from the judges -Uncomfortable and socially unacceptable treatment choice
Principles of bioethics	Autonomy that provides conflict	<ul style="list-style-type: none"> -Against the views of medical profession -Autonomy against preserving life -Autonomy against sanctity of life -Autonomy and personal interest -Autonomy against deontological principles -Reluctance undermines autonomy -Controversial previous autonomy -Questionable weight of autonomy -Selfdetermining but not autonomous -Autonomy may be self-destructive
	Deontological duty	<ul style="list-style-type: none"> -No obstinacy -Moral conscience of health care providers

		<ul style="list-style-type: none"> -Contradictory principles -Hippocratic duty is distort
Elaboration of the document	Time limits	<ul style="list-style-type: none"> - Disappearance of the document - Procrastination to elaborate AD - Uncertainty about undated information
	Writing, drafting limits	<ul style="list-style-type: none"> - Vague content -Imprecision of preferences -Lack of specificity regarding the future -Required details are not specified -Incompatible wishes -Completeness problems -Unclear term : medical futility
	Validity	<ul style="list-style-type: none"> -Undue influence - Assessment of competencies -Dementia and change of interests -Incompetent person with decision-making capacity -Competence to perceive the violation of the autonomous directive -Need to test competences -Restriction to certain situations -Document accessibility issues
Temporality	Treatment change	<ul style="list-style-type: none"> -New advance in medical care -Unanticipated newly developed treatment
	Change of mind	<ul style="list-style-type: none"> -Change of mind not communicated - The self-changes - Labile preferences, - Change of interests, - Present interests' problem, -Facing impending incapacity. -The onus about the « continuing validity » -Personal identity problem -Change of personal identity: becoming incompetent -Continuity not obvious
	Anticipating difficulty	<ul style="list-style-type: none"> -Unpredictable future -Mistake about the future -Be unaware about the future
	Change of situations	<ul style="list-style-type: none"> -No fully adaptability -Uncertainty about change of circumstances -Material change of circumstances
	Connexion between present and past	<ul style="list-style-type: none"> -Between competent and incompetent -Becoming incompetent: lack of psychological relationship -Conflict between autonomy and welfare (well-being) as incompetent -To underestimate the quality of life of incompetent
Communication	Patients/doctor relationship	<ul style="list-style-type: none"> -A procedural contract -Patients could lose confidence -HCP discharge themselves of their

		duty -Risk to lose sense of responsibility -Discharge themselves of their duty -Consultation's time constraint -Autonomy diminishing communication -No interest in defining a good quality of life or what constitutes a burden. -Need of education, -Difficulty being educational rather than formalistic -Conversation short vague and tendentious
	Information	-Risk of persuasion, -Non-exhaustive information, -Healthcare providers lie -Uncertainty about sufficient informed consent -Non-certified communication skills -Too much information -Not informed decision -No exigence -Poor quality of information -Lack of information -Incorrect information -Uncertain information -Superficial reflection
Interpretation	Understanding limits	-Fear of misinterpretation -Legal consequences of misinterpreting -Misunderstanding -Interpretation as a practical and ethical problem -Interpretation subjective, -Different interpretations -Directives are not self-executing -Extrapolated directive

Figure 3. Mind map



IV - Discussion:

Thematic analysis allowed the identification of problems relating to the binding nature of ADs in the general population. The diversity of studies has enabled a qualitative analysis that meets the quality criteria of qualitative research.

ADs bring autonomy to the heart of the caregiver - patient relationship. Multiple questions, such as the quality of the information and the continuity of identity over time, can show the weak points of the binding nature of the law.

The results of the thematic analysis identified several problems lead by the binding law of the advance directives. Each selective code is discussed and compared to current literature.

The general population includes people as individuals and their personal sphere: entourage, society and health- and legal-professionals. All are in daily interactions as shown in the mind map.

A. The problems lead by the binding law of advance directives, in the main population

1. Individual Sphere

a) Emotional involvement

Despite the enforceability of the law, some people had "fear of abuse by physician"(2,13), fears that ADs "leads to worsening of care in end-of-life situations"(13).

Some people wanted to avoid "negative thinking"(2). Death was an unpleasant subject"(13,14). People "hesitated to broach the topic"(15). They needed to be aware of being exposed to the death to feel affected (2). Requests could be "based on panic" in acute situations(14).

Some seniors were skeptical of the interest of ADs due to the high cost of the health care, and the ageist attitude(16).

This is in agreement with the thesis of Dr Zambonino(1) which shows that the drafting of ADs leads to mental suffering and a fear of the loss of decision-making capacity.(17)

The best time to start an ADs discussion is "when patients are physically and emotionally stable".(18)

b)Influence

ADs could be influenced by age, socio-economic status, surroundings, culture, illness experience, depression, hospitalization and the gravity of the decision (2,8,13,19–23).

All of the information could have an influence, an inherent limit (21,24).

“Strategies to promote advance care planning seem to overlook engagement with religious communities”(25).

2. Entourage

a)Family interaction

Relatives of the patient could disagree with AD regarding the concept of best interest (8,21,26,27).

ADs could “weaken the family's sense of responsibility”(19). “Giving no burden to their family” is a motivation for developing ADs(28).

“Family influences are pointed out as reasons for the negative attitudes of physicians towards the patient's choices”(29).

b)Surrogate decision maker

Surrogates who were family members tended to make prediction errors of overtreatment(13,27,30). “The proxy directives remained practically useful but did not represent a true extension of patient autonomy”(16). Facilitating “communication between the patient-family-clinician triad to ensure that surrogate decision makers know which treatment is consistent with patients' preferences can reduce the emotional burden on surrogate decision makers”(31).

3.Caring Sphere

a)Attitude

Patients autonomy was not compatible with paternalistic medicine,(32,33) and could be contrary to “good medical practice”(21,24,27,34,35). HCP could procrastinate to invoke

the ADs,(15) others had an ageist attitude and “the promotion of AD could be seen as a cynical move”(16).

“Although most physicians demonstrate positive attitudes towards AD, the attending team does not always follow the plan of care established in the AD”(29,36).

b)Emotional involvement

HCP could feel “uncomfortable”,(24,27) be “reluctant”(24,30,34) to speak about death. It could be painful for their patient,”(14) and was contrary to the physician's beneficence-based role”(27).

They could be afraid of liability (34). Others disagreed with the ADs (14) : accepting “unusual” practice could be difficult (14).

There is a social taboo around death, with discomfort in the medical world(1,37). This subject is an “emotionally heavy burden” on physicians(38), regarding euthanasia too.

4.Society

a)Care access

Healthcare cost caused problems (16,33), especially in countries that operated with private insurance. Some intensive care unit did not admit patients with “do not resuscitate orders” (14). It influences the completion of the AD (29).

b)Social limits

There feared about a social expectation of suicide (13). A part of the population was unaware about the existence of the ADs (13). Others thought ADs hard to execute (15).

“AD completion rate remains low in many countries” (39), because of a lack of information (7).

5.The Court

a)Limits of the enforceability

There was a gap regarding liability (2).

Indications of using the AD were determined by the HCP, but the surrogate or a family member could question them (40).

The validity could be conditional : lack of information or lack of capacity for example (35,41,42). This was contrary to the principle that treatment could “be refused for irrational reasons, or even no reason at all” (42).

If there was any doubt, the decision should be in favour of preserving life. The Catholic Church view could influence (30); as the judge’s personal opinion(42,43). “An objective assessment of the facts” was complicated (43).

“Justices' action leaves intact an appeals court decision that preserves physicians' ability to use their medical judgment in end-of-life cases”(44).

b)Emotional involvement

Judges could feel a “moral or emotional reluctance to reach a decision that will result in the death of a vulnerable individual”(43), or feel uncomfortable regarding a “socially unacceptable treatment choice”(43).

6.Principles of bioethics

a)Autonomy that provides conflict

There were two main arguments supporting the "right to die": the utilitarian argument of the quality of life and the liberal one of autonomy(33). The concept of prior autonomy could be controversial (23) regarding the concept of “sanctity of life”(24,33,35,43). People challenged the possibility that there might be a “best interest” in conflict with “the patient’s will”(13,22,32,35,40).

Autonomy presupposed “a narrow view of the self as independent and rationally controlling”(15). It had less “value in countries that are community oriented” (8), but elsewhere could “be placed above the doctor’s duty to save life”(19,21,32,43).

ADs not always enhanced autonomy (42), because predicting the future was complex (22,26,27). Irrational or mistaken directives were applied”(8,42). They were respected, even if they caused suffering or death(23,42).

There is “a drift of conceptions of autonomy to meet all needs”(1,45). “The individualistic view of autonomy does not sufficiently capture the relational and social complexities of the decision-making process of advance care planning (=ACP)” (46). “Most physicians are interested in respecting autonomy”(29).

b)Deontological duty

The recognition of the right to die distorted “the traditional deontological Hippocratic duty.” “Avoiding therapeutic obstinacy” was “implicit in the very meaning of deontological duty” (33). There was “often significant tension between respect for the patient autonomy and the principles of nonmaleficence, beneficence, and justice”(14,21,32).

This tension seems “to demonstrate the lack of confidence between men.”(1,47)

7.Elaboration of the document

a)Time limits

Time interfered on several points. Undated directives raised concerns about their current validity (24,42). A person could procrastinate to elaborate the ADs(15,42), or forgot that “old and informal directives” existed (2,42). The document could disappear(15).

Procrastination is “frequently highlighted as a reason of low AD completion rate”(48,49) .

b)Writing, drafting limits

The ADs posed “serious practical and ethical problems related to completeness”(2,33). Wishes could be incompatible with each other (15,21,33), or be ambiguous (8,13,19,21,24,27,35,41,43). Required details were not specified for a directive to be valid (35). Achieve specificity and comprehensiveness was “at the expense of simplicity and clarity” (32). “The concept of medical futility” was often invoked but was “difficult to define”(20).

Writing limits reinforced misunderstanding, and courts disapproval (15). “This highlights the need for a conversation between the patient and their HCP in order to gain a better understanding of the patient’s expressed preferences in an AD, and to suggest and share thoughts on medical treatments that align to the patient’s values” (50).

c)Validity

The ADs could be under undue influence (16,19,24,41–43), but it was difficult to have certainties, and not all influence would be “regarded as undue”(21).

Applicability could be restricted to certain situations, as “terminal stages of incurable disease” in several countries (40).

An incompetent person could have “decision-making capacity”(20), as people under drugs or with dementia. It was proposed that a valid AD could “be ignored in favor of the present interests of the patient” regarding the demented patients(35).

There was a “need for a functional test of competence” (41), since “capacity” was used as an argument against the ADs (24,42).

“Treatment decision-making capacity is undermined when there is a serious divergence between the person's “will” and a currently expressed treatment “preference”; while a person's “best interests” are served by acting so as to give effect to the person's “will””(51).

8.Temporality

a)Treatment change

“New treatments could have been discovered” (15,19,23,32) and questioned the validity of the directive (26,35,42). “Some situations deemed incurable” could be modified (33), and if the patient “had known would have made another decision”(13,52).

b)Change of mind

The later experiences and desires of the incompetent individual were not accurate reflections of the “core interests” of “the previous decision” (21,23). The present interests could change confronted by illness and death (13–15,19,21,23,42,45), and conflict with the ADs(35). Most severely ill patients felt “fleeting desires to die”(14).

Some people had “trouble recognizing that their views have changed”(15), or had “fluctuating preferences”(15,19,26,35). A change could “not be communicated to the relevant HCP and thus” could “be ignored” (42).

Some articles evoked this “practical and ethical problems related to continuity” (2,22,33,43).

“The temporal dissonance characterizing ADs has to be borne in mind when interpreting and implementing the patient’s wishes in clinical practice” (52).

c)Anticipating difficulty

The future was “too epistemically opaque for a future-binding decision to be a rational one to make”(13,23,33). Projecting in a context without a future was difficult (13,15,22,32,33,35,41,42). This was “prone to misjudgment”.(26)

The anticipation of the end-of-life remains helpful.(53)

d)Change of situations

A rigid directive could “not be fully adaptable to patient’s individual needs”(14). Circumstances could change and no longer match (21,24,42). This change was used as an argument against the applicability of the ADs (35).

”Each situation has to be assessed in the present moment”.(52)

e)Connection between present and past

The possibility of a conflict between the exercise by a competent person of a future-oriented autonomy and his well-being as an incompetent individual was not always addressed (22). There was “an insufficient connection between the competent and incompetent adult”(21,42). People tended to underestimate the quality of life of disabled or incompetent people (42).

“The ADs debate raises questions on a range of issues, such as the authority of ADs in light of possible discontinuities in a person’s identity beyond dementia onset, differences in the scope or limits of autonomy before and after the onset of dementia”.(54)

9.Communication

a)Patients/doctor relationship

There was a “time constraints” during consultations (16,27), which was rarely dedicated to the ADs. It was difficult to be educational for the HCP rather than formalist (34). The conversations were “ordinarily short, vague, and tendentious”(15,16).

The doctor/patient relationship could be distorted by the autonomy and “become a cold procedural contract” (13,20,33). HCP risked to “lose their sense of responsibility” (19). “Thus, patients could lose confidence in their physician’s professional competence” (19,41).

The basis of the patients/doctor “relationship is the informed consent that allows the patient’s autonomy to be satisfied on the one hand, and the professional competence and responsibility of the doctor on the other” (55).

b)Information

There was a need of education of the public and the professionals (16,27,42).

It was difficult to have an exhaustive information (16,41). “The patients could be overwhelmed with too much information and too little communication”(15,19). A degree of persuasion could be present subconsciously (41).

Assessing the quality of information was difficult. It was used as an argument against the ADs (24), even if there was no exigence of information to elaborate them (16,21,24,27,30,40–43). A superficial reflection was problematic (15) because the weight of autonomy remained the same.

“There is from patients the hope for frequent appointments and good collaboration with the HCP, which included receiving clear and honest information” (50).

10.Interpretation

Interpretation of the ADS posed problems(2), because they were not “self-executing” (15). It was not always objective (2,8). A HCP could “arrogate the right to interpret non-expressed wills”(33), or “knowingly or not, introduce personal interests or normative values into their assessment”(15,41). Misinterpreting a situation could lead the HCP to “paying the legal consequences if another reading of the AD was deemed more appropriate”(8). The “great scope for interpretation” “allowed treating physicians or judges to justify whatever outcome they thought best”(42).

There is few instances in which clinicians and patients are congruent in their understanding and conceptualization of advance care planning (56).

B.Implications for practice

This study shows the limits of the ADs and possible problems related to it. It allows to know how to improve practice for the HCP, what questions and concerns to prepare for, and better anticipate the future practice. Dedicated consultations would improve people's education and experience in relation to guidelines. This could be added to the French Shared Medical Record to allow better access. It would be advisable to improve education on ADs for young HCP and to strengthen continuing education on this subject.

This systematic review of the literature is a starting point for future research, in focus group for example. The aim is to improve the low rate of writing of ADs and make them known to the public.

C.Strengths and limitations

This study has several limitations.

1.Sampling limits:

Using a search query limits the sampling. To minimize it, the search query was discussed in group consensus, to be defined sufficiently large. There is a time limit too, but data were compared to the current literature.

2.Selection limits:

During the exclusion all abstracts of the documents were not fundable. To minimize this problem the PRISMA criteria were followed and the snowballing process were applied. The selection of articles on the language used is a limit. The exclusion and inclusion were made by two different persons and then discussed for consensus.

3.Information limits:

Two articles were not found in the literature review. The thematic analysis allowed saturation of the super codes and selective codes. The mind map and the results were presented and discussed in consensus group in order to ensure that there were no troubles related to non-extracted information.

4.Confusion limits:

Subjective interpretation is inevitable in a systematic review, especially during the thematic analysis. It was performed in double blind to minimize this limit.

D.Conclusion

This systematic literature review allowed to identified several problems related to the law, now binding, of the ADs.

10 themes were dominating: the individual sphere, the entourage, the caring sphere, the society, the Court, the principles of bioethics, the elaboration of the document, the temporality, the communication, and the interpretation.

These problems may explain the low rate of ADs completion and the questioning of the general population about ADs. Exploring these problems is a start to improving the practice related to the end of life, and accompanying social evolution on its relationship with death.

Qualitative and quantitative studies are being developed in our consensus group on the various issues arising from ADS.

V - Funding :

No funding has been received for this paper.

VI - List of abbreviations:

AD : advance directive
ACP : advance care planning
HCP : healthcare providers
GP : general practitioner

VII - Bibliography

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VIII – Appendix

A. Annexe 1 : Table of the extraction of raw datas and their coding

<u>Super Codes = Themes</u>	<u>Selective Codes = Sub themes</u>	<u>Axial Codes = Focus codes</u>	<u>Open codes</u>	<u>References</u>	<u>Raw Data</u>
Malpas P. Advance directives and older people: Ethical challenges in the promotion of advance directives in New Zealand.					
Individual Sphere	Emotional involment	Suspicion and scepticism	Older individuals may come to view the the AD with some suspicion and scepticism	p2 c1 l59	When healthcare costs are often very high-it is not difficult to see that older individuals may come to view the active promotion of AD with some suspicion and scepticism.
Society	Care access	Financial limits : Costs of illness	The high cost of Healthcare let the people suspicious.	p2 c1 l59	When healthcare costs are often very high-it is not difficult to see that older individuals may come to view the active promotion of AD with some suspicion and scepticism.
Society	Care access	Financial limits : Costs of illness	There is a cost containment issue of the treatments	p2 c1 l62	They may well be viewed as a cost containment issue; more about justifying in the rationing of healthcare resources than truly reflecting individual's self-determined decision-making about medical treatment and care.
Society	Care access	Financial limits : Costs	There is a cost	p2 c2 l5	It is probably also self-

		of illness	containment issue of the treatments		evident to state that many older individuals will recognize the need for prudent financial management of these resources.
Caring sphere	Attitude	Ageism	Nursing students claim that the care of older people is "uninteresting"	p2 c2 l22	They reflect that many nursing students claim that the care of older people is "uninteresting" and "unchallenging".
Caring sphere	Attitude	Ageism	Advance directives shift the burden of medical decision making on to patients	p2 c2 l53	If the general attitude towards older people was that they were "bed blockers", that their treatment and care was of low status, that they were likely to be treated less vigorously than younger people, and that as they were unlikely to be cured they were viewed as failures, then the promotion of AD could be seen as a cynical move to shift the burden of medical decision making on to patients and away from healthcare professionals.
Individual Sphere	Influence	Ageism	Ageist attitudes influence patient's decision making	p2 c2 l61	When ageist attitudes are prevalent in the medical setting, it is not difficult to imagine older individuals being encouraged to articulate (clearly) that

					they do not want "this" or "that" medical treatment.
Communication	Patients/doctor relationship	Consultation's time constraint	Primary care have time constraints and skill at communicating is not certified.	p3 c1 l10	Although primary care would seem to be an obvious setting in which to initiate advance directive conversations, I believe a number of challenges lie in this environment, particularly in terms of time constraints and ensuring GPs are adequately skilled at communicating with older persons about life-sustaining medical treatment issues.
Communication	Information	Non-certified communication skills	Primary care have time constraints and skill at communicating is not certified.	p3 c1 l10	Although primary care would seem to be an obvious setting in which to initiate advance directive conversations, I believe a number of challenges lie in this environment, particularly in terms of time constraints and ensuring GPs are adequately skilled at communicating with older persons about life-sustaining medical treatment issues.
Communication	Information	Non-exhaustive information	it is difficult to inform about a lot of situation of decision-making	p3 c1 l45	For many patients with a number of comorbidities, the kind of decision-making

					they would need to consider in order to state their preferences for medical treatment accurately may be very difficult to determine.
Communication	Patients/doctor relationship	No interest in defining a good quality of life or what constitutes a burden.	The physician involved in discussing advance directives rarely asked patient to define a good quality of life, or what constitutes a burden.	p3 c1 l 56	The physician involved in discussing advance directives with their patients 'rarely asked patient to define a good quality of life, and none enquired about what constitutes a burden, even though not wanting to suffer or to be a burden was frequently stated as a reason for refusing life sustaining treatment'.
Communication	Information	Lack of information	A directive may be written without health practitioner information	p3 c2 l21	An advance directive can be written down or verbally stated by an individual without their having discussed their particular medical issues with a health practitioner.
Communication	Information	Poor quality of information	Directives may be based on bad information	p3 c2 l25	It is thus not unreasonable to assume that directives may be based on assumptions that are false, information that is incorrect, or on incomplete information about the risks and benefits of any future medical treatments or interventions.

Elaboration of the document	Validity	Undue influence	There is an uncertainty about the influence and the quality of the information	p3 c2 l48	How, for instance, could one be certain undue influence had not occurred, that the patient had been sufficiently informed and competent, and that they wanted the instructions to apply in the current circumstances?
Communication	Information	Uncertain information	There is an uncertainty about the influence and the quality of the information	p3 c2 l48	How, for instance, could one be certain undue influence had not occurred, that the patient had been sufficiently informed and competent, and that they wanted the instructions to apply in the current circumstances?
Entourage	surrogate decision maker	Not a true extension of patient's autonomy	proxy directives do not represent a true extension of patient autonomy.	p1 c2 l20	He claims that instructional directives "have virtually no value in decision making for the incompetent patient while proxy directives remain practically useful but do not represent a true extension of patient autonomy.
Buller T. Advance consent, critical interests and dementia research.					
Temporality	Change of mind	Change of interests	the later desires of the incompetent individual are not accurate reflections of these	p1 c2 l38	The legitimacy of this approach is based on the understanding that whereas the previous

			core interests		decision is reflective of the person's core or critical interests and hence part of their autonomy, the later experiences and desires of the incompetent individual are not accurate reflections of these core interests, and hence, should be accorded less weight.
Temporality	Change of mind	Change of interests	the loss of competence entails that the relevance and value of the core interests are diminished	p2 c1 l1	Critics of this notion have argued that the loss of competence entails that the relevance and value of the core interests are substantially diminished, and accordingly our obligation is to respect the interests of the later incompetent individual.
Temporality	Anticipating difficulty	Unpredictable future	The future is opaque	p2 c1 l14	The future is too epistemically opaque for a future-binding decision to be a rational one to make.
Temporality	Change of mind	Change of interests	Beliefs and values may change	p2 c1 l19	The person may now have a different set of beliefs and values, new treatments may have been discovered.
Temporality	Treatment change	New advance in medical care	new treatments may have been discovered	p2 c1 l19	The person may now have a different set of beliefs and values, new treatments may have been discovered.

Communication	Information	Uncertainty about sufficient informed consent	is the antecedent consent sufficiently informed	p2 c1 l21	We can raise similar epistemic worries with regard to advance directives for research, and ask whether the antecedent consent can ever be sufficiently informed.
Temporality	Treatment change	Unanticipated newly developed treatment	Future treatments will may be discovered	p2 c1 l34	The patient and the physician do not know what a future with dementia will be -like or whether future treatments will be discovered.
Temporality	Change of mind	Change of interests	interests may change	p2 c1 l57	A person has an interest in fulfilling an experiential interest only if at the time of undertaking the relevant action she still believes the experience to be desirable.
Principles of bioethics	Autonomy that provides conflict	Controversial previous autonomy	the concept of precedent autonomy has a controversial degree.	p4 c1 l65	To participate in research appears to be somewhat troubling, for it would seem to expand the concept of precedent autonomy to a controversial degree.
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	some people believes that the future life has no intrinsic value	p4 c2 l16	we might limit the scope of precedent autonomy by excluding future-binding decisions in which the person believes that the future life has no intrinsic value.
Individual sphere	Influence	Prevent financial hardship	An advance directive spare family from the	p5 c2 l35	This supposed difference between the

			financial hardship		treatment and research contexts is complicated, however, by consideration of the fact that altruism and beneficence can lay a part in a person's decision to forego life-sustaining treatment, for example, to spare family and loved ones from the financial and emotional hardship of having to care for the person.
Principles of bioethics	Autonomy that provides conflict	Questionable weight of autonomy	the previously competent person's wishes prevail	p6 c1 l41	It is morally appropriate to sacrifice life or to permit an incompetent person to suffer considerable pain rather than to over-ride the previously competent person's wishes.
Schiktanz S. Interpreting advance directives: Ethical considerations of the interplay between personal and cultural identity.					
Temporality	Change of mind	Continuity not obvious	Continuity is a practical and ethical problem of advance directives.	p2 l6	It is known, however, that advance directives (or so called "living wills") pose serious practical and ethical problems related to continuity, liability, completeness, interpretation and the relationship between rejected and demanded medical

					treatments, all of which have been intensively discussed.
The Court	Limits of the enforceability	Practical and ethical problem	Liability is a practical and ethical problem of advance directives.	p2 l6	It is known, however, that advance directives (or so called "living wills") pose serious practical and ethical problems related to continuity, liability, completeness, interpretation and the relationship between rejected and demanded medical treatments, all of which have been intensively discussed.
Elaboration of the document	Writing, drafting limits	Completeness problems	Completeness is a practical and ethical problem of advance directives.	p2 l6	It is known, however, that advance directives (or so called "living wills") pose serious practical and ethical problems related to continuity, liability, completeness, interpretation and the relationship between rejected and demanded medical treatments, all of which have been intensively discussed.
Interpretation	Understanding limits	Interpretation as a practical and ethical problem	Interpretation is a practical and ethical problem of advance	p2 l6	It is known, however, that advance directives (or so called "living

			directives.		wills") pose serious practical and ethical problems related to continuity, liability, completeness, interpretation and the relationship between rejected and demanded medical treatments, all of which have been intensively discussed.
Communication	Information	Lack of information	There is a lack of information about the possibility to create advance directives.	p2 l21	A lack of information regarding the opportunity to create advance directives, fear of abuse by physicians but also a moral confusion and avoidance of "negative thinking".
Individual sphere	Emotional involvement	Fear of abuse	There is a fear of abuse by physician	p2 l21	A lack of information regarding the opportunity to create advance directives, fear of abuse by physicians but also a moral confusion and avoidance of "negative thinking".
Individual sphere	Influence	Personal experience	Concrete decisions depends on specific experience	p3 l9	Here, "being affected" means to gain specific experience and to be confronted with concrete decisions. But the status of being affected itself depends on epistemic and normative premises which can differ strongly.

Individual sphere	Emotional involvement	Feeling "affected"	People who are aware of being exposed to higher risks of life-threatening injuries, may regard themselves as "being affected" by end of life decisions .	p3 l13	For example, young healthy persons enjoying a risky life style (e.g., by hand gliding, or motor bicycling) may regard themselves as "being affected" by end of life decisions because they are aware of being exposed to higher risks of life-threatening injuries.
Individual values	Experience	Personal experience	People who are aware of being exposed to higher risks of life-threatening injuries, may regard themselves as "being affected" by end of life decisions .	p3 l13	For example, young healthy persons enjoying a risky life style (e.g., by hand gliding, or motor bicycling) may regard themselves as "being affected" by end of life decisions because they are aware of being exposed to higher risks of life-threatening injuries.
Individual sphere	Emotional involvement	Death as an unpleasant subject	Thinking of death and illness may have negative impacts on the psyche	p5 l4	If I am convinced that dealing with illness and death in a near or remote future would have negative long-time impacts on my psyche, then good reasons are at hand not to formulate an AD.
Interpretation	Understanding limits	Directives are not self-executing	Proxies, doctors, and lawyers often must interpret these documents	p5 l11	Proxies, doctors, and lawyers often must interpret these documents, which means construing and assessing these

					wishes and preferences under new circumstances.
Temporality	Change of mind	Change of personal identity	Applicability is problematic when there is a cognitive disorder.	p8 l4	A moral problem exists in applying a person's AD if this person is unable to remember having drawn this document.
Temporality	Change of mind	Change of personal identity	the personal and cultural dimensions of identity are situationally decoupled.	p10 l 15	In the case of end of life situations where a patient is not competent or conscious anymore, the personal and cultural dimensions of identity are situationally decoupled.
Interpretation	Understanding limits	Directives are not self-executing	Third persons will interpret the document and act on behalf of their interpretation.	p10 l23	In the context of AD, we have to be aware that there are always two different, but not totally independent processes of interpretation : on the one side there is the complex process for the author of an AD of finding a personal stance towards one's own decisions in the end of life questions and the other side where there are third persons who will interpret the document and act on behalf of their interpretation.
Interpretation	Understanding limits	Interpretation subjective	This process is a "dialectic" process of	p10 l29	This process should be understood as a

			interpretation and action.		"dialectic" process of interpretation and action and not as an objective, deterministic way of "applying" such a document.
Temporality	Change of mind	Change of personal identity	A qualitative identity also presupposes certain stabilities and continuities.	p10 l33	This idea of a qualitative identity also presupposes certain stabilities and continuities of our interests, moral attitudes and interpretations.
Individual sphere	Influence	Surrounding	The patient's surrounding must be taken into account	p11 l22	One can thus conclude that the promotion of AD without reflection on the broader meaning for the individual and their surroundings provokes new problems.
Palazzani L. Advance directives and Living Wills.					
Elaboration of the document	Writing, drafting limits	Imprecision of preferences	The Living Wills is an extremely precise advance directive	p1 c1 l22	The Living Wills is not the same as Advance directives, but is an extremely precise advance directive (it therefore has a more - limited semantic context) : it is a matter of expression of the last wishes.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	Does a right "to die" exist	p2 c1 l15	To what extent, in what measure, within what limits can the individual decide on his own death? (...) To what

					point and in what measure can one interfere with process of end of life? Does a right "to die" exist, or is it a right to decide about one's own life and death (...)? Are the specific conditions identifiable (...) which may justify its putting into effect? (...) Is the demand for the legalization of the living will legitimate?
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	quality of life justifies advance directives	p2 c1 l29	There are two main arguments supporting the "right to die", according to the points set down in the Living Will: the utilitarian argument of the quality of life and the liberal one of autonomy.
Society	Care access	Financial limits : Costs of illness	the costs benefits calculation changes the consideration of the quality of life	p2 c2 l3	It is also considered lawful (if not dutiful) to suppress lives (with or without consent) that are considered not worth living as they do not enjoy sufficient quality of life in relation to the cost's benefits calculation.
Society	Care access	Costs of illness	Lives may be considered as without sufficient quality of life	p2 c2 l3	It is also considered lawful (if not dutiful) to suppress lives (with or without consent) that are considered not worth living as they do not enjoy sufficient

					quality of life in relation to the cost's benefits calculation.
Elaboration of the document	Writing, drafting limits	Incompatible wishes	the wills may expressed contrasting and incompatible wishes	p4 c2 l5	Diverging and opposed (or, if the wills expressed contrasting and incompatible wishes), the right would not be able to manage the conflict neutrally, but would end up letting the strongest will prevail (the subject's) over the weakest (who would be reduced to object).
Caring sphere	Attitude	Moral conscience	the subject is master of the doctor's conscience	p5 c1 l6	Either the subject is master of the doctor's conscience or the doctor is master of the subject's life.
Society	Care access	Not a private agreement	The living will is not a private agreement.	p5 c1 l44	The Living Will could not be a private agreement, but would have inevitable implications on the entire health care system (on the consideration of the medical profession's role).
Principles of bioethics	Deontological duty	Hippocratic duty is distort	the right to die distort the traditional deontological Hippocratic duty	p5 c1 l48	The recognition of the right to die would radically distort the traditional deontological Hippocratic duty, (...) it would distort the doctor/patient relationship which, instead of being a

					therapeutic alliance and the entrusting of the vulnerable patient to the doctor would become a cold procedural contract.
Communication	Patients/doctor relationship	A procedural contract	the doctor/patient relationship become a cold and procedural contract	p5 c1 l48	The recognition of the right to die would radically distort the traditional deontological Hippocratic duty, (...) it would distort the doctor/patient relationship which, instead of being a therapeutic alliance and the entrusting of the vulnerable patient to the doctor would become a cold procedural contract.
Interpretation	Understanding limits	Extrapolated directive	the wills are interpreted	p5 c2 l12	The doctor would not only be the executor of a will, but would also arrogate the right to interpret non-expressed wills.
Temporality	Anticipating difficulty	Unpredictable future	is the consent about the future really informed	p5 c2 l26	How can we be certain that the will can express a really informed consent about a future situation that it does not know (even though all the details have been supplied descriptively)?
Individual sphere	Influence	Choice under pressures	pressures surrounding the person may exist	p5 c2 l29	How can we not at least doubt that implicit or explicit pressures

					surrounding the person in some way condition the will?
Temporality	Change of mind	The self changes	Choices may change in time	p5 c2 l32	How can the doctor and the tutor be certain that the autonomous will may not change in time, as the conditions of life change considerably?
Temporality	Anticipating difficulty	Competence and projection into the future	it's may be hard to project his will into a completely different context	p5 c2 l39	How can an autonomous individual in existential conditions of efficiency, an individual who has still an open and indefinite future in front of him, project his will into a completely different context, which furthermore ha has never previously experienced, a context where there is no future?
Temporality	Change of mind	The self changes	the will can change	p6 c1 l9	In short, the will can change with respect to the initial decision, or can also alternate in different states of mind and in contrasting requests, when confronted by illness and death.
Temporality	Treatment change	New advance in medical care	some situations deemed incurable can be modified because of the progress in biomedical knowledge	p6 c1 l15	Given the continuous evolution of the progress in biomedical knowledge, some situations deemed incurable can be modified (...) but could

					also reach the situation in which there is no more congruity between what is written and what is reality?
Temporality	Change of mind	Personal identity problem	the same identity of the individual when there is a loss of consciousness?	p8 c1 l17	There is also the problem, in the specific case of the Living Will, of recognizing the same identity of the individual who is the signatory of the card, in the measure in which he finds himself living an existential condition of intermittent loss of consciousness (would it be the same person?)
Principles of bioethics	Deontological duty	No obstinacy	avoiding therapeutic obstinacy is implicit in the very meaning of deontological duty.	p9 c1 l7	If the objective of the Living Will is that of avoiding therapeutic obstinacy, it proves to be of no use at all :is should not be indispensable to declare one's will with regard to this writing, as it is implicit in the very meaning of deontological duty.
Wiesing U., Jox R.J., Heßler H. J.; Borasio G. D. A new law on advance directives in Germany.					
Elaboration of the document	Validity	Restriction to certain situations	Question concerning the scope of advance directives	p1 c2 l18	Was the validity of AD restricted to situations in which patients were in the terminal stages of incurable disease?

Interpretation	Understanding limits	Legal consequences of misinterpreting	There is legal consequences when there is misinterpreting.	p2 c2 l8	Those not abiding by the procedure will risk misinterpreting the situation and then paying the legal consequences if in hindsight another reading of the AD is deemed more appropriate.
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	Autonomy prevails over the beneficence	p3 c1 l42	German law is much more oriented towards the principle of autonomy (patient's will) than beneficence (patient's best interest). However, some scholars even dispute the possibility that there might be a "best interest" in conflict with the patient's will.
The Court	Limits of the enforceability	Physician's judgement : legal consequences	The physician judge the indications of the directives.	p3 c2 l30	Indications are most often not mathematically determined; they are a matter of judgment by the physician, but what happens if the surrogate or a family member questions the indication? (...) It is recommendable that physician themselves present this possibility as a means of strengthening the trust relationship between the involved parties.

Communication	Information	Lack of information	No counseling is required	p3 c2 l38	The law does not require counselling before writing an advance directive.
Pascalev, Assya; Vidalis, Takis Vague Oviedo ': Autonomy, culture and the case of previously competent patients.					
Interpretation	Understanding limits	Misunderstanding	Interpretation is restricted to the explicit guidance	p3 c1 l10	Although this interpretation is in principle restricted to the explicit guidance of the advance directive, the role of the proxy may become more decisive if the content of the advance directive is vague or dubious.
Elaboration of the document	Writing, drafting limits	Vague content	if the content of the advance directive is opaque, there is interpretation	p3 c1 l30	This would happen only when the wording of an advance directive is opaque permitting different interpretations.
Interpretation	Understanding limits	Interpretation subjective	if the content of the advance directive is opaque, there is interpretation	p3 c1 l30	This would happen only when the wording of an advance directive is opaque permitting different interpretations.
Principles of bioethics	Autonomy that provides conflict	Autonomy may be self-destructive	choices may be idiosyncratic or mistaken	p6 c2 l17	To act on one's choices even when they are idiosyncratic or mistaken.
Principles of bioethics	Autonomy that provides conflict	Questionable weight of autonomy	autonomy places too much weight on the self as independent and rationally controlling.	P7 c1 l51	One apparent limitation to the autonomy-based approach is that it places too much weight on the individual's right to

					self-determination and presupposes a narrow view 'of the self as independent and rationally controlling.
Principles of bioethics	Autonomy that provides conflict	Autonomy may be self-destructive	respect for whatever choice the patient makes, including choices that are idiosyncratic, mistaken or self-destructive	p7 c2 l2	This model ignores other relevant considerations such as the best interest of the patient (respecting autonomy implies respect for whatever choice the patient makes, including choices that are idiosyncratic, mistaken or self-destructive) or the common good.
Individual sphere	Emotional involvement	Emotions and the social embeddedness	emotions and the social embeddedness of the individual are undervalued.	p7 c2 l6	It undervalues emotions and the social embeddedness of the individual.
Principles of bioethics	Autonomy that provides conflict	Questionable weight of autonomy	people may value interpersonal connections more than personal autonomy.	p7 c2 l8	The autonomy-based model may work well for countries with liberal individualistic orientation like the USA but it will be of little value in countries that are community oriented, with a strong tradition of collective decision-making and where people value interpersonal connections more than personal autonomy.
Individual sphere	Influence	Culture	culture influences a person's autonomous choices.	p7 c2 l49	Every person is embedded in a culture, which in turn influences a person's

					autonomous choices.
Interpretation	Understanding limits	Different interpretations	there is a risk of interpretation	p8 c1 l16	Advance directives, as any written text, will remain subject to different interpretations.
Entourage	surrogate decision maker	Conflict between the prior wishes of a patient and the views of the legal representative	Conflict arises between the wishes of a patient and the views of the legal representative	p2 c1 l23	It seems, however, that the Oviedo Convention does not provide enough substance for deriving legally and morally sound solutions in such cases, especially when a conflict arises between the prior wishes of a patient unable to consent and the views of the legal representative(s), and especially when the patient lacks an advance directive and his prior wishes have been stated only informally.
Seifert A. Legitimate advance directive in Germany.					
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	A balance has to be established between autonomy and the behavior turning to the welfare	p2 c1 l1	A balance has to be established between autonomous decisions of the patient and the behavior of physicians turning to the welfare of the patient.
Temporality	Treatment change	New advance in medical care	An AD should not be valid in case of newer medical developments	p3 c2 l15	An AD should not be valid in case of newer medical developments, for example,

					therapeutic alternatives, which the patient did not know about when writing the AD, and if he had known would have made another decision.
Individual sphere	Emotional involvement	Fear of abuse	fear of abuse limits their employment	p5 c1 l46	Despite the majority's belief that advance directives may influence treatment at the end of life, other facts limit their employment, such as fear of abuse.
Individual sphere	Emotional involvement	Death as an unpleasant subject	death is an unpleasant subject	p5 c2 l2	It is not pleasant for people to be confronted with death and dying.
Temporality	Anticipating difficulty	Unpredictable future	The imagination of the future situations is vague	p5 c2 l3	The imagination of the future situations is vague; there is a lack of information and consultation.
Individual sphere	Emotional involvement	Feeling of risk	Prospective orders are very risky	p5 c2 l5	Prospective orders are very risky and insecure.
Society	Social limits	Unaware about the existence of the directive	physicians were not aware about the existence of the patient's directives.	p5 c2 l19	Between 65 and 76% of physicians whose patients had an advance directive were not aware that it existed.
Elaboration of the document	Writing, drafting limits	Vague content	Language in advance directives was too nonspecific to provide clear instruction	p5 c2 l32	Language in advance directives was usually too nonspecific and general to provide clear instruction
Individual sphere	Influence	Personal experience	a patient's preference for decision-making	p5 c2 l49	Previous research has found that a patient's

			varies with age		preference for involvement in decision-making varies with age, socio-economic status, illness experience, and the gravity of the decision.
Individual sphere	Influence	Prevent financial hardship	a patient's preference for decision-making varies with socio-economic status	p5 c2 l49	Previous research has found that a patient's preference for involvement in decision-making varies with age, socio-economic status, illness experience, and the gravity of the decision.
Individual sphere	Influence	Personal experience	a patient's preference for decision-making varies with illness experience	p5 c2 l49	Previous research has found that a patient's preference for involvement in decision-making varies with age, socio-economic status, illness experience, and the gravity of the decision.
Individual sphere	Influence	Personal experience	a patient's preference for decision-making varies with the gravity of the decision.	p5 c2 l49	Previous research has found that a patient's preference for involvement in decision-making varies with age, socio-economic status, illness experience, and the gravity of the decision.
Temporality	Anticipating difficulty	Unpredictable future	people are not able to foresee situations.	p6 c1 l14	Critic argue that people are not able to foresee situations with

					precision and to anticipate preferences of treatment.
Temporality	Change of mind	Change of interests	the interests of people are changing	p6 c1 l16	They point out that the interests of people are changing.
Individual sphere	Emotional involvement	Fear of worsening of care	There are fears of worsening of care in end-of-life situations.	p6 c1 l19	There are fears that the discussion of ad leads to worsening of care in end-of-life situations.
Individual sphere	Influence	Economic impact	decisions that have an economic impact might lead to undertreatment.	p6 c1 l23	The discussion of limited resources in the public health system will lead to decisions that have an economic impact. Professionals are afraid that this may have far-reaching impact, such as undertreatment.
Caring sphere	Attitude	Indifference of physicians towards patients	the autonomy of the patient might lead to indifference of physicians towards patients	p6 c1 l34	There are apprehensions that the focus on the autonomy of the patient leads to indifference of physicians towards patients or, at worst, to inadequate treatment.
Society	Social limits	Social expectation of suicide	There are fears that a patient's autonomy can turn to social expectation of suicide	p6 c1 l39	There are fears that a patient's autonomy can turn to social expectation of suicide of ill, handicapped or old people.
Entourage	surrogate decision maker	Prediction errors of overtreatment	Surrogates tended to make prediction errors of overtreatment	p5 c2 l41	Surrogates who were family members tended to make prediction errors of overtreatment even if they had reviewed or

					discussed the advance directive with the patient or assisted in its development.
Horn R.J. Legitimate advance directive in Germany					
Elaboration of the document	Validity	Undue influence	the statement must be informed and free from undue influence.	p3 l5	Further cases confirmed that a patient has the right to refuse treatment as far as, at the time the statement is made, the patient is informed, that they are not under undue influence and that the statement concerns a specific situation or treatment.
Principles of bioethics	Autonomy that provides conflict	Autonomy against the views of medical profession	autonomy can be placed above the doctor's duty to save life.	p3 l13	In English law a person's right to make their own decisions can be placed above the doctor's duty to save life.
Temporality	Change of mind	The self changes	doubts may exist that the patient changed in faith	p3 l27	The advance directive would have been binding if there would have been no doubt that the patient changed in faith and if she would have mentioned the AD in the course of a hospital appointment and knowing of her illness.
Temporality	Connexion between present and past	Between competent and incompetent	we will never be able to know what decision a currently incompetent person would make in	p4 l33	One of the problems is that we will never be able to know what decision a currently

			a concrete situation		incompetent person would make in a concrete situation if she happened to be competent, and whether she would stick to the wishes she expressed in previous situations.
Principles of bioethics	Autonomy that provides conflict	Autonomy against preserving life	the two imperatives are the respect for autonomy and welfare/protection of life.	p5 l5	Cases point to the difficulty in determining the right balance between the two imperatives of respect for autonomy and welfare/protection of life.
Temporality	Change of mind	The self changes	A patient may change their mind over the years	p6 l24	A patient may change their mind over the years and medical techniques and treatment opportunities may develop and thus invalidate an anticipated wish.
Temporality	Treatment change	Unanticipated newly developed treatment	medical techniques and treatment opportunities may develop	p6 l24	A patient may change their mind over the years and medical techniques and treatment opportunities may develop and thus invalidate an anticipated wish.
Communication	Patients/doctor relationship	Risk to lose the sense of responsibility	the authority of Ads : risk that physicians lose their sense of responsibility	p7 l16	The key themes here seem to be : the problem of the authenticity of autonomy; the authority of Ads; the risk that physicians lose their sense of

					responsibility to take care of the patient; and, thus the risk of abandoning the patient.
Interpretation	Understanding limits	Fear of misinterpretations	The people fear misinterpretations	p7 l27	The people fear misinterpretations of their Ads not being taken into consideration.
Individual sphere	Influence	Personal experience	preferences change between healthy people and ill people	p7 l28	Other studies evidence that individuals may express different treatment preferences when they are healthy than when they are ill.
Temporality	Change of mind	The self changes	mind may change	p8 l2	This objection concerns the risk of misinterpretations or changes of mind between the time the person has written the directive and the time of its application.
Communication	Patients/doctor relationship	Reduced to be executor	Physicians will be reduced to executors of patient's wishes	p8 l26	Physicians will be reduced to executors of patient's wishes, without their own power of judgement, if they were to be obliged to respect Ads.
Communication	Patients/doctor relationship	Discharge themselves of their duty	physicians could abandon their patients and discharge themselves of their duty to care for them.	p8 l28	Thus, patients could lose confidence in their physician's professional competence and physicians could abandon their patients and discharge themselves of their duty to care for them.

Communication	Patients/doctor relationship	Patients could lose confidence	patients could lose confidence in their physician's professional competence	p8 l28	Thus, patients could lose confidence in their physician's professional competence and physicians could abandon their patients and discharge themselves of their duty to care for them.
Entourage	Family interaction	Risk to lose the sense of responsibility	it may weaken both the family's and physician's sense of responsibility	p8 l32	ADs may weaken both the family's and physician's sense of responsibility for the patient's physical welfare and solidarity with the vulnerable person.
Communication	Patients/doctor relationship	Risk to lose the sense of responsibility	it may weaken both the family's and physician's sense of responsibility	p8 l32	ADs may weaken both the family's and physician's sense of responsibility for the patient's physical welfare and solidarity with the vulnerable person.
Principles of bioethics	Autonomy that provides conflict	Autonomy against deontological principles	the duty to respect patient autonomy seems to be overridden by the principle of beneficence	p8 l34	Following this conception of responsibility, the duty to respect patient autonomy seems to be overridden by the principle of beneficence.
Communication	Information	Too much information	The patients could be overwhelmed with too much information	p9 l8	The patients could be overwhelmed with too much information and too little communication.
Elaboration of the document	Writing, drafting limits	Vague content	there is ambiguity in the wording of the	p9 l13	A doctor in England has to consider

			directive		carefully whether a patient may have changed his or her mind, there have been advances in treatment since the directive was written or there is ambiguity in the wording of the directive.
Erin C.A. Living wills: Anticipatory decisions and advance directives.					
Principles of bioethics	Deontological duty	Contradictory principles	There is tension between autonomy and the other principle	p2 c1 l45	From the standpoint of the health care professional, there is often significant tension between respect for the patient autonomy and the principles of non-maleficence, beneficence, and justice.
Principles of bioethics	Autonomy that provides conflict	Autonomy against the deontological principles	There needs no conflict between the moral principles.	p2 c1 l48	However, in this area there need be no great conflict between doing harm, doing good for others, and acting fairly on the hand and respecting the informed decisions of the patient on the other.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	Autonomy overrides the sanctity of life	p2 c2 l45	If AD are to be taken seriously, it is implicit that the principle of autonomy of persons overrides any absolutist view of the

					sanctity of life.
Caring sphere	Attitude	Paternalism	Clinical freedom is constraint.	p3 c2 l6	This places a substantial constraint on what many understand by "clinical freedom".
Temporality	Treatment change	Unanticipated newly developed treatment	The art in therapeutics is changing	p4 c2 l2	Should the author of an advance directive bear responsibility for its contents when these may have been in keeping with the then current state of the art in therapeutics at the time of its drafting, but which, at the time of its implementation is out of date and clearly not in line with the best interests of the patient?
Temporality	Anticipating difficulty	Unpredictable future	It is not possible for the author to imagine all future exigencies	p5 c1 l36	It is not always possible for the author of an AD to imagine or account for all future, possible exigencies, and those attempts at designing AD, such as the "Medical Directive", which provide exhaustive coverage of hypothetical contingencies tend to be cumbersome documents, since the attempt to achieve specificity and comprehensiveness as at the expense of

					simplicity and clarity.
Elaboration of the document	Writing, drafting limits	Completeness problems	The attempt to achieve specificity and comprehensiveness is at the expense of simplicity and clarity	p5 c1 l36	It is not always possible for the author of an AD to imagine or account for all future, possible exigencies, and those attempts at designing AD, such as the "Medical Directive", which provide exhaustive coverage of hypothetical contingencies tend to be cumbersome documents, since the attempt to achieve specificity and comprehensiveness is at the expense of simplicity and clarity.
Temporality	Treatment change	Unanticipated newly developed treatment	Directives are complex because of the medical technology progresses	p5 c2 l3	And as medical technology progresses, we may expect a concomitant increase in the complexity of such documents as, to be effective, they will need to be continually updated with the patient's wishes regarding the use of new aggressive therapies as and when they become available.
Principles of bioethics	Autonomy that provides conflict	Questionable weight of autonomy	is it not also absurd to speak of the protection of the autonomy of the mentally incompetent	p6 c1 l18	A permanent loss of competence, by definition, implies a loss of the capacity for autonomy. Thus, just as it is absurd to talk of

					the autonomy of dead, is it not also absurd to speak of the protection of the autonomy of the mentally incompetent?
Henig N.R., Faul J.L., Raffin T.A. Biomedical ethics and the withdrawal of advanced life support.					
Communication	Patients/doctor relationship	Discharge themselves of their duty	physicians leave the decision maker in the dark at the most critical juncture	p4 l33	Too often, physicians make the hundreds of decisions to treat an ill patient but then leave the decision maker in the dark at the most critical juncture, when life support is to be withdrawn.
Individual sphere	Influence	Values of the others	it is important to consider the patient's quality of life values without imposing one's own	p4 l37	The third principle of decision making is to consider the patient's quality of life values without imposing one's own.
Elaboration of the document	Writing, drafting limits	Unclear term : medical futility	Medical futility is difficult to define	p8 l23	Although the concept of medical futility is often invoked in discussions of withdrawal of life support, medical futility itself is difficult to define.
Elaboration of the document	Validity	Incompetent person with decision-making capacity	a significant number of people legally incompetent have decision-making capacity	p9 l17	Most people on life support are rendered legally incompetent by commonly used drugs, but a significant number have decision-making capacity.
Individual sphere	Influence	Depression	Critically ill patients commonly have severe	p9 l23	Critically ill patients commonly have severe

			depressions		reactive depressions that must be addressed.
Howe E.G. Resolving ethical dilemmas, part 2: Ethical and cultural relativism and other issues in decision-making.					
Caring sphere	Emotional involvement	Difficulty accepting an unusual practice	Care providers should accept unusual practices.	p1 c2 l28	In sum, care providers should take initiative on behalf of patients when this is necessary to protect them. Conversely, they should accept some practices, even if they seem unusual or deviant first, if they are widely accepted in the patient's culture and in the long run, are harmful to no one.
Temporality	Change of mind	The self changes	With more time, mind is changing.	p2 c1 l38	If care provider can convince such patients to defer this decision, this can give them time to change their mind.
Principles of bioethics	Deontological duty	Moral conscience of health care providers	Physicians care about their moral conscience.	p3 c 1 l16	Some physicians may feel that if giving pain medication has any chance of bringing about patient's death prematurely, this would violate their moral conscience.
Caring sphere	Emotional involvement	Disagreement	Care providers may not agree	p3 c1 l38	They can make these decisions even if their care providers think that these decisions are wrong.
Society	Care access	No care unit if an AD exists	Patients with DNR are not admitted in intensive care unit.	p3 c2 l5	This situation most commonly occurs when a hospital or

					individual physician has a policy of not admitting a patient into an intensive care unit (icu) if the patient has a DNR.
Society	Care access	No care unit if an AD exists	Patients with DNR are not admitted in intensive care unit.	p3 c2 l26	The physician should explain specifically that a patient who wants a DNR order will not be admitted to the ICU, even if this could make the difference between dying and living for several more years? Patients who are aware of this may want to rescind their DNR request.
Individual sphere	Emotional involvement	Decision based on panic	Requests may be based on panic.	p4 c1 l15	There is no way to discern if such patients' requests to be placed back on a respirator are based on panic or are "genuine".
Communication	Information	Healthcare providers lie	should the physician lie, to benefit their patients.	p5 c1 l43	The question both these situations raise for physicians is whether they should lie, even to a small degree, to benefit their patients.
Communication	Patients/doctor relationship	Healthcare providers lie	lying undermine the system	p5 c2 l5	When care providers lie, on the other hand, they undermine the "system".
Temporality	Change of mind	The self changes	Close to death, mind is changing.	p6 c1 l41	Most severely ill patients feel fleeting desires to die. Usually, however, these feelings are short-lived.

					Thus, if care providers too readily affirm that patients can follow through with this request, they may inadvertently sanction and "cement" this outcome, even though these patients, give more time, will indicate that this is not what they want.
Temporality	Change of situations	No fully adaptability	the living wills are not adaptable	p6 c2 l27	The living will tends to be rigid and may not be fully adaptable to patient's individual needs.
Caring sphere	Emotional involvement	Issues are too painful	care providers think that it's too painful for the patients.	p7 c1 l13	Often, care providers may not initiate these discussions, because they believe that these issues are too painful for their patient.
Individual sphere	Emotional involvement	Death as an unpleasant subject	Thinking about death may be scary	p7 c1 l25	Some don't want to because just thinking about how they might die scares them.
Individual sphere	Emotional involvement	Distrust of the caregiver	Some people distrust the care providers	p7 c1 l 26	Others, however, don't want to fill them out, because they distrust how care providers will use them.
Caring sphere	Attitude	Paternalism	some care providers pressure patients	p7 c1 l29	Regardless, some care providers pressure patients to fill them out.
Individual sphere	Emotional involvement	Difficulty to speak about AD	discussing advance directives can be traumatic	p7 c1 l32	Because discussing advance directives can be traumatic for patients, these discussions should be carried out in several

					steps.
Willmott L., White B., Mathews B. Law, autonomy and advance directives.					
Entourage	Family interaction	Disagreement of the family	An advance directive must be followed, even if family and friends don't agree.	p1 l4	While there are some conditions that need to be satisfied before a directive will be followed, for the most part the common law requires a person's refusal of treatment as expressed in an advance directive to be followed, even if it is unpopular with an individual's family or friends, or is contrary to objective notions of good medical practice .
Caring Sphere	Attitude	Paternalism	An advance directive must be followed, even if it's contrary to good medical practice,	p1 l4	While there are some conditions that need to be satisfied before a directive will be followed, for the most part the common law requires a person's refusal of treatment as expressed in an advance directive to be followed, even if it is unpopular with an individual's family or friends, or is contrary to objective notions of good medical practice .
Elaboration of the document	Validity	Undue influence	Directive may be influenced.	p4 l1	The second condition is that the person was free of undue influence at the time the directive

					was made. Not all influence will be regarded as undue.
Communication	Information	Lack of information	Relevant information is not required	p4 l23	Accordingly, while informed decision-making is preferable, it is argued here that the common law does not require a person to have received relevant information before an advance directive can be binding.
Elaboration of the document	Writing, drafting limits	Vague content	The terms of an advance directives must be clear	p5 l15	Where the terms of an advance directive are uncertain or ambiguous so that it cannot be said to apply to the circumstances that have arisen.
Temporality	Change of situations	Uncertainty about change of circumstances	The circumstances may change.	p5 l5	Where there has been a change in circumstances since the directive was made such that the person would not have intended it to govern the situation.
Communication	Information	Incorrect information	Incorrect information or assumption are not applicable	p5 l29	Where an advance directive will not be applicable to the circumstances is where it is based on incorrect information or an incorrect assumption.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	There are conflicting interests between personal autonomy and sanctity of life	p7 l7	The "relevant but in some cases conflicting interests" of "a competent adult's right of autonomy or self-

					determination" and "the interest of the state in protecting and preserving the lives and the health of its citizens".
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	Autonomy should prevail over the sanctity of life	p7 l11	The principle of autonomy should prevail over the principle of sanctity of life.
Caring Sphere	Attitude	Paternalism	A directive inconsistent with good medical practice may not be follow	p9 l3	A health professional is excused from following an advance health directive if he or she has reasonable grounds to believe that a directive is inconsistent with good medical practice.
Caring Sphere	Attitude	Paternalism	imposition of medical treatment is against liberty and autonomy	p13 l9	Imposition of medical treatment against a person's wishes not only interferes with the person's liberty but infringes on their autonomy.
Caring Sphere	Attitude	Paternalism	paternalistic position must be justified	p13 l28	Those who support the provision of treatment against one's wishes may seek to justify their paternalistic position
Principles of bioethics	Deontological duty	Contradictory principles	There are conflicts with the principles of beneficence and non-maleficence.	p16 l12	In some contexts of refusion life-sustaining treatment, it can lead to patient harm and, therefore, conflicts with the principles of beneficence and non-maleficence.

Continuity	Change of personality	Degenerative disease	Individuals with degenerative disease will change.	p18 l3	Individuals who suffer from some kind of degenerative disease or illness, such as dementia, will undergo changes in their personal characteristics, often to a significant degree.
Temporality	Connexion between present and past	Between competent and incompetent	There is no connection between the competent and incompetent person.	p18 l12	There is an insufficient connection between the competent and incompetent adult to regard the previous directions given when competent as morally binding on the incompetent adult.
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	An autonomous decision may disagree with the notion of a person's wellbeing	p20 l25	A failure to give effect to an autonomous decision simply because it does not accord with more objective notions of a person's wellbeing cannot be sustained.
Communication	Information	Lack of information	lack of information may not represent the autonomous choice	p20 l30	The decision may not be an informed one, and therefore may not represent the autonomous choice of the person who is refusing treatment.
Individual sphere	Influence	Personal experience	there is a lack of information when people are not concerned by the illness	p20 l32	This is particularly likely to be so where an advance directive is given before a person suffers from condition or illness for which a treatment decision ultimately needs to be

					made.
Communication	Information	Uncertain information	some people may not take steps to ensure their decision is an informed one	p21 I14	The likelihood that some people may not take steps to ensure their decision is an informed one is not sufficient to deprive others of an ability to make an autonomous decision to refuse medical treatment.
Temporality	Change of mind	The self changes	The same person's treatment choice may change	p21 I26	A decision recorded in an advance directive, and possibly made when a person is well, may not reflect the same person's treatment choice at a later time.
Individual sphere	Influence	Personal experience	Person view change with maturity and experience	p21 I30	The person view about treatment may simply evolve through personal experience and maturity.
Temporality	Change of mind	Labile preferences	The same person's treatment choice may change	p21 I31	A person's treatment choice is likely to change when he or she becomes ill and is closer to death.
Individual sphere	Influence	Personal experience	The treatment choice change when the person is hospitalized	p21 I34	A person's treatment setting may affect choices. There is empirical evidence that people who are hospitalized are more likely to opt for medical intervention than those in the community.
Caring Sphere	Emotional involvement	Lack of confidence in AD	Doctors haven't confidence in advance	p21 I36	It is difficult for doctors to have confidence that

			directives.		an advance directive made at earlier time, possibly in a different context, and perhaps when the person was well, still reflects a current treatment choice.
Temporality	Change of mind	Labile preferences	a current treatment choice may change	p21 l36	It is difficult for doctors to have confidence that an advance directive made at earlier time, possibly in a different context, and perhaps when the person was well, still reflects a current treatment choice.
Individual sphere	Influence	Influencing information	Directive depends on how is given the information	p22 l30	A person may give a different directive depending on how the question about treatment is conveyed (in a negative or positive -light) or how the treatment is described.
Elaboration of the document	Writing, drafting limits	Incompatible wishes	Directives may be inconsistent.	p22 l32	Similarly, people sometimes insert inconsistent statements into an advance directive.
Willmott L. Advance directives and the promotion of autonomy: a comparative Australian statutory analysis.					

Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	the principles of autonomy and sanctity of life are brought into conflict	p3 l18	It is also this kind of directive for which the principles of autonomy and sanctity of life are brought into sharp conflict, as is reflected in many of the common law decision.
Caring Sphere	Emotional involvement	Reluctance	there is a reluctance of medical professionals to discontinue treatment	p7 l22	It also observed the reluctance of medical professionals to discontinue treatment where there was any doubt about the patient's competence or wishes.
Elaboration of the document	Validity	Undue influence	No undue influence or any other vitiating factor is required.	p12 l1	The directive must have been given by the adult free of undue influence or any other vitiating factor.
Caring Sphere	Emotional involvement	Reluctance	medical professionals can be reluctant to adhere to an advance directive	p13 l2	This barrier is the fact that, at least in some circumstances, medical professionals can be reluctant to adhere to a common law advance directive to withhold or withdraw life-sustaining medical treatment.
Caring Sphere	Emotional involvement	Concerns about validity	a medical professional may have concerns about its validity or applicability.	p13 l7	As a matter of principle, a medical professional may be willing to comply with advance directive, but may have concerns about its validity or applicability in a particular case.

Elaboration of the document	Validity	Requisite capacity in question	The medical professional may be not satisfied that an individual has requisite capacity	p13 l10	The medical professional is not satisfied that an individual had requisite capacity when he or she completed the advance directive.
Elaboration of the document	Writing, drafting limits	Vague content	The statements made by an individual may be too vague.	p13 l12	The statements made by an individual may be too vague to provide a medical professional with sufficient confidence that the individual intended treatment to be discontinued in a given situation.
Communication	Information	Non-exhaustive information	the individual did not receive all relevant medical information before giving the directive.	p14 l9	The medical professional is not prepared to follow an advance directive because he or she is aware that the individual did not receive all relevant medical information before giving the directive.
Caring Sphere	Attitude	Paternalism	the directive may be estimated as contrary to good medical practice.	p14 l12	The medical professional is not prepared to follow an advance directive because he or she is of the view that the directive is contrary to good medical practice.
Temporality	Change of situations	Uncertainty about change of circumstances	there is uncertainty about a change of circumstances	p17 l1	Such factors may include uncertainty regarding the directive or a change of circumstances that

					have occurred since the individual completed the directive.
Elaboration of the document	Time	Uncertainty about undated information	without information about when an advance directive was given, there is legitimate concerns about whether the individual retains the views previously articulated	p21 l21	Where a medical professional does not have information about when an advance directive was given, he or she may have legitimate concerns about whether the individual retains the views previously articulated in the advance directive.
Communication	Information	No exigence	directives are valid too without relevant information	p25 l18	In other words, an advance directive will be valid even if the adult had not received medical information that was relevant to treatment decisions prior to making the directive.
Caring Sphere	Emotional involvement	Discomfort	when the directive is uninformed, the professional may feel uncomfortable	p25 l25	A medical professional may feel uncomfortable about following an individual's advance directive unless that person has been fully informed about possible treatment options.
Temporality	Change of situations	Uncertainty about change of circumstances	the circumstances may change	p33 l9	The circumstances of the person may have changed to the extent that he or she would not have intended the advance directive

					refusing treatment to apply in the changed circumstances.
Elaboration of the document	Writing, drafting limits	Vague content	The language of the advance directive might be uncertain	p33 l12	The language of the advance directive might be uncertain and it is impossible for a medical professional to be confident that the person would have wanted the directive refusing treatment to be followed.
Individual sphere	Influence	Influencing information	Correct information may change the choice,	p33 l15	If the person had been apprised of the correct information, he or she may not have given the directive.
Lewis P. Medical treatment of dementia patients at the end of life: can the law accommodate the personal identity and welfare problems?					
Individual sphere	Influence	Prevent financial hardship	Advance directives prevent financial hardship.	p2 l26	Advance directives can also be a mechanism of doing good to others, such as family members, by preventing emotional suffering and financial hardship.
Principles of bioethics	Autonomy that provides conflict	Controversial previous autonomy	there is doubts about the validity of the projection of autonomous choice into the future.	p3 l6	The "personal identity problem" raises doubts about the validity of the autonomy rationale supporting the projection of autonomous choice into the future, which will bind the incompetent.

Temporality	Connexion between present and past	Conflict between autonomy and welfare (well-being) as incompetent	there is a possible conflict between a future oriented autonomy and her welfare as an incompetent individual.	p3 l8	With regard to the duties owed to incompetent persons, current legal doctrine... fails to address the possibility of conflict between a competent person's exercise of future oriented autonomy and her welfare as an incompetent individual.
Temporality	Change of mind	Change of personal identity	when there is a loss of personal identity the person is not the same as the creator of advance directive	p3 l13	The argument is that some sub-set of incompetent persons will, by virtue of their illness or disability, experience a loss of personal identity so that they cannot be said to be the same person as the creator of advance directive purporting to govern their care.
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	Autonomy does not always coincide with welfare.	p5 l6	The coincidence of autonomy and welfare will not always be present, however.
Temporality	Connexion between present and past	Conflict between autonomy and welfare (well-being) as incompetent	Autonomy does not always coincide with welfare.	p5 l6	The coincidence of autonomy and welfare will not always be present, however.
Temporality	Anticipating difficulty	Be unaware about the future	some people may be unaware of the threat to her future welfare	p5 l14	The creator of an advance directive refusing treatment may be unaware of the threat to her future welfare if the directive is implemented.

Temporality	Anticipating difficulty	Mistake about the future	People may be mistaken about their future interests	p5 l17	People may be mistaken about their future experiential interests as incompetent individual.
Temporality	Change of mind	Change of personal identity	the person may be no longer the same person	p7 l9	A decision based on the individual's previously competent preferences may be imposed on the competent who is no longer the same person.
Temporality	Change of mind	Personal identity problem	The personal identity and welfare problems are present.	p11 l10	The personal identity and welfare problems are present in any autonomy-based decision-making on behalf of incompetent persons.
Kessel A.S., Meran J. Advance directives in the UK: legal, ethical, and practical considerations for doctors.					
The Court	Limits of the enforceability	Validity is conditional	There are conditions for an advance directive to be legally valid.	p1 c2 l21	The court outlined the conditions for a legally valid, anticipated refusal as follows:
Communication	Information	Uncertain information	Information is required	p1 c2 l24	the patient must be informed in broad terms about the nature and effect of the procedure
Elaboration of the document	Validity	Undue influence	To be free from undue influence is required.	p1 c2 l28	the patient must be free from undue influence when issuing the declaration
Elaboration of the document	Validity	Need to test competences	There is a need for a functional test of competences.	p2 c1 l8	Recently, the Law Commission voiced the need for a "functional" test of competence.

Communication	Information	No exigence	Negligence about information doesn't viciate a consent	p2 c1 l24	There is a "duty to inform about likely risks (including any special risks attaching to the treatment being administered by particular persons), but a failure to perform this duty sounds in negligence and does not, as such, vitiate a consent or refusal."
The Court	Limits of the enforceability	No sufficient information	An advance directive will be invalid if there is no sufficient information	p2 c1 l31	If an incapacitated person can be shown to have made an advance directive without sufficient information, the directive may be deemed invalid.
Communication	Information	Uncertain information	Doctors cannot assume that insufficient information was given.	p2 c1 l33	However, doctors cannot assume that insufficient information was given, and cannot presume that, if the patient had the necessary capacity (now), she would reverse her decision.
Elaboration of the document	Writing, drafting limits	Vague content	advance directive are often too general	p2 c1 l36	An obvious problem exists in that advance statements are often couched in general terms
The Court	Limits of the enforceability	Doubts	If there is any doubt, it will be in favour of preserving life	p2 c1 l38	If there is any doubt, with regard to the intended scope of an anticipated refusal, it will be decided in favour of preserving life.

Communication	Information	Not informed decision	To believe to know without being aware of the possibilities	p2 c2 l1	A person may have what she believes to be a clear idea of a given situation without being aware of the clinical spectrum of possibilities.
Temporality	Anticipating difficulty	Unpredictable future	It is impossible to anticipate all the future	p2 c2 l3	It is virtually impossible to foresee every circumstance that may arise, and consequently there will often be a doubt as to whether the individual had truly anticipate the situation that occurs.
Interpretation	Understanding limits	Interpretation subjective	Interpretation by physicians is subjective	p2 c2 l24	It encourages subjective interpretation by physicians who may, knowingly or not, introduce personal interests or normative values into their assessment.
Individual Sphere	Influence	Duress not easy to define	definition of duress is complicated	p2 c2 l29	Deciding what constitutes duress may not be straightforward.
Communication	Information	Risk of persuasion	Informations may be given with a degree of persuasion.	p2 c2 l46	So the consensus of informed consent can be considered to apply to advance directives, whereby a degree of persuasion may be anticipated but coercion is unacceptable.
Communication	Patients/Doctor relationship	Autonomy diminishing communication	individualism leads to a decrease in communication	p3 c1 l35	There is a legitimate concern that the corollary of individualism and

					technological advancement is diminishing communication with doctors, which may result in patients being literally "abandoned to their own autonomy".
Doukas D.J., MD, McCullough L.B. The values history. The evaluation of the patient's values and advance directives.					
Interpretation	Understanding limits	Interpretation subjective	there is a subjective interpretation	p1 c2 l15	Their language is general and imprecise, leaving them open to subjective interpretation.
Communication	Information	Lack of information	there is no obligation to consult a doctor to formulate directives	p1 c2 l18	They do not obligate the physician and the patient to work together prospectively, in anticipation of possible hospitalization or admission to a critical care unit, to identify the patient's beliefs and values concerning terminal care, quality of life, aggressive treatment to sustain life, interests of family members, and other issues.
Principles of bioethics	Autonomy that provides conflict	Selfdetermining but not autonomous	Living Wills not always enhance autonomy.	p2 c1 l39	While living wills and durable powers of attorney protect decision-making authority, they do not always enhance autonomy.

Caring Sphere	Attitude	Paternalism	to judge the validity of AD belongs to paternalism	p2 c2 l33	To judge the validity of another person's values is a gross and wholly unacceptable form of medical paternalism.
Elaboration of the document	Writing, drafting limits	Vague content	doubt about vague decisions may exist	p2 c2 l48	Doubt about health decisions at risk for being too vague, too general, or only loosely connected to the patient's values are reduced.
Entourage	Family interaction	Disagreement of the family	family members may want to interfere with the patient's preferences	p3 c2 l1	to negate future attempts of family members to interfere with physician compliance with the patient's preferences
Entourage	Family interaction	Against conflict of interest with the family	directives help against conflict of interest with the family	p4 c2 l13	This directive may be useful to exclude a family member with differing philosophy toward life and medical care, or if the patient suspects some conflict of interest or will.
Communication	Patients/Doctor relationship	Consultation's time constraint	The physician may have difficulty to spending time setting discussing advance directives.	p4 c2 l37	The physician may have difficulty with accepting the concept of spending time in the outpatient setting discussing advance directives, much less values, with their patients.
Caring sphere	Emotional involvement	Difficulty to speak about death	discussing the possibility of death may be seen as against the beneficence-based role	p5 c1 l1	The physician may perceive that discussing the possibility of death with the patient as a

					harmful act, contrary to the physician's beneficence-based role.
Caring Sphere	Emotional involvement	Discomfort	Physician may feel uncomfortable	p5 c1 l3	The physician could also feel constrained by discomfort in disclosing the eventuality of death or by a paternalistic desire to wait the "right time".
Entourage	Family interaction	Disagreement of the family	A family member may try to ignore the patient's advance directives	p5 c1 l30	A family member may try to ignore the patient's advance directives to withhold or withdraw certain therapies, challenging the patient's decisions and the physician's duty to carry them out.
Communication	Patients/Doctor relationship	Need of education	a family member needs to be educated about AD	p5 c1 l34	Educating such a family member on the patient's right to refuse specific interventions can help here.
Entourage	surrogate decision maker	Risk to fail to follow the directives	the person holding the durable power of attorney may fail to follow the patient's prior autonomous directives.	p2 c1 l34	There is evidence that communication between the competent patient and the patient's appointed agent has not always taken place, with the possibility that the person holding the durable power of attorney may fail to follow precisely the patient's prior autonomous directives.

Capron A.M. The Patient Self-Determination Act: not now.					
Caring Sphere	Attitude	Attitude ingrained	Professional attitudes are ingrained.	p1 c2 l16	The barriers to their use that remain -in personal reluctance to employ them and in ingrained professional attitudes - are rapidly being overcome.
Caring Sphere	Emotional involvement	Reluctance	There is a personal reluctance to employ the advance directives.	p1 c2 l16	The barriers to their use that remain -in personal reluctance to employ them and in ingrained professional attitudes - are rapidly being overcome.
Communication	Patients/Doctor relationship	Difficulty being educational rather than formalistic	Information has to be educational rather than formalistic.	p1 c2 l37	Nor is the person who plays this role likely to be able to explain the possible documents well and to enter into a discussion that would be truly educational rather than merely formalistic.
Caring Sphere	Emotional involvement	Physician's fear of liability	There is a fear of liability	p1 c2 l2	The only sure consequence was a great deal of resentment on the part of physicians and hospital personnel, along with more trips to the courthouse induced by fear of liability.
Caring Sphere	Emotional involvement	Resentment	There is a resentment on the part of physicians and hospital personnel	p1 c2 l2	The only sure consequence was a great deal of resentment on the part of physicians and

					hospital personnel, along with more trips to the courthouse induced by fear of liability.
Jox R.J., Michalowski S., Lorenz J. Substitute decision-making in medicine: comparative analysis of ethico-legal discourse in England and Germany.					
Elaboration of the document	Validity	Document accesibility issues	advance directives frequently do not reach the decision-makers in due time	p1 c2 l18	The reasons are manifold : advance directives frequently do not reach the decision-makers in due time and if so, they are too often inapplicable; Physician are reluctant to follow even applicable advance directives partly because anticipatory treatment preferences are sometimes based on insufficient medical information and critically dependant on the way information is presented.
Caring Sphere	Emotional involvement	Reluctance	Physician are reluctant to follow even applicable advance directives because of insufficient medical information	p1 c2 l18	The reasons are manifold : advance directives frequently do not reach the decision-makers in due time and if so, they are too often inapplicable; Physician are reluctant to follow even applicable advance directives partly because anticipatory

					treatment preferences are sometimes based on insufficient medical information and critically dependant on the way information is presented.
Communication	Information	Poor quality of information	Physician are reluctant to follow even applicable advance directives because of insufficient medical information	p1 c2 l18	The reasons are manifold : advance directives frequently do not reach the decision-makers in due time and if so, they are too often inapplicable; Physician are reluctant to follow even applicable advance directives partly because anticipatory treatment preferences are sometimes based on insufficient medical information and critically dependant on the way information is presented.
The Court	Limits of the enforceability	Church disagreement	the catholic church does not agree the AD	p5 c1 l12	The Catholic Church and pro-life groups did not accept that anyone should have the power to decide about when and how another person will die.
The Court	Limits of the enforceability	The courts can override the directives	some court decision overrules advance directives	p6 c1 l48	There are some disturbing court decision overruling advance directives.
The Court	Limits of the enforceability	Doubts	in case of doubt the preservation of life is favored	p5 c2 l16	If there is uncertainty about what serves the patient's well-being, the courts adhere to

					the traditional maxim in dubio pro vita favouring the preservation of life in cases of doubt.
Entourage	surrogate decision maker	Bad predictions of patient preferences	the next of kin's predictions of patient preferences are disappointingly poor	p2 c1 l39	While multiple studies have shown that the next of kin's predictions of patient preferences are disappointingly poor, this does not necessarily question their aptitude for decision making, because patients surprisingly often want their substitute decision-makers to use their own judgment rather than blindly execute preferences previously expressed by themselves.
Michalowski S. Advance refusals of life-sustaining medical treatment: The relativity of an absolute right.					
Elaboration of the document	Writing, drafting limits	Vague content	broad terms make it difficult to evaluate directives	p2 l6	Many advance directives will be phrased in broad and general terms, and it will often be difficult, if not impossible, to evaluate to what degree the patient had intended the advance directive to cover the situation.
Caring Sphere	Attitude	Paternalism	An error about the judgement of the	p2 l14	If the patient's treatment decision is

			validity is against autonomous choices		erroneously regarded as invalid or inapplicable, the patient's autonomous choices are disregarded.
The Court	Limits of the enforceability	Doubts	if there are uncertainties the choice will be in favour of preserving life.	p2 l26	Uncertainties regarding the validity and applicability of an advance refusal of life sustaining treatment should be resolved by applying a presumption in favour of preserving life.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	the law's approach is based on two distinct principles	p2 l33	Patient autonomy, on the one hand, and the sanctity or inviolability of human life, on the other.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	when law tips in favour of preserving life, it encourages the physician to disregard the AD	p3 l32	The physician is therefore clearly encouraged to disregard, rather than to follow advance-directives. This was justified by the consideration that in the context of life-saving treatment, the law should be clearly tipped in favour of preserving life.
The Court	Limits of the enforceability	Capacity : not a static concept	As capacity is not a static concept a bias in favour of preserving life might arise	p6 l31	As capacity is not a static concept, but instead depends on the severity of the decision that needs to be made, a bias in favour of preserving life might nevertheless

					arise when determining whether or not a patient is in fact competent to make the decision to refuse life-sustaining medical treatment.
Elaboration of the document	Writing, drafting limits	Vague content	advance directives may be unclear and ambiguous	p8 l29	A serious problem in the context of advance treatment refusals is that they are frequently not entirely clear and unambiguous.
Temporality	Anticipating difficulty	Unpredictable future	It is difficult to predict all eventualities	p9 l10	It is difficult to predict with any certainty all the potential situations that might at some point arise, and to make specific provision for all eventualities
Elaboration of the document	Writing, drafting limits	Vague content	general terms leave room for ambiguity	p9 l12	It is equally clear that advance directives which are phrased in such general terms leave ample room for ambiguity.
Elaboration of the document	Writing, drafting limits	Vague content	It is difficult to make an unambiguous directive.	p10 l5	Given how difficult it is to make an entirely unambiguous advance directive and to make clear provision for all foreseeable contingencies, every other approach will undermine patient autonomy in favour of the views of medical profession and/or society.
Principles of bioethics	Autonomy that provides conflict	Autonomy against the views of medical	when there is no interpretation the	p10 l5	Given how difficult it is to make an entirely

		profession	patient autonomy is undermined by the views of medical profession and/or society.		unambiguous advance directive and to make clear provision for all foreseeable contingencies, every other approach will undermine patient autonomy in favour of the views of medical profession and/or society.
Interpretation	Understanding limits	Interpretation as a practical and ethical problem	Directives are interpreted	p12 l1	All uncertainties currently existing with regard to the interpretation of advance directives.
Elaboration of the document	Writing, drafting limits	Required details are not specified	detail required are not specified	p12 l9	It is not clear what detail is required in order for a refusal of a "specified treatment" to be valid.
Temporality	Change of situations	Uncertainty about change of circumstances	relevant circumstances may changed between the making of the directive and the moment of its implementation.	p 12 l 19	Even if an advance directive is clear and unambiguous, questions about its applicability might arise if relevant circumstances changed between the making of the directive and the moment of its implementation.
Temporality	Treatment change	Unanticipated newly developed treatment	an incurable illness may become curable	p12 l29	If, by the time the patient is incompetent and indeed diagnosed with this illness, a cure has been developed, so that life can be prolonged and the pain controlled, it needs to be considered whether

					the patient's otherwise unambiguous decision applies.
The Court	Limits of the enforceability	Doubts	unsubstantiated doubts might be sufficient to invalidate the advance directive.	p14 l25	it is for the patient to prove that the directive is still valid, even unsubstantiated doubts raised by an interested party might be sufficient to invalidate the advance directive.
Temporality	Change of mind	Change of interests	when relevant religious convictions have changed that advance directives conflict with the present interests of the now incompetent patient.	p15 l36	It is not only in cases in which relevant religious convictions have changed that advance directives potentially conflict with the present interests of the now incompetent patient.
Elaboration of the document	Validity	Competences : dementia and change of interests	Patient's interests are changing with dementia	18 l4	It is nevertheless suggested that the advance directives of demented patients should be disregarded where they run counter to the patient's present interests, what is in fact proposed is that a valid advance directive can be ignored in favour of the present interests of the patient.
Temporality	Change of mind	Present interests problem	to protect the present interests of a patient is problematic	p18 l 18	To disregard a valid and applicable advance directive in order to protect the present interests of a patient is moreover problematic for other than merely

					legalistic/technical reasons.
Principles of bioethics	Autonomy that provides conflict	Autonomy and personal interest	autonomy is less important than the current interests	p18 l28	The argument is based on the premise that the anticipated exercise of autonomy is less important than the current interests of the patient, if the two appear to be in conflict with one another.
Elaboration of the document	Validity	Competence to perceive the violation of the autonomous directive	are advance directives binding when the patient does not have the capacity to perceive the violation of the past autonomous decision?	p19 l13	If the binding effect of advance directives were to depend on the patient's ability to perceive the violation of the past autonomous decision as harmful, it would follow that in most cases in which advance directives kick in, where the once competent patient has lost the competence to make valid treatment decisions, these decision would not be binding.
Maclean A. Advance directives and the rocky waters of anticipatory decision-making					
Temporality	Connexion between present and past	Becoming incompetent : lack of psychological relationship	there is a lack of psychological relationship between the competent and incompetent person.	p2 l4	The gist of criticism is that the person making the directive lacks the authority to bind the incompetent individual because they lack the necessary psychological

					relationship.
Principles of bioethics	Autonomy that provides conflict	Questionable weight of autonomy	is the weight of autonomy just	p2 l7	The second type of attack is directed at the weighting given to autonomy and the third is focused on the pragmatic difficulties of implementing and relying on advance directives.
Principles of bioethics	Autonomy that provides conflict	Autonomy against preserving life	AD may be irrational	p3 l13	This holds even if it is wholly irrational and will result in the patient's death.
The Court	Limits of the enforceability	Doubts	a doubt falls to be resolved in favour of the preservation of life	p3 l22	In case of doubt, that doubt falls to be resolved in favour of the preservation of life or if the individual is to override the public interest, he must do so in clear terms.
Elaboration of the document	Writing, drafting limits	Vague content	An AD must be in clear terms	p3 l22	In case of doubt, that doubt falls to be resolved in favour of the preservation of life or if the individual is to override the public interest, he must do so in clear terms.
The Court	Limits of the enforceability	Finding incompetent	the courts avoid the issue by finding the patients incompetent.	p4 l31	In most of the cases where the patient's decision is overruled, the courts effectively avoid the issue by finding the patients

					incompetent.
The Court	Limits of the enforceability	Values of the judge : personal bias in favour of life	the judge may find that a life is worthwhile	p5 l2	This approach appears to be motivated, as Thorpe L.J. noted, by a desire to avoid the death of a life that the judge sees as worthwhile.
Principles of bioethics	Autonomy that provides conflict	Autonomy against deontological principles	The courts are prepared to protect a person right to self determination	p5 l16	The courts are prepared to protect a person right to self-determination even when it may result in his or her death, which might otherwise have been avoided.
Elaboration of the document	Validity	Requisite capacity in question	the courts will assess the patient's competence	p6 l11	In deciding whether to accept a refusal of treatment, the courts will assess the patient's competence on the basis of the outcome of the choice that he or she has made.
The Court	Limits of the enforceability	An irrational choice should be accepted	This is contrary to the principle that treatment may be refused for irrational reasons	p6 l13	This is contrary to the principle that treatment may be refused for irrational reasons, or even no reason at all.
The Court	Limits of the enforceability	No sufficient information	information is required	p10 l5	This means that they must provide sufficient certainty that an advance directive exists, the treatment and circumstances that it applies to and that, at the time of drafting, that patient was competent, sufficiently

					well informed and not unduly influenced.
Elaboration of the document	Validity	Undue influence	AD must not be influenced	p10 l5	This means that they must provide sufficient certainty that an advance directive exists, the treatment and circumstances that it applies to and that, at the time of drafting, that patient was competent, sufficiently well informed and not unduly influenced.
Elaboration of the document	Validity	Undue influence	AD must not be influenced	p11 l 1	If an advance directive must be formally drafted in writing and witnessed by an independent third party, this provides an opportunity to check the patient has capacity, is well informed and is not being subject to undue influence.
Interpretation	Understanding limits	Interpretation subjective	there is a risk of interpretation by allowing advance directives to be revoked	p12 l2	Allowing advance directives to be revoked by inconsistent behaviour provides great scope for interpretation, which may allow treating physicians or judges to justify whatever outcome they thought best.
Temporality	Change of mind	Facing impending incapacity	there may be change of mind at the last minute	p12 l15	Some cases will arise where there has been a change of mind at the last minute, when

					facing impending incapacity.
Principles of bioethics	Autonomy that provides conflict	Selfdetermining but not autonomous	change of mind may be a non-autonomous-choice	p12 l18	If autonomy requires rational reflection to arrive at a settled position, then it is arguable that this change of mind, in the face of incapacity, is an unreflective- and hence non-autonomous- choice.
Temporality	Change of mind	Change of mind not communicated	change may not be communicated to the relevant healthcare professional	p12 l31	A further problem with informal revocation or alteration is that the change may not be communicated to the relevant healthcare professional and thus may be ignored.
Communication	Patients/doctor relationship	Need of education	Professions and the public have to be educated	p13 l8	This will require concerted efforts to inform and educate, not just the professions, but also the public.
Communication	Information	No exigence	there is no formal requirements to be sufficiently well informed	p14 l13	There is no formal requirement that the author of an advance directive be sufficiently well informed to make a reasonable decision.
Temporality	Anticipating difficulty	Be unaware about the future	Without information, individuals may be less able to predict their future	p14 l29	Without good information, individuals may be less able to predict their future medical state and the possible options and treatments available to them.

Temporality	Connexion between present and past	Underestimate the quality of life of incompetent	competent people tend to underestimate the quality of life of incompetent people.	p16 l2	This is particularly relevant once it is acknowledged that able bodied and competent people tend to underestimate the quality of life of disabled or incompetent people.
Elaboration of the document	Writing, drafting limits	Lack of specificity regarding the future	to be sufficiently specific is hard	p16 l20	One of the well-known problems with advance directives is the difficulty of drafting a sufficiently specific directive that anticipates the future circumstances when the individual would like treatment to stop.
Temporality	Anticipating difficulty	Unpredictable future	It is difficult to anticipate the exact circumstances	p17 l4	It is difficult to anticipate the exact circumstances and treatments that together would be objectionable.
Temporality	Change of situations	Material change of circumstance	A "material change of circumstance" avoid the directive to be effective	p18 l1	When there as been a "material change of circumstance", the directive will fail.
Elaboration of the document	Time	Procrastination to elaborate AD	the author may have procrastinated	p18 l11	It may not be possible to know whether an old directive has not been updated because it still represents the person's wishes, or because the author has procrastinated or, particularly for very old and informal directives, he or she has forgotten that the directive

					exists.
Temporality	Treatment change	Unanticipated newly developed treatment	the use of newly developed, but unanticipated treatment, is possible	p19 l9	They also provide substantial protection against the possibility that an advance directive could prevent the use of newly developed, but unanticipated treatment.
Willmott L. Advance directives refusing treatment as an expression of autonomy: do the courts practise what they preach?					
Principles of bioethics	Autonomy that provides conflict	Autonomy against preserving life	These two principles do not sit together comfortably	p2 l27	These two principles do not sit together comfortably in the context of a competent adult's contemporaneous or advance decision to refuse life-sustaining medical treatment.
The Court	Limits of the enforceability	Values of the judge : personal bias in favour of life	a bias that some lives are worth preserving may exist	p3 l22	Commentators have argued that unjustifiable decisions have been reached because judges apply legal principles from a particular bias. This bias can stem from judge's particular perception of the meaning of autonomy or from a personal bias in favour of life, or from a bias that some lives are worth preserving regardless of expressed wishes.

The Court	Limits of the enforceability	Judge's perception of autonomy	judge's particular perception of the meaning of autonomy may exist	p3 l22	Commentators have argued that unjustifiable decisions have been reached because judges apply legal principles from a particular bias. This bias can stem from judge's particular perception of the meaning of autonomy or from a personal bias in favour of life, or from a bias that some lives are worth preserving regardless of expressed wishes.
The Court	Emotional involvement	Emotional reluctance from the judges	Judges have a moral or emotional reluctance to reach a decision that will result in the death of a vulnerable individual	p4 l4	Many judges find an advance refusal to be invalid or not applicable to a medical situation because of a moral or emotional reluctance to reach a decision that will result in the death of a vulnerable individual.
Principles of bioethics	Autonomy that provides conflict	Reluctance undermines autonomy	This reluctance undermines personal autonomy	p4 l35	This reluctance is undesirable, not only for the adult whose previously expressed directive has been ignored, but for all of those in our society who wish to plan for medical treatment or non-treatment at the end-of-life. Such an approach undermines personal autonomy, a principle that underpins

					our liberal democracy and judicial doctrine.
Principles of bioethics	Autonomy that provides conflict	Autonomy against sanctity of life	The principle of autonomy prevails over that sanctity of life. (p5 l14)	p5 l14	The principle of autonomy prevails over that sanctity of life.
Elaboration of the document	Validity	Undue influence	Any undue influence affects the validity of the advance directive.	p7 l1	Any undue influence or other vitiating factor that was exerted on the adult at the time of signing may also affect the validity of the advance directive.
The Court	Limits of the enforceability	Values of the judge : personal bias in favour of life	the courts are not objective, in favour of life	p15 l6	The courts seem to be overly influenced by or concerned about the "bias in favour of life", which results in decisions being made that are not supportable on an objective assessment of the facts.
Communication	Information	No exigence	the laws accepts that the decision can be made in the absence of information	p17 l31	If the laws accepts that a competent adult may refuse life-sustaining medical treatment even if his or her reasons for doing so are "irrational, unknown or even non-existent", it must follow that the decision can be made in the absence of knowledge or information that would inform the decision.
Communication	Information	No exigence	The decision could be made without relevant information.	p17 l35	The suggestion that the reasons for the decision may be "non-

					existent" implies that the decision could be made without good cause, or without all or any of the relevant information.
Communication	Information	No exigence	to disregards an advance directive because it is based on insufficient information is unacceptable	p18 l18	If a court disregards an individual's advance directive because it is based on insufficient knowledge or information, the court will effectively be compelling the individual to receive medical treatment, an outcome that is demonstrably unacceptable when considered in the context of a contemporaneous refusal.
Elaboration of the document	Validity	Undue influence	a decision overborne by the influence is not be legally effective	p19 l13	If a person lacks capacity or his or her decision is overborne by the influence of another, the refusal treatment will not be legally effective.
Temporality	Change of mind	The onus about the "continuing validity"	there is an onus about the "continuing validity"	p22 l 26	Imposing an onus about the "continuing validity" on an individual is problematic.
Temporality	Change of mind	Continuity not obvious	is there a continuing validity?	p23 l2	First, the applicant (the hospital) is not "seeking to establish" the existence, continuing validity or applicability of the

					advance directive in the sens of arguing for a particular position. Secondly, there is no evidence at all of its continuing validity.
The Court	Emotional involvement	Uncomfortable and socially unacceptable treatment choice	the judiciary talk about lack of capacity when the choice is unacceptable	p 31 l15	The argument is that, at the outset the judiciary is drawn to a conclusion that the adult lacks capacity because of the uncomfortable and socially unacceptable treatment choice he or she made.
Elaboration of the document	Writing, drafting limits	Vague content	terms have to be clear to govern treatment.	p33 l3	As part of this assessment, it must be determined whether the terms of the advance directive are sufficiently clear to govern treatment.
The Court	Emotional involvement	Anxiety of judges	Judges are anxious to decide cases	p35 l26	Judges are anxious to decide cases in a particular way, namely that life-sustaining medical treatment should not be withheld from an incompetent individual pursuant to an instruction in an advance directive so that he or she is left to die.
Fagerlin A., Schneder C. Enough : the failure of the living will					
Communication	Information	Lack of information	people don't know enough about living wills	p3 c2 l29	Why people flout the conventional wisdom? They don't know

					enough about living wills, they think living wills hard to execute, they procrastinate, they hesitate to broach the topic to their doctors.
Elaboration of the document	Time limits	Procrastination to elaborate AD	people procrastinate	p3 c2 l29	Why people flout the conventional wisdom? They don't know enough about living wills, they think living wills hard to execute, they procrastinate, they hesitate to broach the topic to their doctors.
Society	Social limits	Believe that living wills are hard to execute	people think living wills hard to execute	p3 c2 l29	Why people flout the conventional wisdom? They don't know enough about living wills, they think living wills hard to execute, they procrastinate, they hesitate to broach the topic to their doctors.
Individual Sphere	Emotional involvement	Hesitation to broach the topic	people hesitate to broach the topic to their doctors	p3 c2 l29	Why people flout the conventional wisdom? They don't know enough about living wills, they think living wills hard to execute, they procrastinate, they hesitate to broach the topic to their doctors.
Individual Sphere	Emotional involvement	Suspicion and scepticism	there is a suspicion that living wills not change the treatment	p3 c2 l40	Others suspect that living wills do not change the treatment people receive.

Individual Sphere	Emotional involvement	Daunted by the decisions' difficulty	Even contemporary decisions about contemporary illnesses are difficult	p4 c1 l14	Even patients making contemporary decisions about contemporary illnesses are regularly daunted by the decisions' difficulty.
Communication	Information	Too much information	some people falter in gathering information	p4 c1 l17	We humans falter in gathering information, misunderstand and ignore what we gather, lack well-considered preferences to guide decisions, and rush headlong to choice.
Temporality	Anticipating difficulty	Unpredictable future	future is unspecifiable and unidentifiable maladies may have unpredictable treatments	p4 1 l22	How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?
Temporality	Treatment change	Unanticipated newly developed treatment	future is unspecifiable and unidentifiable maladies may have unpredictable treatments	p4 1 l22	How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?
Communication	Patients/doctor relationship	Conversation short vague and tendentious	the conversations are ordinarily short, vague, and tendentious.	p4 c2 l18	Living wills can be executed without even consulting a doctor, and when doctors are consulted, the conversations are ordinarily short, vague, and tendentious.
Communication	Information	Superficial reflection	people regularly know too little and the	p4 c3 l1	Not only do people regularly know too little

			analyze is superficial		when they sign a living will, but often they analyze their choices only superficially before placing them in the time capsule.
Temporality	Change of mind	Labile preferences	preferences are labile, and people have trouble recognizing that their views have changed.	p5 c1 l5	And not only are preferences surprisingly labile, but people have trouble recognizing that their views have changed.
Temporality	Change of mind	Labile preferences	illness and hospitalization change people's preferences	p5 c1 l44	More particularly, illness and hospitalization change people's preferences for life-sustaining treatments.
Individual Sphere	Influence	Personal experience	illness and hospitalization change people's preferences	p5 c1 l44	More particularly, illness and hospitalization change people's preferences for life-sustaining treatments.
Elaboration of the document	Writing, drafting limits	Incompatible wishes	people do inconsistent instructions in living wills	p5 c2 l46	people do, for instance, issue mutually inconsistent instructions in living wills
Elaboration of the document	Writing, drafting limits	Vague content	when it's not clearly enough courts ignore their wishes	p6 c1 l24	If testators didn't say it clearly enough in the right words and following the right procedures, courts coolly ignore their wishes and substitute default rules.
Elaboration of the document	Time limits	Disappearance of the document	its existence may vanish in the mist of time.	p6 c3 l4	The living will may be signed years before it is used, and its existence and location

					may vanish in the mist of time.
Interpretation	Understanding limits	Directives are not self-executing	someone must decide what the living will commands	p6 c3 l35	Living wills are not self-executing: someone must decide whether the patient is incompetent, whether a medical situation described in the living will has arisen, and what the living will then commands.
Interpretation	Understanding limits	Interpretation subjective	The imprecision of living wills stymies interpreters	p7 c3 l3	The imprecision of living wills not only stymies interpreters, it exacerbates their natural tendency to read documents in light of their own preferences.
Elaboration of the document	Writing, drafting limits	Vague content	The imprecision exacerbates their tendency to read documents in light of their own preferences.	p7 c3 l3	The imprecision of living wills not only stymies interpreters, it exacerbates their natural tendency to read documents in light of their own preferences.
Caring Sphere	Attitude	Procrastination to invoke the AD	it was never considered the time to invoke the AD	p7 c3 l20	"Patients were not seen as "absolutely hopelessly ill", and thus, it was never considered the time to invoke the AD".
Society	Social limits	Human psychology and social organization	living wills fail because of human psychology and social organization.	p9 c2 l25	Our survey of the evidence suggests that living wills fail not for want of effort, or education, or intelligence, or good will, but because of

					suborn traits of human psychology and persistent features of social organization.
Communication	Information	Superficial reflection	the living wills without adequate reflection not lead surrogates to make the choices	p9 c3 l41	If, as we argued, patients sign living wills without adequate reflection, lack necessary information, and have fluctuating preferences anyway, then living wills will not lead surrogates to make the choices patients would have wanted.
Communication	Information	Lack of information	the living wills lack necessary information not lead surrogates to make the choices	p9 c3 l41	If, as we argued, patients sign living wills without adequate reflection, lack necessary information, and have fluctuating preferences anyway, then living wills will not lead surrogates to make the choices patients would have wanted.
Temporality	Change of mind	Labile preferences	the living wills have fluctuating preferences not lead surrogates to make the choices	p9 c3 l41	If, as we argued, patients sign living wills without adequate reflection, lack necessary information, and have fluctuating preferences anyway, then living wills will not lead surrogates to make the choices patients would have wanted.

Maclean A. Advance directives, future selves and decision-making					
Entourage	Family interaction	Patient's relatives idea of the best interests	The patient's relatives and careers may feel that an advance directive may not be in the best interests.	p2 l7	The patient's relatives and careers may well feel that following an advance directive may not be in the best interests of the patient.
Principles of bioethics	Autonomy that provides conflict	Self-determining but not autonomous	an advance directive may be self-determining, but not autonomous	p2 l13	The impossibility of predicting exactly what the future would be like means that any advance decision must be one made in ignorance and so, while it may be self-determining, it is not autonomous.
Temporality	Treatment change	New advances in medical care	the patient may miss out on new advances in medical care.	p2 l15	Related to this is the argument that an advance directive refusing treatment may condemn the patient to miss out on new advances in medical care.
Temporality	Anticipating difficulty (Risk to misjudgment)	Unpredictable future	future circumstances are prone to misjudgment	p4 l6	Predictions of future circumstances are more prone to misjudgment.
Temporality	Change of mind	The self changes	the self gradually evolves and changes	p12 l30	Over time, the self gradually evolves and changes, gaining new memories and beliefs, losing old beliefs and forgetting old memories.
Temporality	Change of mind	The self changes	such decisions are subject to a greater risk of error	p30 l10	Since such decisions are subject to a greater risk of error than the

					contemporaneous decision, they should be subject to careful scrutiny.
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B. Annexe 2 : Serment d'Hippocrate

« Au moment d'être admis à exercer la médecine, je promets et je jure d'être fidèle aux lois de l'honneur et de la probité. Mon premier souci sera de rétablir, de préserver ou de promouvoir la santé dans tous ses éléments, physiques et mentaux, individuels et sociaux. Je respecterai toutes les personnes, leur autonomie et leur volonté, sans aucune discrimination selon leur état ou leurs convictions. J'interviendrai pour les protéger si elles sont affaiblies, vulnérables ou menacées dans leur intégrité ou leur dignité. Même sous la contrainte, je ne ferai pas usage de mes connaissances contre les lois de l'humanité. J'informerai les patients des décisions envisagées, de leurs raisons et de leurs conséquences. Je ne tromperai jamais leur confiance et n'exploiterai pas le pouvoir hérité des circonstances pour forcer les consciences. Je donnerai mes soins à l'indigent et à quiconque me le demandera. Je ne me laisserai pas influencer par la soif du gain ou la recherche de la gloire. Admis dans l'intimité des personnes, je tairai les secrets qui me seront confiés. Reçu à l'intérieur des maisons, je respecterai les secrets des foyers et ma conduite ne servira pas à corrompre les mœurs. Je ferai tout pour soulager les souffrances. Je ne prolongerai pas abusivement les agonies. Je ne provoquerai jamais la mort délibérément. Je préserverai l'indépendance nécessaire à l'accomplissement de ma mission. Je n'entreprendrai rien qui dépasse mes compétences. Je les entretiendrai et les perfectionnerai pour assurer au mieux les services qui me seront demandés. J'apporterai mon aide à mes confrères ainsi qu'à leurs familles dans l'adversité. Que les hommes et mes confrères m'accordent leur estime si je suis fidèle à mes promesses ; que je sois déshonoré et méprisé si j'y manque. »

KRURIEN Enora, In the main population, what are the problems lead by the binding law of advance directives? A thematic analysis based on a systematic literature review.

Th. : Méd. : BREST 2020

Abstract:

Introduction: Advance directives (ADs) are little used in the French population. Their binding nature raises ethical problems. The objective of this study is to understand these problems with regard to the general population.

Method: A systematic literature review was performed according to the PRISMA guide, in following databases : Pubmed and Psycinfo. Search queries were: "advance directives" and "ethic" (MESH terms).

Exclusion criteria : "not about the ADs", "not about community", "not about ethic" and "no availability of the abstract".

Inclusion criteria : "about the binding nature of the law", "about the ADs", "about the general population", "available language", "accessibility of the article", "adapted format of the article".

A snowballing was performed, using the same protocol. A thematic analysis was compared to the current literature and the results of a parallel analysis made in the grey literature by Dr Zambonino(1).

Results: Documents extracted: 484 (Pubmed) + 586 (Psycinfo). 28 duplicates. 1042 abstracts submitted for analysis, 921 excluded. 121 articles submitted for eligibility, 17 were included, 2 not found.

Snowballing : 436 references. 41 duplicates. 395 summaries submitted for analysis. 377 excluded. 18 articles subject to eligibility. 6 items included. 23 articles have been integrated.

Thematic analysis : 156 axial codes, 23 selective codes grouped in 10 themes: individual sphere, entourage, caring sphere, society, the Court, the principles of bioethics, elaboration of the document, temporality, communication, interpretation.

Conclusion: Several problems have been identified, which may explain the low completion rate of ADs. Knowledge can improve end-of-life practice.

MOTS CLES :

ADVANCE DIRECTIVES

BINDING LAW

ETHIC

PROBLEM

GENERAL POPULATION

JURY :

Président

Mr le Professeur LE FLOCH Bernard

Membres du jury

Mr le Docteur Patrice NABBE

Mr le Professeur CHIRON Benoit

Mr le Docteur HAZIF-THOMAS Cyril

DATE DE SOUTENANCE :

28.05.2020

Titre : Dans la population générale, quels sont les problèmes posés par la loi opposable des directives anticipées ? Une analyse thématique basée sur une revue systématique de la littérature

Résumé :

Introduction : Les directives anticipées (ADs) sont peu utilisées. Leur caractère contraignant pose des problèmes éthiques. L'objectif de cette étude est de comprendre ces problèmes vis à vis de la population générale.

Méthode : Une revue systématique de la littérature a été réalisée selon le guide PRISMA, dans les bases de données suivantes : Pubmed et Psychinfo. L'équation de recherche était : « directives anticipées » et « éthique ».

Critères d'exclusion : ADs non objets de l'article, communauté non objet de l'article, éthique non objet de l'article et résumé non disponible.

Critères d'inclusion : articles centrés sur le caractère opposable de la loi, les ADs, et la population générale, langue française ou anglaise, article accessible, et format adapté.

Un processus « boule de neige » a été effectué, utilisant le même protocole.

Une analyse thématique suivant un processus de codage en double aveugle a été réalisée. L'analyse a ensuite été comparée à la littérature actuelle et à une analyse parallèle réalisée dans la littérature grise par le Dr Zambonino (1), dans le cadre du groupe de recherche brestois.

Résultats : Documents extraits : 484 (Pubmed) + 586 (Psychinfo). 28 doublons. 1042 résumés soumis à analyse, 921 exclus. 121 articles soumis à éligibilité, 17 ont été inclus, 2 non trouvés.

Boule de neige : 436 références. 41 doublons. 395 résumés soumis à analyse. 377 exclus. 18 articles soumis à éligibilité. 6 articles inclus. 23 articles ont été intégrées.

Analyse thématique : 156 codes axiaux, 23 codes théoriques regroupés en 10 thèmes : sphère individuelle, entourage, sphère soignante, société, la Cour, principes de bioéthique, élaboration du document, temporalité, communication, interprétation.

Conclusion : Plusieurs problèmes ont été identifiés, pouvant expliquer le faible taux d'achèvement des ADs. Leur connaissance peut améliorer la pratique en fin de vie.

Proposition de mots clés en français : *directives anticipées, éthique, population générale, loi d'opposabilité, problèmes*