

# Does any transverse and invariable barrier for writing and carrying out an advance directive exist?

Victor Le Guen

### ▶ To cite this version:

Victor Le Guen. Does any transverse and invariable barrier for writing and carrying out an advance directive exist?. Life Sciences [q-bio]. 2021. dumas-03240463

## HAL Id: dumas-03240463 https://dumas.ccsd.cnrs.fr/dumas-03240463

Submitted on 28 May 2021

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# THESE DE DOCTORAT EN MEDECINE

## DIPLOME D'ETAT

Année : 2021

Thèse présentée par : Monsieur LE GUEN Victor

Thèse soutenue publiquement le 06/05/2021

Titre de la thèse :

#### DOES ANY TRANSVERSE AND INVARIABLE BARRIER FOR WRITING AND CARRYING OUT AN ADVANCE DIRECTIVE EXIST ?

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#### **Remerciements**:

#### A Monsieur Le Professeur Le Floch Bernard.

Vous me faites l'honneur d'accepter de présider ce jury de thèse, après avoir été d'un soutien inestimable sur ces derniers mois. Veuillez trouver ici le témoignage de ma considération et de ma gratitude la plus sincère.

#### À Monsieur le Docteur Nabbe Patrice.

Pour m'avoir aidé à relever la tête, en me proposant ce sujet de thèse et en acceptant de la diriger, au cours d'une période qui s'est éclaircie petit à petit par votre soutien et vos conseils. Trouvez ici la marque d'une estime profonde envers votre pratique au sein de la faculté, auprès des étudiants et auprès des patients. Votre humanité a marqué ma manière d'appréhender la pratique de la médecine.

#### À Madame le Docteur Guillou Morgane.

*Votre engagement dans la recherche et l'enseignement en médecine générale apporte une grande importance à votre jugement. Je vous remercie de siéger dans ce jury.* 

#### À Monsieur le Docteur Hazif-Thomas Cyril.

Pour votre présence enrichissante lors des groupes de thèse. Je vous remercie de siéger dans ce jury. Veuillez trouver ici l'expression de ma sincère gratitude.

#### Aux docteurs Cueff Patrick, Meudec Pierre-Yves, Gobert Jean-Pierre, Grenier Gilles

Pour m'avoir permis d'initier, penser, modeler ma pratique de la médecine générale aux cours des semestres passés dans vos cabinets respectifs. Merci infiniment de votre confiance, travailler avec vous a été un enrichissement constant et d'une chaleur humaine indéfectible.

#### **Remerciements Particuliers:**

#### A mes parents, Dominique et Philippe,

Maman, Papa, ces mots ne suffiront qu'à peine à effleurer la gratitude envers le soutien indéfectible que vous m'avez porté au cours de ces longues années, de la force que je trouvais dans vos mots, dans vos regards quand le mur me paraissait trop haut. Merci du fond du coeur, je vous aime profondément.

#### Une pensée pour mes grands-parents, partis trop tôt

Et plus particulièrement à toi Mamy, ton éducation m'aura porté jusqu'ici et continuera à m'entrainer encore longtemps. Je ne peux qu'imaginer la fierté que tu aurais ressentie en me voyant aujourd'hui.

#### A mon frère, Boris

Pour ton aide précieuse, ton soutien inestimable, et pour me permettre échange après échange, voyage après voyage, de voir la vie par un angle curieux, chaleureux, ludique.

#### A toi Salomé

Pour tout ce que je peux trouver et puiser dans ton regard et ta présence auprès de moi. Pour ta patience à mon égard pendant l'élaboration de cette thèse, mais aussi pour me donner le sourire chaque jour, et surtout pour me l'avoir redonné aux moments où je ne le trouvais plus. Je t'aime!

#### A toi Philippe

Merci du fond du coeur pour m'avoir attendu et soutenu jusqu'à ce moment. C'est avec une fierté immense que je m'apprête à te succéder, j'espère être à la hauteur de ton travail et de ta vision de la médecine. Elle m'a d'abord soignée depuis mon enfance, elle m'a ensuite inspirée dans nombre de situations au cours de ma pratique, et elle me suivra tout au long de ma carrière, sans l'ombre d'un doute.

#### A toi Noéline

Pour l'inspiration que je trouve dans ton énergie débordante, ton empathie et ta façon d'apprehender les épreuves. Ne change rien, je suis très fier d'être ton cousin.

#### A vous Alexandre et Alexis

Pour ces années d'amitié jamais démenties, parce que je sais que je peux avoir une confiance aveugle envers vous, vous me l'avez encore prouvé récemment! A nos discussions, nos verres, nos chants et danses très peu assurés, on continuera à se marrer comme des baleines sous substances, c'est une certitude.

#### A mes ami.e.s, proches et ceux que le temps a éloigné

Trouvez ici le témoignage de mon amitié sans faille d'une part, et de ma gratitude pour ce que vous pouvez m'apporter par votre personnalité d'autre part.

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## Abstract

### Introduction

Advance directives represent a strong societal debate, and improving its completion rate a subject of interest. After the identification of barriers from specific populations accomplished by the EA 7479 SPURBO, a question occurs: does any transverse and invariant barrier for writing and carrying out advance directives exist?

### <u>Method</u>

To resolve the question, a pragmatic approach inspired by the Grounded Theory had been chosen. It combined a set of systematic reviews of the literature and qualitative studies previously done by the EA-7479-SPURBO used as datas. A conceptual model, resulting from the synthesis of all this research, was produced to answer the research question.

### Results

Eleven open codes, three sub themes had been spotted, gathered under an invariant and transversal theme: the conflict anxiety, which represented a transversal barrier as the research question asked.

As a way to understand the mechanism of this barrier, a conceptual model was proposed. Eleven accessible and empirical elements acted in a synergic way to irrigate three theoretical concepts (Altered confidence, advance directive's viability, leading to a change in behaviour) improving uncertainty. By doing so, the three concepts gave access to the core of the conceptual model, the conflict anxiety.

#### **Discussion**

By submitting this, it allowed a broader vision of the advance directive's concept and may allow a better comprehension of that barrier standing against the application of advance directive, and so for every person involved.

Key words: Advance directive, uncertainty, conflict anxiety

## <u>Résumé</u>

### Introduction

Les directives anticipées sont un sujet de débat sociétal prégnant, et améliorer son taux de complétion un sujet d'intérêt. Suite à l'identification de freins spécifiques à certaines populations réalisée par le groupe d'études EA 7479 SPURBO, une question s'imposait : existe t'il des freins invariants et transversaux à l'écriture et l'application de directives anticipées ?

#### <u>Méthode</u>

Afin de résoudre la question, une approche pragmatique inspirée de la théorie ancrée a été choisie. Elle s'appuyait sur des revues de littératures systématiques et des études qualitatives précédemment réalisées par l'EA-7479-SPURBO comme source de données. Après synthèse de ces travaux, un modèle conceptuel a été proposé afin de répondre à la question de recherche.

#### <u>Résultats</u>

Onze codes ouverts, trois sous thèmes ont été relevés, s'agglomérant autour d'un thème invariant et transversal : l'anxiété conflictuelle, qui représentait le frein transversal recherché.

Afin de comprendre les mécanismes de ce frein, un modèle conceptuel a été établi. Onze notions accessibles et empiriques agissaient en synergie pour irriguer trois concepts théoriques (confiance altérée, Viabilité des directives anticipées ; Impliquant un changement de comportement), augmentant l'incertitude. Se faisant, ces trois concepts donnaient accès au cœur du modèle, l'anxiété conflictuelle.

#### **Discussion**

Ce modèle permet une vision élargie du concept de directives anticipées et pourrait participer à une meilleure compréhension de ce frein s'opposant à leur application pour toute personne impliquée.

Mots Clés : Directives anticipées, incertitude, anxiété conflictuelle

## SUBJECT: DOES ANY TRANSVERSE AND INVARIABLE BARRIER FOR WRITING AND CARRYING OUT AN ADVANCE DIRECTIVE EXIST ?

## 1. Introduction

Conjointly of the major development of the medical technology and the undeniable therapeutic progress, patients, citizens and their representatives develop a stronger wish of being actors of their health, and by doing it so, to maintain the medical world in a complex and contradictory reality. Thus, through the XX<sup>th</sup> and XXI<sup>th</sup> centuries, the caregivers have putted the patient at the center of their care, leaving the paternalist pattern (1).

To testify these evolutions and the growing importance of the patient's opinion, the many works about the end-of-life (2,3), which take an essential importance with the technological improvement, the growing life expectancy, and also the massive impact that some stories took in France, as Vincent Lambert or Chantal Sébire's end of life (5-6).

Thereby M. Sicard, MD that accomplished a mission named « Penser solidairement la fin de vie (7), « United thinking about the end of life », in 2012 for the Presidency of the French Republic, said at this time « We believed in the power of medicine just as we believed in God. We have forgotten our own finitude, in the sense of the human condition: to be born and to die ».

It was in this context in France, that appeared the Advance Directives (AD), created by the 2005 Leonetti's Law, for the rights of the terminally ill patients (8). AD express « individual wishes for its own end of life, about the terms of keeping on, limiting, stopping or refusing a life sustaining treatment or medical act », drafting on a « written document, dated and signed by its author ».

Later, the Sicard's works, already mentioned, would lead to an enhancement of the 2005 law: the Clayes-Leonetti's law, in 2016. This one brought two majors updates for the patient's decisional power: an AD is legally enforceable, and the right to a deep and continuous sedation (9).

AD are a mighty symbol of the stronger and stronger willingness that develop the patients to be an active part of their own health, of their own treatments' management, and for their own end of life. However, despite a strong joining in favor of the AD's concept, ADs completion rate is still low in the French population, although in progress (from 2,5% in

2006 (7) to 14% in 2017 (10)). The reasons why remain poorly known.

Based on the hypothesis that it is possible to improve the dissemination and use of advance directives by the general population and caregiver, the EA 7479 SPURBO has built a research team for this purpose. The identification of the barriers and the facilitators modulating the advance directives was a necessary prerequisite.

There was no question of looking for modulating factors specific to a population. But on the contrary, to identify the invariant factors whatever the type of population: general or specific, caregiver or non-carer.

A large-scale study was set up, using the tools of qualitative research. The aim of this study is to identify more precisely the brakes and barriers to the application of ADs throughout the world.

Each country applying them, has specific approaches; but is it possible to find invariant transversal concepts, whatever the language and the culture? And could these concepts be used by France to improve the use and dissemination of ADs among the population?

The research question was: Does any transverse and invariable barriers for writing and carrying out an Advance Directive exist?

## 2. Method

Only the Grounded Theory gives the possibility of carrying out an exploratory study of this importance. But Grounded theory is longitudinal. It requires exploration over several years (11).

By drawing inspiration from this model, a pragmatic approach could be envisaged. It would combine a set of systematic reviews of the literature and interviews using the tools of qualitative research.

A conceptual model, resulting from the synthesis of all this research, could be produced to answer the research question.

In a pragmatic way for saving some time, the data sampling was not theoretical and vertical but pre established and transversal.

### 2.1. Creation of the Thematic Database

A research group has been created, bringing together general practitioners, psychiatrists and geriatricians. The group included a member of the ethics committee.

In focus group, they listed typical populations:

- of patients: the general population, populations with chronic diseases, psychiatric diseases, cognitive diseases, ...

- of caregivers: doctors, nurses, home helpers, ...

The aim was to reach a maximal variation sampling in order to create the thematic database to produce an hermeneutic broadest possible (12 to 22). According the principle that datas exist (23) and could be extracted from technical and non technical literature (24) that fitted with the « all is data » precept (25) established by Glaser, and developed by Charmaz (23)

### 2.2. Technical literature used for analysis

Every included systematic literature review (12 to 18) followed the PRISMA guideline and each focused on a specific population's point of view.

At the end of each review, an article database was created. A thematic analysis was then applied, with two independent researchers. They compared their results at the end of their coding, then they proposed their result of the thematic analysis to the research group. Based on consensus, each of these analyzes was frozen once the process was

completed. Each of these systematic reviews identified the specific's barriers of target populations.

### 2.3. Non technical literature used for analysis

It included a narrative literature review of the grey literature that followed the PRISMA guideline (22). The decision of analyzing this one allowed to realize a non-selected population review for enlarging the population panel.

### 2.4. Qualitative Studies

A series of qualitative studies were carried out, including individual (19) or collective interviews (20) or focus group (21). Each had reasoned sampling in a target population to achieve specific ecological validity. The coding of verbatims was systematically carried out by two independent researchers. Once the axial coding was obtained, the results were compared. The interviews were continued until they reached theoretical saturation

### 2.5. Conceptual model's building

Once all this work was done, the design of a global model could begin.

Every previously quoted source has produced a thematic analysis and a thematic table. Every table contained the open, axial, selective and super codes founded by the researchers.

For every data source, used datas were checked throughout three steps, simultaneously successive and nested as implied in an iterative approach with continuous comparison (11):

- Open Coding
- Axial Coding
- Selective coding

For every data source, the open coding phase was made by using the open codes already available in the thematic analysis table of every source, or, if the open code was not clear enough, by reaching the raw data which was linked to this particular open code. By doing so, the datas were analyzed once again throughout the prism of the research question.

These processes led to a new thematic analysis table focused on transverse and invariable barriers, used to build the conceptual model.

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### 2.6. Scientificness

Each exploited data was contextualized following the Conceptual positioning principles (26), to ensure the study's scientificness.

This one was improved by the variety of the sources used for the data's sampling (25). Triangulation of open coding was made independently by a second researcher. Results were compared and if any discordance occurred, it was discussed until a consensus emerged. This analysis was led until theoretical saturation (27)

### 3.1. Population and authors' characteristics of the thematic database

#### 3.1.1) In Systematic literature reviews

6 systematic literature reviews were used (12-18): 5 of them were centered on caregivers and/or patients point of views.

The last one (18) was centered around the legal and ethical side of ADs.

Table 1 summed up the major characteristics of studied population and highlights the maximum variation reached in 5 literature reviews (12-17).

Every characteristic spotted in every used sources are detailed in Appendix 1.

TABLE 1: Sum up of population's characteristics in systematic literature review	
Number of different countries represented	16
Number of different ethnicities met	6
Number of professions represented among caregivers	18
Number of professions represented among general population	16
Age Range	From 15 to 106 years old
Characteristics of Patients	- Inpatients
	- Outpatients
	- healthy
	- with organic diseases
	- with mental disorder
Patients' proxies	- patient without relative
	- family
	- friends
	- Case managers/surrogate decision makers

The characteristics of main authors of every studies used in the literature review done by E.Krurien (18) are detailed in Appendix 2.

### 3.1.2) In Grey literature review

Multiplicity of used sources in the grey literature review done by M. Zambonino (22), as described in appendix 3, gave access to a large non selected population and point of views from many researchers.

As spotted in the discussion of Krurien's systematic literature review (18), the findings of this literature review and the results of the narrative study of grey literature are coherent.

### 3.1.3) In Qualitative Studies

Three Qualitative studies were used: one using individual interviews' method (19), two using a focus group method (20,21).

Sampling gave access to a representative population (31 women, 23 men) from the population of General Practitioners in Brittany, France, with different characteristics (age range: 26 to 65 years old, several working environments...) as spotted in the Appendix 4.

### 3.2. Open Codes

Indexing details of every analyzed works are showed in Appendix 5

#### 3.2.1) Social acceptability

AD's notion was associated with several concepts in the general population mind, more or less true and accurate: euthanasia, fear of an altered care, social weight, questioning about the deep reason behind the AD's carrying out politic...

« the fear that it would be considered as a request for euthanasia » (13), « many arguments against ADs, such as (...) leading to euthanasia » (16), « It's not something that is mainly accepted in society to speak about unpleasant things when you're feeling ok» (19), « The high cost of Healthcare let the people suspicious » (18)

### 3.2.2) AD's accessibility

ADs were seen as difficult to reach, and so poorly usable. Firstly for the access to already established ADs: in an emergency situation (« Written AD are not reachable for the practicians in an acute situation» (20)), unclear models (« The documents were viewed as to cumbersome by 79% of the clients » (15)) that might be modified before its

application (« Written AD no longer matching with the recent willingness that the patient express»(20)). Secondly, ADs are difficult to reach in its conception: lack of knowledge of the technical terms, not knowing what to put in a AD, lack of public communication, lack of time or logistical problem

#### 3.2.3) Standardization

Subjects that matter for designing an AD are complex to understand, to elaborate, and to writing it down, for the patient and his caregiver («Complex situations, hard to clearly foresee int he written AD» (21) « lack of knowledge regarding the details of the documents completion » (13)). A standard pattern was often seen as a facilitator to writing and carrying out the AD (« providers were critical to the fact that no standard (...) were in place to facilitate Psychiatric Advance Directive implementation » (15)) and to limit the interpretation of the AD (« if the content of the AD is opaque, there is interpretation », « proxies, doctors (...) often must interpret these documents » (18)).

Despite that, standardization is rather seen as a barrier, because of the « clinical freedom constraint » that it could brought, and the risk that it weak « both the family and physician sense of responsibility » reducing them to be the « executors of patient's wish » (18). Furthermore, standardization could fail to reflect the complexity of a situation (« many participants remarked on the limited options of the future treatments » (15), «All ADs are the same and lack of forecast» (21)).

#### 3.2.4) Non Consensual Making Of

AD was made to improve the control of each patient about his end of life, by promoting his autonomy on this subject. But « self determination and free will could lead to a form of loneliness » that could prevent the « storytelling of (a) life » (22). But an AD would not impacted only the patient, but also his relatives and his caregivers, in a dynamic process.

By doing a non-consensual making of an AD, an opposition from a side could born: « medical refusal to honor patient's wishes » (18), « applying a relative's AD with whom we disagree »(20), « a biding directive with which the family did not agree would be subject to an appeal through the court » (17).

Also, it seemed to limit the efficiency of the AD: « not knowing what to include » (15), difficulties to « define the therapeutics' limitation » (20), « surrogates tend to make prediction error of overtreatment » (18). Frequently, this non consensual approach was

the result of a poor communication between the actors: « physicians rarely assist their patients in drafting ADs » (12), « family is uninformed » (14), « difficult to collaborate between the caregivers » (22). Sometimes, this consensual approach was impossible (« cognitive disorders are a barrier to elaborate a AD » (21)) leading to a trouble feeling (« staff discomfort » (14)).

#### 3.2.5) Responsibility

AD is seen as a personal weight (« fear of dying prematurely from negligence in AD »(13) « ADs influence medical decisions » (16)) or as a « burden » given to others « by assuming responsibility for treatment in advance of crisis » (15). The legal framework gave to AD a « binding form through the repeated incitements », which is seen as a « risk of institutional drift » (22). This feeling is enhanced by the reasonable doubt that may surround an AD: what to do with a Do not resuscitate order from a patient with an acute depression? Or when a « demented patient doesn't understand enough the situation » (12)? Or, when « pressures surrounding the person may exist » (13)?

Thus « AD represent unwarranted extension of law into the practice of medecine » (16) which brought doubt in the relation between the actors (« autonomy can be placed above the doctor's duty to save life » but « fear of abuse limit their employment » with the risk of « legal consequences when there is misunderstanding » (18)).

#### 3.2.6) Revocability

Revocability of AD was compelling, to insure that an AD could follow the willingness of the patient that might evolve with any event occurring in his life. « Patient, depending the time before his death, won't have the same identity on a philosophical plan » (22).

This possibility of an evolving AD through time represented a barrier to indeed apply the AD. There was always a doubt that the available AD was still matching the last thought of the patient, or if the AD was still matching with a particular situation, as an emergency, or when the patient had a cognitive disorder. « There are conflict with the principles of beneficence and non-maleficence » (18): this conflict could be seen when an acute situation occur for a demented patient. Even if a DNR order is written in an AD, it seemed impossible to be sure that this particular AD was made when the patient was fully competent, or if this order was still matching with the state of mind of the patient at the

moment of the crisis. (« Caregivers see an ethical obligation to ignore the AD of a severely demented but »happy » patient » (12)).

AD could be seen as pointless, not effective, because of its revocability, when an AD was drafted « too soon »(18), for a young patient which AD was likely to change in the future. Furthermore, revocability introduced the « doubt that (...) ADs are being followed » (13) by caregivers because of their own interpretation of the ADs through their point of view, or if « the family not agreed » (20).

#### 3.2.7) Concept of death

A transversal notion about death is represented by the social taboo that it was: « death taboo in the society » (22), « reluctance to talk about it », « forced to stop talking about it because embarrassing other » (14).

Even if every AD was not about the death itself, the concept of death was radiating at every time that a discussion about AD occurred. Because everybody had a single vision of that concept, builded by belief, religion, culture, ethnicity (« For Afro-Americans AD is considered as a death sentence and not as a freedom of choice »(13)), personal history and professional experience, a discussion about it could lead to a conflict, if the expectations around end of life were different: « patient doesn't realize what is implied by his illness »(20), « Difficult to project oneself in a dependent state, but finally being able to dealing with it »(22) « different background influence decision making process » (12) To foresee death with an AD made it a bit more realistic, and therefore AD was opposite to social convention: « the principle of autonomy and sanctity of life are brought into conflict »(18), or leading to ethical and professional problem: « knowing where to put the limit between the care and the unreasonable care » (16), « there is reluctance of medical profession to discontinue treatment » (18).

#### 3.2.8) Experience

-Elaborated ideas by one person after being exposed to an event that belong to the field of the AD could be lived with a negative feeling: disappointing or painful experiment, or being in conflict with his own willingness or professional practice: « experience in contact with relatives at the end of their life sometimes perceived negatively », « reluctance to write ADs for lack of confidence/historical facts of racism and deep seated discrimination » (13), « physicians are not inclined to comply with ADs if ADs differ from their medical judgement » (12).

### 3.2.9) Lack of Experience

AD were conditional and theoretical. Therefore « concrete decisions depends on specific experience » (18). A lack of experience around a subject concerning ADs is often felt. It brought a feeling of embarrassment, inadequacy that restrained a theoretical projection of oneself in an end-of-life situation. So, it made difficult to value all the potential interest of the AD. This lack of experience concerned several domains:

- patient feeling in a good health (« had never thought about writing them down before, were too young or felt it was too soon »(17))
- lack of public information (« lack of knowledge (not aware of) »(15))
- lack of professional training (« nurses need education to decrease difficulties with ADs » (14))
- New medical situation for a practician (« practician doesn't think about it »(19)
- Lack of knowledge about the patient from caregivers or relatives (« easier to explain themselves to someone who know by experience what are they going through »(15))

#### 3.2.10) Negative thought

To bring up the topic of ADs with someone gave a negative/pessimistic touch to the discussion, via:

- negatives preconceptions (« ADs could lead to euthanasia » (16))
- Painful memories (« experience in contact with relatives at the end of their life sometimes perceived negatively »)
- Dark forecasts (« physician fears that patient'll feel assaulted with a talk about AD » (20), « not talking about AD when patient still has hope for cure » (21) »

The negative thinking experience, brought to oneself or to others, acted as a barrier to AD: « A projection into a future medical situation is often felt as a psychic violence » (22)

#### 3.2.11) Evolution of Illness

Unpredictability and inconstancy that anyone had facing an evolution of an illness, and the experience that is earned may switched the willingness that was expressed in the AD. Thus its implementing could be obsolete. « Imminence of our death changes our

judgements and certainties », « Risk of AD is to remain fixed and to do not take into account the temporality »(22)

Possibility of a new treatment, influence of a treatment or illness on decisional capacities were also barriers to writing and carrying out ADs: « How does one ensure that AD were made when the individual concerned was competent/capable, or take into account new development in knowledge and treatment that occur in the time between making and implementing the AD? »(17)

### 3.3. Sub-themes

### 3.3.1) Leading to a change in behavior

Individual behaviour is set by pre-established notions belonging to some different fields, that could be mobilized by the concept of AD: life story, health status, belief, professional training, knowledge...

Intrusion of AD appeared as an actor of a forced change of this behaviour, brought by the notions already described above, leading to an unknown and uncertain state. Tension that was borne after this inducement participated to brake writing and implementing AD.

#### 3.3.2) Altered confidence

Many uncertainties coming from the notions above carried a lack of confidence for a person, at three different levels:

- Lack of confidence in oneself: « AD may be biased by the utilitarian vision of the society, patient seeing himself as a weight for his relatives » (22).

- Lack of confidence in other: « pressures surrounding the person may exist » « there is a fear of abuse by physicians » (18).

- Lack of confidence about the concept of AD: « Implementing AD is near therapeutic abuse » (20), « AD is seen as useless or dangerous » (22).

Once again, a transversal and invariant concept appeared, with a dynamic between the actors of the writing of AD.

### 3.3.3) AD's Viability

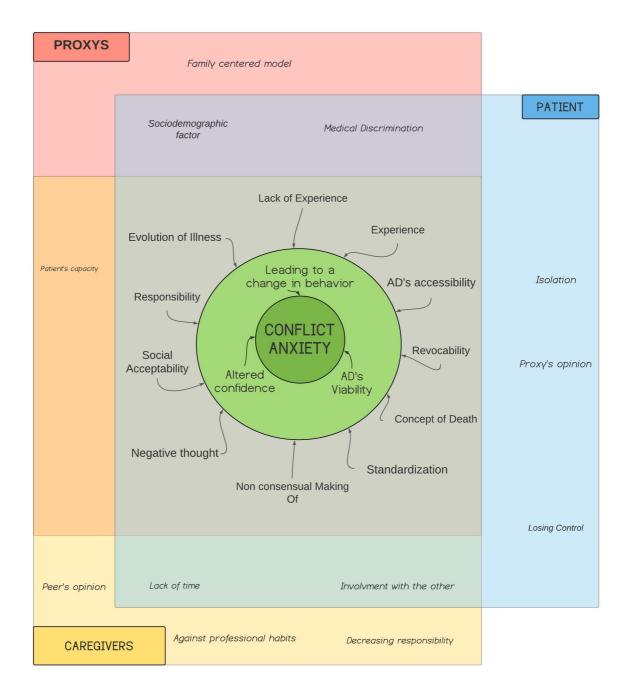
Every doubt borne with all previous notions made the concept of AD questionable: did the AD remain sustainable? The viability was challenged at two levels: the viability at a precise moment and the viability in time flow.

### 3.4. One transversal and invariant theme: Conflict Anxiety

Dealing with AD's concept seemed to set up a fear of conflict in any person's mind.

As conflict is described as « a struggle induced by the meeting of opposite elements », ending on a « relationship structured around an antagonism » (28). Specifically, the conflict was here interpersonal, arising from differences in values, needs, interests, opinions, goals, or objectives (29): « some people distrust the care providers », « conflict arise between the wishes of a patient and the vies of legal representative » (18), « Most of GPs ignore the opinion of the proxies » (16). The potentiality of conflicts that AD's concept permitted, arose anxiety, seen as « a future-oriented emotion characterized by marked negative affect, (...) and chronic apprehension » by Barlow (30).

## Figure 1: Theoretical Conceptualization



## 4. Discussion

### 4.1. Main result

Using the thematic analysis, a theoretical conceptualization (figure 1) emerged from the selective analysis, that allowed an explanation about the making of a major invariant barrier for AD: conflict anxiety.

Open codes were seen as empiric and accessible notions, surrounding a core of more built and theoretical concepts.

All surrounding notions were elaborating the external layer of the core in a synergic way. The external layer contained three concepts (sub themes previously found) that shared one characteristic: increasing the uncertainty around the AD's concept. Here again, these synergic notions were feeding the core of the concept, an invariant and transversal barrier for writing and applying ADs: The Conflict Anxiety.

As the theoretical conceptualization is made, it showed that the barrier is not a static element but a dynamic concept sharing between every population and built from empirical notions that acted in a synergic way to increase uncertainty around AD's concept.

By allowing that, antagonisms were easier to reach, so as conflicts, and yet the conflict anxiety.

### 4.2. Comparison with literature

### 4.2.1) Uncertainty as a source for anxiety

Uncertainty was linked to anxiety through the intolerance of uncertainty (IU) theory. Carleton described IU as « an individual's incapacity to endure the aversive (i.e., fearful) response triggered by the perception of one or more salient or key unknowns and sustained by the associated perception of uncertainty » (31).

Boswell and al (32) saw IU as a causal factor in the Triple Vulnerability Model of anxiety elaborated by Barlow and al (33), and as Hong and Cheung demonstrate, empiric proofs of causal effect of IU on anxiety are growing (34). Gu and al described uncertainty as a fuel of anxiety (35).

#### 4.2.2) Anxiety leading to avoidance behavior

Defense mechanisms against anxiety are developed since Freud worked on the psychoanalysis method (36). American Psychiatric Association built a classification in the DSM IV (37), that is enhanced by Vaillant's work. Here, conflict anxiety enlisted two high adaptation level: anticipation, and suppression (38).

#### 4.2.3) Fear of conflict from other perspectives

If we considered drafting ADs as a task accomplished by people working as a team with a common goal, similarities could be found with some works done in management domain. Teamwork presupposed three types of conflict: relationship, process and task conflicts (39). Process conflict and uncertainty are linked (39), and relationship conflict could inhibit cognitive function (40). At work, role conflict occurred « when the various social roles one is expected to perform provide incompatible behavioural prescriptions ». Attempting to avoid it was one way of deal with it (41).

This strategy of conflict avoidance seemed to be a cognitive function, studied by the lens of neuropsychology (42,43).

### 4.3. Strength and limitations

This study had several limitations

#### 4.3.1) Sampling limit

In a pragmatic way for saving time, sampling was not vertical and theoretical but transversal and pre-established. It was set by a focus group with the willing to reach the maximal variation sampled population.

Qualitative studies were done by sampling only general practitioners. This limit is controlled by the quality and the diversity brought by the systematic literature reviews, especially the ones centered on patient's point of view.

#### 4.3.2) Selection limit

Each systematic literature review had been conducted following the PRISMA method, and each thematic analysis was done by a blind double coding with comparison.

Interviews and focus group answered to the quality norms of qualitative studies as they had been done with a blind double coding and led until theoretical saturation.

### 4.3.3) Information limit

Each include study in literature reviews was read in depth, through the research question. Interviews and focus group were conducted to control the leader effect, and by insuring the participation of every subject. For the present study, open coding was done from the open codes or raw datas, and the results were submitted to a double reading from another researcher. If a disagreement occurred, it was discussed.

### 4.3.4) Confusion limit

Thematic analysis was done after the hermeneutic, that led to a heuristic outline for each literature review and qualitative study.

Thematic analysis and outlines were done after that the results were frozen.

Our own work was done after checking the relevance of the previous results by doing the analysis through the open codes and the raw datas if the open codes induced confusion.

### 4.4. Implication for practice

To spot the existence of an invariant barrier for writing and applying ADs would allow a better understanding of the dynamic implied behind a reluctance to carry on ADs, both for an internal one as a practitioner and the patient's, or proxy's, one. To expose the accessible notions that participate to elaborate a conflict anxiety would allow a better communication by defusing the trigger of the uncertainty.

### 4.5. Implication for research

Firstly, this theoretical conceptualization needs to be checked through a study using a longitudinal and vertical methodology as the Ground Theory requests.

Secondly, the spotting of a transversal barrier opens the way to research a transversal facilitator, maybe which will answer the conflict anxiety.

Seeing AD's barrier through the lens of management could be a track for solving that problem.

## 5. Conclusion

This study spots the existence of an invariant barrier to writing and carrying out AD: the conflict anxiety. It also considers this barrier as a construct, following steps with several notions also transversal and invariant. By doing so it may allow a better understanding of the triggers that prevent a better AD's completion rate.

By opening the problematic of AD to other domains it may offer original ways to improve this completion rate.

## **Abbreviation**

AD: Advance Directive AED: Advance Euthanasia Directive CPR: Cardio Pulmonary Resuscitation **DA Directives Anticipées** DMP Dossier Médical Partagé DNR: Do Not Resuscitate DSM Diagnostic and Statistical manual of Mental disorders ECP: Elderly Care Physicians EHPAD Etablissement d'Hébergement pour Personnes Agées Dépendantes EOL: End Of Life ER: Emergency Room **GP: General Practitioner** IM: Intra Muscular IU Intolerance of Uncertainty JCP: Joint Crisis Plan MG: Médecin Généraliste MHAD: Mental Health Advance Directive MT: Médecin Traitant PAD Psychiatric Advance Directive PCP Primary Care Physician PRISMA Preferred Reporting Items fir Systematic reviews and Meta Analyses SAMU: Service d'Aide Médicale d'Urgence SMI: Serious Mental Illness

#### **Acknowledgment**

A special thank to the research group of the EA 7479 SPURBO who allowed this study by their remarkable previous works: BOYER Isabelle, COSQUER Anthony, COTTEREAU Léa, KRURIEN Enora, LEBRUN Alexandra, MACIEJEWSKI Laure, MOUSTER Axel, PANCHER Jeanne, POISSON Fanny, SOUCHET Claire, ZAMBONINO Marine and to the manager Dr Patrice NABBE.

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3.De la Gontrie and al. Proposition de loi visant à établir le droit de mourir dans la dignité n°20-131 du 17 novembre 2020 (en ligne) Disponible sous

4. Béguin F. « Alain Cocq demande à Emmanuel Macron le « droit à une mort digne » ». Le Monde 2020/09/01

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#### **Appendix 1**: Population's characteristics in systematic literature review: specifics

#### Titles of the systematic literature reviews used in the table below

A) MACIEJEWSKI L. - Point of view of the population suffering from psychiatric illnesses about Advanced Directives. A thematic analysis based on a narrative systematic literature review. [Thèse de doctorat, Faculté de médecine et de sciences de la santé]. Brest : Université de Bretagne Occidentale ; 2020

**B)** LEBRUN A. What factors limiting advance directives writing highlighted in patients? A systematic literature review [Thèse de doctorat, Faculté de médecine et de sciences de la santé]. Brest : Université de Bretagne Occidentale ; 2020

**C)** COSQUER A. - Perspective, attitude and experience of medics/paramedics on advance directives among demented patients. A systematic literature review. [Thèse de doctorat, Faculté de médecine et de sciences de la santé]. Brest : Université de Bretagne Occidentale ; 2020

**D)** SOUCHET C. – Perspective, knowledge and experience of general practitioners on advance directives. A systematic literature review. [Thèse de doctorat, Faculté de médecine et de sciences de la santé]. Brest : Université de Bretagne Occidentale ; 2020

**E)** MOUSTER A. - What are the barriers to the implementation of advance directives related to the surroundings of the patients with unfixed psychiatric illness ? A systematic literature review. [Thèse de doctorat, Faculté de médecine et de sciences de la santé]. Brest : Université de Bretagne Occidentale ; 2019

Systematic literature review:		A)	B)	C)	D)	E)
Country:	USA	х	х	х	х	х
	Australia	х			х	
	India	Х				
	United Kingdom	Х	Х	Х	Х	Х
	Netherland	Х		Х		Х
	France	Х	Х			Х
	Belgium	Х		Х		Х
	Canada		Х	Х	Х	
	Germany		Х	Х		Х
	Switzerland		х		х	
	Spain		Х			
	Japan		Х			
	China		Х			
	South Korea		Х			
	Sweden			Х		
	Singapore				х	
Ethnicity:	White/ Caucasian	Х	Х	Х	Х	Х

Systematic literature review:		A)	B)	C)	D)	E)
	Black	Х	х	Х	Х	х
	Asian	Х	Х	Х		Х
	Hispanic/ Latino	Х	Х	Х		Х
	Native Americans	Х				
	Pacific Islanders		Х			
Gender:	Man	Х	Х	Х	Х	Х
	Woman	Х	Х	Х	Х	Х
Professions represented	Nurses	Х	Х	Х	Х	Х
among caregivers	Palliative Care Nurse				Х	
	Psychologist	Х				Х
	Occupationna I therapist	Х				
	Psychiatrist	Х				Х
	General Practitioner	Х	Х	Х	Х	Х
	PhD in public health	Х				
	Mental health clinician	Х				
	Psychiatric emergency clinician	Х				Х
	Specialist practitioner		Х	Х	Х	
	Pharmacy		х			
	Music Therapist		Х			
	Integrative Therapist		Х			
	Elderly Care Physician			Х	Х	
	Nursing Home Manager			Х		
	Internal Medecine Practitioner				Х	

Systematic lite	erature review:	A)	B)	C)	D)	E)
	Emergency Physician				Х	Х
	Jail Mental Health Service					Х
Professions represented	Unemployed	Х	х			
among general population	Homemaker	Х				
	Student	Х				
	Crisis Card Counselors	Х				
	Police officer	Х				Х
	PhD in philosophy	Х				
	Social Worker	Х		Х		Х
	Professional and managers of non manual labor		Х			
	Routine non manual employees					
	Self employed artisans		Х			
	Farm Workers		х			
	Veterans		х			Х
	Advocate					х
	Administrator s					Х
	Clergy					Х
	Researcher					Х
Characteristi cs of patients	Inpatient	Х	Х	Х	Х	Х
	Outpatient	Х	х	Х	Х	Х
	Mental Disorder Disease	Х	Х	Х		Х

Systematic lite	erature review:	A)	B)	C)	D)	E)
	Organic Disease		Х	Х	Х	
	Terminal State Disease		Х	Х	Х	
	Living in a nursing home		Х	Х		
	Living at home		Х	Х		
	Rated as in good health	Х	Х			
Proxy's link to the patient	Patient without relatives	х	Х			
	Family	Х	Х	Х	Х	х
	Friends					х
	Case Manager/ surrogate decision maker	Х				Х
Age Range		18 to 75 years old (YO)	18 to 92 YO	15 to 106 YO	21 to 92 YO	20 to 88 YO

# Appendix 2: Main author's characteristic of studies included in Krurien's literature review

KRURIEN E. 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

Title	Source	Year	Author	Country	Major author's job description
The Patient Self- Determination Act: not now.	U	1990	Alexander Morgan Capron	USA	Professor of law and Medicine
The values history. The evaluation of the patient's values and advance directives.	-	1991	David J, Doukas, and Laurence B, McCullough	USA	MD from the department of family practice, university of Michigan
Living wills: Anticipatory decisions and advance directives.		1994	Charles A. Erin, John Harris	England	Searchers at centre for social ethics and policy, University
Advance directives in the UK: legal, ethical, and practical considerations for doctors.	,	1998	Anthony S. Kessel, J. Meran	England	GP, medical ethicist
Biomedical ethics and the withdrawal of advanced life support.		2001	Noreen R. Henig, John L. Faul, Thomas A. Raffin	USA	Pulmonologist
Advance directives and Living Wills.	NeuroRehabilita tion	2004	Laura Palazzani	Italy	Professor of philosophy of law at University of Roma
Enough: the failure of the living will	Hastings Center Report	2004	Angela Fagerlin, Carl E. Schneider	USA	Professor at the population health science department of Utah University/ Professor of Law and Professor of Internal Medicine Michigan University
Advance refusals of life- sustaining medical treatment: The relativity of an absolute right.	The Modern Law Review	2005	S a b i n e Michalowski	England	Senior lecturer in Law, University of Essex
Advance Directives, Future Selves and Decision-Making		2006	Alsdair R. Maclean	England	Senior Lecturer in Law

# KRURIEN E. 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

Medical treatment of dementia patients at the end of life: can the law a c c o m m o d a t e th e personal identity and welfare problems?	-	2006	Penney Lewis	Netherlands	Reader in law
Legitimate advance directive in Germany.	Journal of Public Health	2008	Angela Seifert	Germany	
Substitute decision- making in medicine: comparative analysis of ethico-legal discourse in England and Germany.	Health Care and	2008	Ralf J. Jox, Sabine Michalowski, Jorn Lorenz, Jan Schildmann	Germany	Interdisciplinary centre for palliative médecine Munich/ senior lecturer in Law university of Essex UK
Advance directives and the rocky waters of anticipatory decision- making		2008	Alsdair R. Maclean	England	Senior Lecturer in Law
Advance Directives Refusing Treatment as an Expression of Autonomy: Do the Courts Practise What They Preach?		2009	Lindy Willmott	Australia	Professor at the faculty of law in Queensland
Interpreting advance directives: Ethical considerations of the interplay between personal and cultural identity.	analysis	2009	Silke Schicktanz	Germany	Professor at departement of medical ethic at the University Medical Center Goettingen
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	Member of Institute for ethics and history of medicine in Tübingen
Vague Oviedo: Autonomy, culture and the case of previously competent patients.	Bioethics	2010	Assya Pascalev, Takis Vidalis	USA	Bioethicist/lawyer

# KRURIEN E. 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

		1			
Resolving ethical dilemmas, part 2: Ethical and cultural relativism and other issues in decision-making.		2010	Edmund G. Howe	USA	Professor of Psychiatry
Law, autonomy and advance directives.	Journal of law and medicine	2010	Lindy Willmott, Ben White and Ben Mathews	Australia	Professor at the faculty of law in Queensland
Advance directives and the promotion of autonomy: a comparative Australian statutory analysis.	Journal of law and medicine	2010	Lindy Willmott	Australia	Professor at the faculty of law in Queensland
Advance directives and older people: Ethical challenges in the promotion of advance directives in New Zealand.	<b>`</b>	2011	Phillipa J. Malpas	N e w Zealand	Member of department of psychological medicine, university af Auckland
Advance directives in English and French law: Different concepts, different values, different societies.		2012	Ruth Judith Horn	England	Member of a Centre for ethics in medicine
Advance consent, critical interests and dementia research.	Journal of medical ethics	2015	Tom Buller	USA	Philosophist

#### Appendix 3: Authors' characteristics in Grey literature review: specifics

Zambonino M;, What are the factors that have hindered the achievement of the anticipated guidelines for the community since the Claeys-Leonetti Act? A thematic analysis based on the grey literature review Th.: Med : BREST 2019

Title	Source	Year	Author	Country	Major author's job description
La loi du 2 février 2016 créant de nouveaux droits des malades et des personnes en fin de vie : Rupture ou continuité ?	Book: « Fins de vie, éthique et société » (End of Life, ethic and society)	2016	Doublet	France	Former director of the French Constitutional council legal section
Soins appropriés en fin de vie	Rapport	2017	Mistiaen et al.	Belgium	Nurse researcher
Histoire et définition d'un mot	Book: « L'euthanasie: «Que sais-je? » » ( Euthanasia: What do I know?)	2016	Aumonier et al. *	France	Biologic Philosopher
Législation étrangère	Book: « L'euthanasie: «Que sais-je? » » ( Euthanasia: What do I know?)	2016	Aumonier et al. *	France	Biologic Philosopher
Le droit de la fin de vie	Book: « L'euthanasie: «Que sais-je? » » ( Euthanasia: What do I know?)	2016	Aumonier et al. *	France	Biologic Philosopher
Euthanasie : est-ce ainsi que les hommes meurent ?	Book: « Fins de vie, éthique et société » (End of Life, ethic and society)	2016	Chabert	France	Philosopher
Les personnes en fin de vie : quelle prise en compte de leur parole ?	Dissertation	2016	Belna et al.	France	Searcher from High School of Public health

	Zambonino M;, What are the factors that have hindered the achievement of the anticipated guidelines for the community since the Claeys-Leonetti Act? A thematic analysis based on the grey literature review Th.: Med : BREST 2019				
La loi no 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie : un nouvel équilibre décisionnel ?	Article from « Medecine & loi » (Medicine & law)	2016	Véron et Vialla	France	Conference master of private law and criminal science/ Lawyer
Aspects éthiques des situations de refus et arrêt de traitement	Social Science Thesis	2016	Basset	France	PhD in ethic
Mort par sédation : une nouvelle éthique du « bien mourir ?»	Book: « Mort par sédation : une nouvelle éthique du « bien mourir ?» » (Death by sedation: a new ethic of the well- dying?)	2016	Hirsch	France	Bioethic Teacher
Approche éthique et vulnérabilité en fin de vie	Article from « « Éthique & cancer (s). Cancer psy. 2016 » (Ethic & cancer)	2016	Hirsch	France	Bioethic Teacher
Les enjeux sociaux et éthiques d'une médicalisation de la fin de vie	Book: "Les enjeux sociaux et éthiques d'une médicalisation de la fin de vie » (Social and ethic stakes about the end of life)	2017	Castra	France	Conference master of the faculty of sociology and anthropology
A la recherche d'une fin de vie apaisée	Article from Les tribunes de la santé (Healthcare forum)	2017	Stasse	France	Economist

Zambonino M;, What are the factors that have hindered the achievement of the anticipated guidelines for the community since the Claeys-Leonetti Act? A thematic analysis based on the grey literature review Th.: Med : BREST 2019

			BREGIZEITE		
Directives anticipées et récit de vie	Article from Revue Théologique du Louvain (Louvain Theological magazine)	2017	Jacquemin	France	Priest, Nurse, bioethic phD
Les Directives anticipées : un analyseur privilégié d'un rapport social inédit à la mort	Article from Ethique & santé (Ethic and healthcare)	2016	Marchal et al.	France	Sociologist
Ethique, psychique, pratique, sociétale : quatre fonctions pour les directives anticipées	Article from Laennec santé médecine éthique (Laennec health medicine and ethic magazine)	2016	Mallet et Chaumier	France	Palliative Unit Clinician

#### <u>Appendix 4</u>: Population's characteristics in Qualitative studies: specifics

COTTEREAU L. What are the fa advance directives (AD) within relationship? Qualitative focus gr practionners in Brittany	Quantity	
Country	France	28
Job description	General practice	20
	Student in Medical Internship	8
Age Range	26-65 years old	
Gender	Female	17
	Male	11
Professional environment	Urban	4
	Sub Urban	10
	Rural	6

PANCHER J. What are the barr directives for the general praction interviews Th. : N	Quantity	
Country	France	16
Job description	General Practice	
	Student in medical internship	
Gender	Female	8
	Male	8
Age range	26-63 years old	
Working environment	Urban	
	Rural	
Professional setting	Group activity	
	Single activity	

POISSON F. What are the diffic introduce and discuss advance direc study by individual intervie	Quantity	
Country	France	10
Job description	General Practice	10
	Endocrinology	1
	Palliative care unit	1
	Nursing home's Physician	1
Gender	Female	6
	Male	4
Age range	30-61 years old	
Working environment	Urban	4
	Sub urban	3
	Rural	3
Professional setting	Group activity	9
	Single activity	1
	Liberal activity	10
	Salaried activity	3

RAW DATAS	SUB THEME	OPEN CODES					
<u>1) SOUCHET C. – Perspective, knowledge and experience of general practitioners on advance</u> <u>directives. A systematic literature review. Th. : Méd. : Brest 2020</u>							
ADs are not specific enough to aid GPs	AD's Viability/Altered confidence	Standardization/Access to DA/ Responsibility					
ADs could lead to euthanasia	Leading to a Change in Behavior/AD's Viability	Negative thinking/Experience/ Responsibility/Concept of Death/Social acceptability					
GPs may ignore AD or proxy opinion if they think that is better for the patient	Leading to a Change in Behavior/AD's Viability/Altered confidence	No Consensual Making Of/ Experience/Evolution of Illness/ Revocability					
Most of the GPs ignore the opinion of proxies	Leading to a Change in Behavior/Altered confidence	No Consensual Making Of/ Experience					
Talking about ADs is difficult with sick patients	Leading to a Change in Behavior	Negative Thinking/Concept of Death					
GPs prefer that patient initiates the discussion	Altered confidence	Access to DA/Lack of experience/Negative Thinking					
GPs' views can be affected by erosion of the doctor's moral values under legal constraints if patient has an AD	Leading to a Change in Behavior/AD's Viability/Altered confidence	Standardization/Negative Thinking/Responsibility/ Experience					
Current ethical and legal standards are in conflicts with the moral intuitions of many GPs	Leading to a Change in Behavior	Social Acceptability/Concept of Death/Negative Thinking/ Responsibility/Experience					
Family disagreement is a reason for non compliance with an AD	Leading to a Change in Behavior/Altered confidence	Social Acceptability/Negative Thinking/Revocability					
AD is a source of discomfort and stress in an emergency situation	Leading to a Change in Behavior/AD's Viability/Altered confidence	Evolution of Illness/Access to DA/Revocability/Experience					
GPs are concerne about discordance between an enduring guardian and a substitute decision maker	Leading to a Change in Behavior/AD's Viability/Altered confidence	No Consensual Making Of/ Responsibility					
GPs tend to interpret ADs in a subjective way	Leading to a Change in Behavior/AD's Viability	Standardization/Experience					
GPs do not follow AD all the time	Leading to a Change in Behavior/Altered confidence	Evolution of Illness/Experience					
ADs reduce physician's authority over treatment decisions	Leading to a Change in Behavior/AD's Viability	Responsibility/Experience					
The low level of knowledge of GPs can be explained by the low number of patients discussing ADs	AD's Viability/Altered confidence	Lack of experience/Access to DA					
Near half of GPs do not instruct patients on how to obtain AD forms	AD's Viability	Lack of experience/Access to DA					

RAW DATAS	SUB THEME	OPEN CODES
In end-of-life care, spontaneous decision-making limits the influence of ADs	Leading to a Change in Behavior/AD's Viability/Altered confidence	Evolution of Illness/ Responsibility/Experience
GPs rarely update ADs	Leading to a Change in Behavior	Access to DA
Half of GPs do not have advanced knowledge of ADs	Leading to a Change in Behavior	Lack of experience
ADs lead to lower standard of care for all patients	Leading to a Change in Behavior/AD's Viability/Altered confidence	Standardization/Negative Thinking/Experience
ADs represent unwarranted extension of law into the practice of Medecine	Leading to a Change in Behavior/Altered confidence	Standardization/Negative Thinking/Responsibility/ Experience
GPs think they are in a better position to decide than patient	Leading to a Change in Behavior/AD's Viability/Altered confidence	No Consensual Making Of/ Experience/Revocability
An illness that is not terminal is a reason for non compliance with an AD	Leading to a Change in Behavior/AD's Viability	Evolution of Illness/Revocability
GPs have the responsibility to initiate the AD discussion	Leading to a Change in Behavior/Altered confidence	Access to DA/Lack of experience
Healthy Patients are not able to anticipate	AD's Viability/Altered confidence	Evolution of Illness/Lack of experience
ADs do not improve the accuracy of GPs in predicting patients' life sustaining treatment preference	AD's Viability/Altered confidence	Revocability/Evolution of Illness
Some GPs discuss ADs systematically at the first consultation	AD's Viability	Standardization/Evolution of Illness
AD discussion should occur later in the course of the disease	AD's Viability	Evolution of Illness/Lack of experience
GPs favor AD when children are affected by life threatening illness	AD's Viability	Evolution of Illness

# 2) BOYER I. - What is needed for nurses to help patients draft an Advance Directive ? A thematic analysis of the nurses' point of view based on a systematic literature review. Th. : Méd. : Brest 2020

Family is uninformed	AD's Viability/Leading to a change in behavior/Altered confidence	Social acceptability/Non consensual Making of/Lack of experience
Inappropriate place	AD's Viability/Leading to a change in behavior	Social acceptability/Negative Thinking/access to AD
Physicians' culture of cure	Leading to a change in behavior	Social acceptability/Concept of Death/Experience

RAW DATAS	SUB THEME	OPEN CODES
Physicians discomfort	Leading to a change in behavior/Altered confidence	Negative Thinking/Experience
Curative culture	AD's Viability/Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking/ Experience
Patients are unprepared	AD's Viability/Altered confidence	Social acceptability/Evolution of Illness/Lack of experience/ Negative Thinking
Lack of communication from physicians	AD's Viability/Altered confidence	Non consensual Making of
No collegial decision	AD's Viability/Altered confidence	Non consensual Making of
AD process is unclear	AD's Viability/Leading to a change in behavior	Access to AD/Revocability
Nurses' discomfort	Leading to a change in behavior/Altered confidence	Negative Thinking/Experience/ Responsibility
Medical refusal to honor patients' wishes	AD's Viability/Leading to a change in behavior/Altered confidence	Non consensual Making of/ Revocability/Responsibility
Patients and public are uncomfortable	Leading to a change in behavior/Altered confidence	Negative Thinking/Social acceptability
Family refuses to honor the ADs	Leading to a change in behavior/Altered confidence	Social acceptability/Negative Thinking/Non consensual Making of
Family has another point of view	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Non consensual Making of
Negative opinions regarding ADs	Leading to a change in behavior/Altered confidence	Social acceptability/Negative Thinking
Nurses have role related issues	Leading to a change in behavior/Altered confidence	Negative Thinking/access to AD/Responsibility
Lack of proper pamphlets or forms	AD's Viability/Altered confidence	Standardization/access to AD
Risk of formalization of care	AD's Viability/Leading to a change in behavior	Standardization/Responsibility/ Experience
Ethical concerns	Leading to a change in behavior	Negative Thinking/Experience
Patients are uncomfortable	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Lack of agency support	AD's Viability/Leading to a change in behavior/Altered confidence	Revocability/Responsibility

RAW DATAS	SUB THEME	OPEN CODES
Inappropriate forms	AD's Viability/Altered confidence	access to AD
ADs forms are unclear	AD's Viability/Altered confidence	access to AD
Inappropriate Time	AD's Viability	Social acceptability/Evolution of Illness/access to AD
Legal concerns	AD's Viability/Leading to a change in behavior/Altered confidence	Negative Thinking/ Responsibility/Lack of experience
Lack of honesty from physicians	Altered confidence	Negative Thinking/ Responsibility/Concept of Death
Staff discomforts	AD's Viability/Leading to a change in behavior/Altered confidence	Negative Thinking/Non consensual Making of
Staff Conflicts	AD's Viability/Leading to a change in behavior/Altered confidence	Negative Thinking
Physicians have negative attitude	AD's Viability/Leading to a change in behavior/Altered confidence	Negative Thinking/Experience
Resources are difficult to find	AD's Viability/Leading to a change in behavior/Altered confidence	Access to AD
<u>3) MOUSTER A What are the barn the surroundings of the pat</u> review. Th. : Méd. : Brest 20	<u>ients with unfixed psychiatric il</u>	dvance directives related to Iness ? A systematic literature
There was a significant and + relationship between legal defensiveness and operational barriers for the psychiatrists	Altered confidence/Leading to a change in behavior	Revocability/Responsibility
About 24% of participants indicated a high degree of legal defensiveness associated with clinical decisions to initiate or stop a course of treatment for a patient with several mental illness	Altered confidence/Leading to a change in behavior	Revocability/Responsibility

illness			
Judges in my community would likely uphold professional recommendations for treatment over the directives of the person with mental illness	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Revocability	

RAW DATAS	SUB THEME	OPEN CODES
Psychiatrists who worried most about being sued for any adverse outcomes of their treatments decisions were significantly more likely to override the PAD	Altered confidence/Leading to a change in behavior	Social acceptability/ Revocability/Negative Thinking
Some professionals feared that a binding directive with which the family did not agree would be subject to an appeal through the courts or be the source of litigation against the practionners	AD's Viability/Altered confidence/Leading to a change in behavior	Non consensual Making of/ Responsibility
The documents can be inflexible to the conditions of an actual crisis and is only good if it is frequently updated	AD's Viability/Leading to a change in behavior	Evolution of Illness/access to AD
Staff were unsure whether to follow a PAD for a consumer who was determined to be incompetent to revoke a PAD but who nevertheless wanted to revoke the document	AD's Viability/Altered confidence/Leading to a change in behavior	Evolution of Illness/Revocability
The consumer will have made inappropriate treatment request for the crisis situation	Altered confidence/Leading to a change in behavior	Access to AD/Experience
Clinicians felt this to be in the holder's best interest	Altered confidence/Leading to a change in behavior	Revocability/Experience
Both psychiatrist and psychologists were more likely than social workers to report that inappropriate treatment requests may be a problem with PADs	Leading to a change in behavior/Altered confidence	Revocability/Responsibility/ Experience
Concern about limiting professionals' ability to use their clinical judgement in the best interests of the patient and that this compromised their duty of care. This was sometimes expressed as making it difficult to give patients helpful treatments	Altered confidence/Leading to a change in behavior	Social acceptability/ Standardization/Negative Thinking/Responsibility
They wondered whether consumers needed to meet a legal definition of incompetence in order for the PAD instructions to be followed or of an agent to have authority under a DPOA	AD's Viability/Altered confidence/Leading to a change in behavior	Revocability/Responsibility
Psychiatrists 48,8% were also more likely to express concerns about the risk of violence	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Psychiatrists who were more concerned about patients' violence risk were significantly more likely to say they would override a PAD refusal of treatment	AD's Viability/Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Experience
Clinical Barriers to PADs n=100 « risk of violence from treatment refusal in a PAD »	AD's Viability/Leading to a change in behavior/Altered confidence	Evolution of Illness/Negative Thinking/Experience
The surrogate were reluctant to mention the PAD	AD's Viability	Access to AD/Social acceptability
« In time of crisis professionals will not want to hear about a person's psychiatrist advance directive » 50% of family members agree	AD's Viability/Leading to a change in behavior	Evolution of Illness/Social acceptability/Revocability
Several care professionals indicated that some of their colleagues were skeptical toward the crisis card and doubted its benefits	Leading to a change in behavior/Altered confidence	Experience
Clinicians who assigned great importance to the wishes of the patients family were significantly less likely to report that they would follow a patients' treatment refusal in an advance directive	Leading to a change in behavior	Social acceptability/ Responsibility/Revocability/ Non consensual Making of
« I worry that PAD could be used to keep a person in a perpetual state of mental illness if the directive is to withhold treatment »Judge	Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking
Psychiatrists most inclined to override PAD refusals of treatments were more resigned to the necessity of involuntary treatment	Altered confidence/Leading to a change in behavior	Evolution of Illness/Experience
Over 90% of respondents agreed with the concern that the consumer would be too psychotic during a crisis to remember to notify providers that they have an AD	AD's Viability/Altered confidence	Evolution of Illness/
Consumer will be too psychotic in a crisis to remember that s/he has an AD	AD's Viability/Altered confidence	Evolution of Illness/access to AD
In time of crisis people with mental illness will not be able to inform professionnels that they have an AD	AD's Viability	Evolution of Illness/access to AD
Others were concerned that locating and interpreting such a document especially if it were legally binding would make the process of delivering care slower	AD's Viability/Leading to a change in behavior	access to AD

RAW DATAS	SUB THEME	OPEN CODES
Psychiatrists were significantly more likely than both psychologist and social workers to report as a barrier Leading to a change in behaviorlack of quality information » contained in the PAD	AD's Viability/Altered confidence	access to AD
Clinical barriers to PAD n=100 Lack of quality information in the PAD »	AD's Viability/Altered confidence	Standardization/access to AD
In the absence of other evidence delusional reasons for medication refusal may be sufficient for some clinicians to decide M.Smith was not competent when he wrote his PAD and the directive is therefore not valid	AD's Viability/Altered confidence	Evolution of Illness/Negative Thinking/access to AD/ Revocabilityc/Responsibility
Participants wondered how they would know whether a consumer had been competent at he time a PAD was executed	AD's Viability	Evolution of Illness/Revocability
How does one ensure that AD were made when the individual concerned was competent/capable	AD's Viability	Evolution of Illness/access to AD
Honouring of PAD statements requires an evaluation of the patient's competences at the time of the completion of the document	AD's Viability	Evolution of Illness/access to AD/Lack of experience
It has been my experience that when a person with mental illness is doing well, could be when they are in most danger of deciding to discontinue their medications so I am a bit conflicted about a student writing what meds they want to be given (should their condition deteriorate) while they are feeling good because that is when many decide they do not really need meds any longer	AD's Viability/Altered confidence	Evolution of Illness/Experience/ Revocability
However staff worked that they might unduly influence the process undermining consumer choice	AD's Viability/Altered confidence/Leading to a change in behavior	Access to AD/Revocability
How does one ensure that AD represent the views of the AD maker without undue pressure or coercion from anyone	AD's Viability/Leading to a change in behavior	Negative Thinking
Some participants were concerned that the information in PADs would not be current and would therefore not be useful	AD's Viability	Social acceptability/Evolution of Illness

RAW DATAS	SUB THEME	OPEN CODES
How does one ensure that Ad take into accounts new development in knowledge and treatments that occur in the time between making and implementing the AD?	AD's Viability/Altered confidence	Social acceptability/Evolution of Illness
95% of administrators agreed that consumers would want to change their minds about their ADs during crisis	AD's Viability	Evolution of Illness/Revocability
THE CONSUMER WILL WANT TO CHANGE HIS/HER MIND about the content during the crisis	AD's Viability/Altered confidence/Leading to a change in behavior	Evolution of Illness/ Revocability/access to AD
JCP specified more contact with her care team. C was told that she did not get this because she had chosen to disengage	AD's Viability/Altered confidence	access to AD
55% of psychiatrists reported that Leading to a change in behaviorconsumers desire to change their mind during a crisis » would be problematic	AD's Viability/Altered confidence/Leading to a change in behavior	Evolution of Illness/access to AD
Clinical barriers to PADs n=100 « the patients potential to change his or her mind about the content of a PAD during a crisis »	AD's Viability/Altered confidence/Leading to a change in behavior	Evolution of Illness
How does one ensure that AD represent the current views of the AD maker?	AD's Viability	access to AD
Staff felt it was not in the patient's interest to follow the plan	AD's Viability/Leading to a change in behavior	Experience
JCp refused IM medication but she was given an injectable depot while subject to the Mental Health Act temporarily as not improving on oral medication	AD's Viability	Standardization
Service providers asked a number of questions about how to consider PADs that include treatment preferences inconsistent with clinical standards of care	AD's Viability/Leading to a change in behavior	Experience
Clinical need, including the need for involuntary treatment was the reason most commonly reported by case managers for care that was not consistent with directive treatment instructions	Leading to a change in behavior/AD's Viability	Evolution of Illness/Experience

RAW DATAS	SUB THEME	OPEN CODES
Clinical barriers to PAD n=100 « Inappropriate treatment request »	AD's Viability/Altered confidence/Leading to a change in behavior	Experience
It will be too difficult to assess the capacity of the consumer in crisis in order to determine whether the AD should be invoked or not	AD's Viability/Altered confidence	Evolution of Illness/Negative Thinking/access to AD
How does one ensure that AD are activated only when the individual concerned was competent/capable	AD's Viability	Evolution of Illness/access to AD
In addition, our finding suggest that faculty may have limited ability to recognize mental illness symptoms in students, which would limit their ability to support students with PADs and other accommodations and strategies	AD's Viability	Social acceptability/Lack of experience
Althought care professionals are familiar with the crisis card, they do not often inform clients about it. According to interviewees this is because it is not part of the routine, they forget to consider the crisis card	AD's Viability/Altered confidence/Leading to a change in behavior	Lack of experience/access to AD
While a majority of patients and family members, agreed that AD would help people with serious mental illness stay well clinicians were less likely to agree with this statement	AD's Viability/Altered confidence	Social acceptability
Thus it appears that many clinicians are somewhat skeptical about PADs as an efficacious mechanism for either treatment refusal or directing specific treatment options	AD's Viability/Altered confidence	Social acceptability/Experience
The majority of them didn't remember the patients' directive or find it useful in the management of the patients care	AD's Viability/Altered confidence	Access to AD/Experience
As a result their experience of routine rather than of crisis care was likely to have a greater impact on decisions such as whether to continue service use	Leading to a change in behavior	Experience
They were also the most likely to believe that the benefits of PAD could be out weight by the disadvantage of patietns' being able to refuse medication	Leading to a change in behavior/Altered confidence	Evolution of Illness/Experience

RAW DATAS	SUB THEME	OPEN CODES
There was a significant and + relationship between legal defensiveness and operational barriers for the psychiatrists	Altered confidence/Leading to a change in behavior	Responsibility
Psychiatrists most inclined to override PAD refusals of treatments were more resigned to the necessity of involuntary treatment and had a more negative opinion about the state of community based services thet they are available to patients with SMI	Leading to a change in behavior/Altered confidence	Social acceptability/Negative Thinking/Experience
JCP specified that he should be admitted voluntary before an involuntary admission became necessary. B and CPN did not feel admission was needed but rest of the team and hostel staff disagreed B was admitted involuntarily	AD's Viability	Non consensual Making of
There will be no way to get access to an advance directive in a crisis	AD's Viability/Altered confidence	access to AD
Staff were unaware of it	AD's Viability/Altered confidence	access to AD
He went to Scotland without the JCP and was admitted there	AD's Viability/Altered confidence	access to AD
Ward staff were not aware of the JCP	AD's Viability/Altered confidence	access to AD
B's nominee was is CPN who was absent on the day of admission and was informed on his return	AD's Viability	access to AD
The inpatient staff were not aware of the JCP	AD's Viability	access to AD
Due to ignorance	AD's Viability	access to AD
Providers 80% were critical to the fact that no standards or procedure were in place to facilitate PAD implementation	AD's Viability/Altered confidence/Leading to a change in behavior	Standardization
Leading to a change in behaviorlack of access to the document »83,6% of psychologists 81,8% of psychiatrists 76,2% of social workers endorsed this as a potential barrier	AD's Viability/Altered confidence	access to AD
Implementation/logistical difficulties	AD's Viability	access to AD

Appendix 5: THEMATIC ANALISIS (CONFLICT ANALETT)		
RAW DATAS	SUB THEME	OPEN CODES
The practice issue most frequently raised by participants was how crisis service and inpatients staff would know whether a consumer had a PAD and how the PAD would be available 24h/day	AD's Viability	access to AD
Directives where accessed in 20% of the 450 crisis events examined in the study	AD's Viability	access to AD
Many participants identified barriers to PAD implementation associated with providers' lack of knowledge of or overall inertia to PADs. In many cases participants indicated that clinicians were unaware of what PAD was, were unwilling to believe that the consumer had a PAD or did not recognize the PD as an instrument to facilitate treatment	AD's Viability/Altered confidence	Access to AD/Lack of experience
Service systems barriers to PADs n=115 Leading to a change in behaviorlack of access to the PAD »	AD's Viability	access to AD
Of the 450 total criss events directives were accessed in 90 events 20% overall rate of accessing directives	AD's Viability	access to AD
Severarl care providers and a police officer mentioned the lack of structural integration of the crisis card in care process as an obstacle to its distribution and implementation	AD's Viability	access to AD
How does one ensure that PAD can be located at critical time	AD's Viability	access to AD
Logistical problems getting PAD information when needed was also a frequently mentioned disadvantage	AD's Viability	access to AD
PAD document should be registered in a central database with secure access In addition to those who signed it	AD's Viability	access to AD
PAD documents should be registered	AD's Viability	access to AD
We found strong positive consensus that lack of knowledge about MHADs emergency room and psychiatric inpatient providers, and lack of communication between outpatients providers and ER and in patients providers present significant barriers to MHAD access	AD's Viability	Access to AD/Non consensual Making of

Appendix 5. THEMATIC ANALISIS (CONFLICT ANALETT)		
RAW DATAS	SUB THEME	OPEN CODES
In one case because a patient was admitted in another part of the country without showing his JCP	AD's Viability	access to AD
Participants asked whether consumers or service providers would inform them to the presence of PADs	AD's Viability	access to AD
Another participant commented on how difficult it was to remember PAD once in a crisis	AD's Viability	Access to AD/Evolution of Illness
There will not be enough time in a crisis to review an advance directive	AD's Viability	access to AD
Regarding Leading to a change in behaviorlack of time to review the document » 35,8% of psychologists thought this would happen often or very often compared to 43% of psychiatrist or 47,2% for social workers	AD's Viability	access to AD
Service systems Barries to PADs n=115 Leading to a change in behaviorlack of time to review the document »	AD's Viability	access to AD
The interviewees indicated that many people outside the institution are unaware of the fact that clients can carry crisis cards with them, and as a consequence they rarely ask or search for it in the event of a crisis	AD's Viability	access to AD
Few family members reported having received information about PADs	AD's Viability/Altered confidence	Access to AD/Non consensual Making of
Crisis staff and inpatient clinicians will not communicate about AD	Altered confidence	Access to AD/Non consensual Making of
Another issue was that the consumer could not communicate with the outpatient provider	AD's Viability	access to AD
Social workers reported Leading to a change in behaviorlack of communications between staff »as a potential barrier at the highest rate 65,8% however there were no significant between-group differences	Altered confidence	Access to AD/Non consensual Making of/Lack of experience
The most frequent reason mentioned for not agreeing upon JCPs with patients was the Leading to a change in behaviorlack of need » to do this	Altered confidence	Social acceptability/Negative Thinking

Appendix 5: THEMATIC ANALYSIS (CONFLICT ANXIETY)		
RAW DATAS	SUB THEME	OPEN CODES
Psychiatrists were significantly less convinced of the need for AD than other groups	Altered confidence	Social acceptability/Negative Thinking
4) COSQUER A Perspective, atti- directives among demented	tude and experience of medics/ I patients. A systematic literatur	
2020		
PCPs are less likely to document ADs than ECP	Leading to a Change in behavior	Lack of experience
Nurses need education to decrease difficulties with ADs	Leading to a Change in behavior/Altered confidence	Negative Thinking/access to AD/Responsibility/Lack of experience
Nurses should be able to initiate discussion on ADs with adequate education	Leading to a Change in behavior	Access to AD/Lack of experience/Non consensual Making of
Living wills are the most discussed on ADs	AD's Viability	Standardization
Durable power of attorney is discussed half of the time	AD's Viability/Altered confidence	Social acceptability/ Revocability/Responsibility
End of life care is discussed half of the time	AD's Viability	Standardization/Lack of experience/Evolution of Illness
Nursing home care is often discussed	AD's Viability	Standardization
Physicians refer to others	Leading to a Change in behavior/Altered confidence	Negative Thinking/Lack of experience
PCP are not knowledgeable	AD's Viability/Altered confidence	Access to AD/Standardization
Physicians do not adequately discuss ADs	Leading to a Change in behavior/Altered confidence/ AD's Viability	Access to AD/Lack of experience
ADs are more often restrictive	AD's Viability/Altered confidence	Standardization/access to AD
Caregivers very often encourage DNR orders	Leading to a Change in behavior/	Social acceptability/Concept of Death/Experience/ Responsibility
Physicians rarely inform their patients about ADs	Leading to a Change in behavior	Access to AD/Experience
Physicians rarely assist their patients in drafting ADs	Leading to a Change in behavior	Access to AD/Experience/Non consensual Making of
Patient rarely express their wishes according to the nurses	Leading to a Change in behavior/Altered confidence	Non consensual Making of
Nurses speak about ADs with patients in 9,7% of cases	Leading to a Change in behavior	Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
For physicians AED should not be view as a substitute of high quality supportive care	Altered confidence	Social acceptability/Experience/ Negative Thinking
Impossible to decide when to comply with AED	Altered confidence/AD's Viability	Social acceptability/Negative Thinking/Responsibility
Physician rarely. Updates ADs, ADs become more restrictive when updated	AD's Viability	Evolution of Illness
Different philosophy between ECPs and PCPs regarding resuscitation care	AD's Viability	Standardization/Social acceptability/Experience
ADs influence medical decision	Leading to a Change in behavior/AD's Viability	Standardization/Responsibility
It is important to discuss ADs with caregivers early in the disease	AD's Viability	Standardization/Evolution of Illness
ADs are rarely discussed in primary care	Leading to a Change in behavior/AD's Viability	Lack of experience
Loos of decisional capacity	Altered confidence/AD's Viability	Revocability/Responsibility/ Negative Thinking
Loss of decisional capacity	AD's Viability	Revocability/Responsibility/ Negative Thinking
Caregivers are mainly focused on current wellbeing	AD's Viability	Evolution of Illness/Experience
Caregivers are mainly focused on current wellbeing	Leading to a Change in behavior/AD's Viability	Evolution of Illness/Experience
Caregivers are mainly focused on current wellbeing	Leading to a Change in behavior/AD's Viability	Evolution of Illness/Experience
Demented patient doesn't understand enough their situation	AD's Viability	Evolution of Illness/Social acceptability/Revocability/ Responsibility
AED for demented patient is not a valid request	Altered confidence//AD's Viability	Evolution of Illness/ Revocability/Responsibility
Relatives ask ECP to comply with AED	AD's Viability	Social acceptability/Concept of Death/Experience
For caregivers ADs should be done at the admission	AD's Viability	Evolution of Illness/ Standardization
Impossible to decide when to comply with AED	AD's Viability	Experience/Evolution of Illness
Caregivers are mainly focused on current wellbeing	AD's Viability	Evolution of Illness/Experience
For caregivers ADs should be done at the admission	AD's Viability/Leading to a change in behavior	Evolution of Illness/ Standardization

RAW DATAS	SUB THEME	OPEN CODES
Patients are too emotionally overwrought at admission	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Responsibility
Few caregivers think patients on admission have the cognitive capacity to complete a health care proxy	AD's Viability	Negative Thinking/ Standardization/Evolution of Illness/Responsibility
Doctors should be responsible for ADs	Altered confidence/Leading to a change in behavior	Non consensual Making of
Discuss ADs later when patients are more emotionally prepared	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking
Physiscians report not knowing presence of ADs in 18% of the case	AD's Viability	access to AD
Physicians were more likely than nurses to report not knowing of the directive or feeling that a given directive was not applicable	AD's Viability	access to AD/Non consensual Making of
Physicians are not inclined to comply with ADs if ADs differ from their medical judgement	Leading to a Change in behavior/AD's Viability	Experience
Actual quality of life and family wishes is more important than ADs for physicians	Leading to a Change in behavior//AD's Viability	Social acceptability/Evolution of Illness/Experience
Medical judgment and influences of relatives over AD	Leading to a Change in behavior/AD's Viability	Experience/Responsibility/ Social acceptability
Patinets are mostly not involved in ADE	Altered confidence/AD's Viability	Negative Thinking/access to AD
AED is too drastic	Altered confidence/"	Standardization/Responsibility
ECP never comply with AEDof an incompetent patient	AD's Viability	Negative Thinking/access to AD
AED is inconceivable if the patient is not competent	Leading to a Change in behavior/AD's Viability	Evolution of Illness/Negative Thinking/Responsibility
ECP rarely comply with ADE	Altered confidence/AD's Viability	Experience
For three quarters of ECPs dementia is not a valid reason to comply with AED	Altered confidence/AD's Viability	Revocability/Responsibility/ Evolution of Illness/Experience
For most ECPs it is impossible to determine when to comply with AED	Altered confidence/AD's Viability	Evolution of Illness/ Responsibility
For most ECPs dementia is not a valid reason to comply with AED	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Responsibility/ Experience

RAW DATAS	SUB THEME	OPEN CODES
For most ECPs it is impossible to determine when to comply with AED (« determining the unbearableness of the suffering »)	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking/Responsibility/Lack of experience
For most ECPs it is impossible to determine when to comply with AED (Leading to a change in behaviorperforming euthanasia being the key issue in the reticence of ECPs »)	Altered confidence/AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/ Responsibility
Positive attitude toward AED (Leading to a change in behaviorthis attitude seems to be limited to the situation of competent patient »)	AD's Viability	Evolution of Illness
ADs do not always result in written record but just may involve conversation with caregivers	AD's Viability/Altered confidence	access to AD
Ideally ADs are discussed in the last phase of life	AD's Viability	Evolution of Illness
Importance of planning ADs until it is too late	Leading to a Change in behavior/AD's Viability	Evolution of Illness/Experience
Discussion about ADs seem to take place at the end of life when patient is no more competent	AD's Viability	Evolution of Illness/Negative Thinking
Discussion on ADs should start at home or shortly after NH admission	Leading to a Change in behavior/AD's Viability	Evolution of Illness/Experience/ Standardization
Almost all physicians need patients to confirm theirs wishes and the unbearableness of suffering	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience/Responsibility
Patients can change their preferences	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Communication is essential to comply with an AED	Altered confidence//AD's Viability	Evolution of Illness/Non consensual Making of
Caregivers see an ethical obligation to ignore the AD of a severely demented but »happy » patient	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking/Experience
When ADs are present, the directives are often of poor quality	AD's Viability/Altered confidence	Access to AD/Standardization
ECPs patients have more restrictive ADs	Leading to a Change in behavior	Lack of experience
Reluctance of physicians to discuss ADs	Leading to a change in behavior	Negative Thinking
Discussing ADs is not easy	Altered confidence/Leading to a change in behavior	Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Reluctance of physicians to discuss ADs	Leading to a Change in behavior/Altered confidence	Negative Thinking
More then a half think it is inconceivable to comply with AED	Altered confidence	Experience/Negative Thinking
Most frequent argument for AED (Leading to a change in behaviorconceivable if () it was legal 20% »)	Altered confidence/Leading to a change in behavior	Responsibility
Most arguments against AEDs (Leading to a change in behaviorAED is not a valid request 37% and euthanasia for demented patient is unacceptable 32% »)	Altered confidence/AD's Viability/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Responsibility/ Experience
AED for demented patient is not a valid request	Altered confidence	Evolution of Illness/ Standardization/Responsibility
AED for demented patient is not a valid request	Altered confidence	Evolution of Illness/ Standardization/Responsibility
AED is unacceptable because of religious or philosophy in life	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking
Religious beliefs influence nurses' opinion on ADs	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
Religious beliefs influence opinion on ADs	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking/Concept of Death
More nurses than physicians are willing to comply with AEds	Leading to a Change in behavior	Non consensual Making of
ADs are consistant with the law (Leading to a change in behaviorphysicians () consider following an AD if this is consistant with the law »)	Leading to a change in behavior/Altered confidence	Responsibility
Physicians have more responsibilities	Leading to a change in behavior/Altered confidence	Responsibility
AED for demented patient is unacceptable	Altered confidence	Evolution of Illness/ Standardization/Responsibility/ Negative Thinking
Less than half social worker think they are the best suited to discuss ADs	Leading to a Change in behavior	Social acceptability/Lack of experience
Difference in interpretation nurses/ physicians	/Leading to a Change in behavior	Non consensual Making of/ Negative Thinking/ Standardization/Experience

RAW DATAS	SUB THEME	OPEN CODES
Physicians have a passive attitude about ADs	Leading to a Change in behavior	Experience/Negative Thinking
Treatment directives are of low medical quality for physicians	Altered confidence/Leading to a Change in behavior/AD's Viability	Standardization/access to AD
ECPs have more experience with AED	Leading to a Change in behavior/Altered confidence	Lack of experience
Althought compliance with AED was discussed in 76% of the cases in which a patient with dementia died after being treated by a physician who knew about the directive, euthanasia was seldom performed »	Altered confidence/AD's Viability/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Revocability/ Experience
ECps are most influenced by their personal attitude and the presence of a serious additional illness than by AED	Leading to a Change in behavior	Evolution of Illness/Negative Thinking/Experience
Physicians rarely comply with AED	Altered confidence/Leading to a Change in behavior	Experience/Negative Thinking
ECP never comply with AED of an incompetent patient	Altered confidence/Leading to a Change in behavior	Experience/Revocability/ Responsibility
Different background influence decision making process	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
Two thirds of ECps do not adhere to AED	Altered confidence	Experience/Negative Thinking
Religious beliefs influence opinion on ADs	«/AD's Viability	Social acceptability/Concept of Death
Physicians do no adhere to AED, but AED can influence treatment decision	Leading to a Change in behavior	Evolution of Illness/ Responsibility
AED gives patients false hope	Altered confidence/Leading to a change in behavior	Negative Thinking
Determining unbearable suffering is one of the most important element in not adhering to AED	Altered confidence	Negative Thinking/Lack of experience
Physicians do no adhere to AED, but AED can influence treatment decision	Altered confidence	Evolution of Illness/ Responsibility
AED is too much responsibility according to ECP	Leading to a change in behavior/Altered confidence	Responsibility/Negative Thinking/Lack of experience
ECp rarely comply with AED	Leading to a change in behavior/Altered confidence	Experience/Negative Thinking
Physicians rarely comply with AED	Altered confidence	Negative Thinking

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RAW DATAS	SUB THEME	OPEN CODES
Religious beliefs influence opinion on ADs	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
Religious beliefs influence opinion on ADs	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
Physicians often hesitate to discuss EOL	Altered confidence	Negative Thinking
Caregivers more often communicate with relatives than with the patients	Altered confidence	Non consensual Making of
Physicians consider AED problematic	Altered confidence	Negative Thinking/ Responsibility
Physicians prefer using AED as non- treatment directive	Altered confidence/Leading to a Change in behavior	Standardization
Comply with an AED in a patient with advanced dementia would be Burdensome for the physician	Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking
Physicians do not agree with euthanasia on a basis of an AED in case of advanced dementia	AD's Viability/Leading to a change in behavior/Altered confidence	Negative Thinking/Social acceptability/Experience
Comply with AED is known to have an emotional impact on physicians	Leading to a change in behavior	Negative Thinking
Caregivers are reticent to implement ADs that reduce the number of treatments provided, because this will also reduce the amounts they are paid	Leading to a Change in behavior/	Social acceptability/Negative Thinking
ADs are not easy subject to discuss	Altered confidence/Leading to a change in behavior	Negative Thinking
5) MACIEJEWSKI L Point of view Advanced Directives. A then review. Th. : Méd : Brest 20	<u>matic analysis based on a narra</u>	
Clients ranked 7 factors for importance () involving one's religious leader	Leading to a change in behavior	Social acceptability/Concept of Death
Demand for PADs was significantly higher among female and non white participants, those who had been arrested and those who felt pressured by others to take medication, and lower among college educated participants and those with	Altered confidence	Social acceptability/Concept of Death/Evolution of Illness

educated participants and those with a high degree of personal autonomy

RAW DATAS	SUB THEME	OPEN CODES
PAD completion was significantly more common among participants who were currently married and had been involuntary hospitalized in the past and among those who reported having another person(s) providing direct assistance with their treatment	Altered confidence	Social acceptability/Concept of Death/access to AD
Among geriatric patients under age 70 76% chose CPR compared with 47% of patients 70 years of age or older	Altered confidence	Evolution of Illness/Social acceptability/Concept of Death/ Experience
Reviewing past experiences	AD's Viability/Altered confidence	Negative Thinking/Experience
Reflecting on one's own mental illness was often reported to be challenging aspect of developing an Advance Agreement	AD's Viability	Negative Thinking/Lack of experience
53% des patients interrogés se disent intéressés par la réalisation des AD	Altered confidence	Social acceptability
The odds of wanting PADs was significantly higher among those who reported feeling pressured by others to take medication, and significantly lower among those who reported a high degree of personal autonomy	Altered confidence	Social acceptability/Evolution of Illness/access to AD
Participants with undocumented preferences explained that they had »never thought about writing them down before » were too young » or « felt it was too soon »	Altered confidence	Social acceptability/Lack of experience
PAD completion was significantly more likely among participants with relatively high insight scores	Altered confidence	Lack of experience
34,7% of consumer participants reported a desire for assistance from a case manager for creating a PAD	Altered confidence/AD's Viability	Access to AD/Standardization
13% reported not having the time to create a PAD	Altered confidence	access to AD
It can be very confrontational to develop it because it reminds them of experiences they prefer to forget, or label them as mad, as well as feel shame for being ill	AD's Viability/Altered confidence	Negative Thinking/Experience

RAW DATAS	SUB THEME	OPEN CODES
Factors that might lead students not to create PAD: most common response had to do with students willingness to accept their SMI vs being in denial	Altered confidence	Lack of experience
Hope that they would not have another episode of mental illness	Altered confidence	Evolution of Illness/Negative Thinking
Some consumers put signifivcant amount of effort into contemplating issues related to their mental illness and past treatments, while others stated their already knew their preferences	Altered confidence	Experience/Evolution of Illness
Déni de la pathologie psychologique 19%	Altered confidence/AD's Viability/	Evolution of Illness/Negative Thinking
19% denied having a mental illness	Altered confidence/AD's Viability/	Evolution of Illness/Negative Thinking
Overall 91 patients 48% not wanted CPR (study based on patients with suicidal ideations)	Altered confidence/AD's Viability/Leading to a change in behavior	Evolution of Illness/ Revocability/Responsibility/ Negative Thinking
Participants reported little experience with advance care planning	Altered confidence/AD's Viability	Social acceptability/Lack of experience
Nine clients 64% cited not liking to sign legal documents	Altered confidence	Social acceptability
Have a copy of the recovery plan (memory problems) they could refer to	Altered confidence/AD's Viability	Access to AD/Standardization
Inquietude concernant la rupture du secret medical et leur souhait que les informations ne soient pas diffusées à des personnes non concernées par leur prise en charge	Altered confidence	Negative Thinking/Social acceptability/Responsibility
Clients ranked 7 factors for importance () not letting family or friends know about their treatment	Altered confidence/Leading to a change in behavior	Responsibility/Social acceptability
Greatest concern was violation of confidentiality and resultant stigma of being identified as having SMI	Altered confidence	Social acceptability/Negative Thinking/Responsibility
Having AD would alleviate the burden on others by assuming responsibility for treatment in advance of crisis	Altered confidence/	Negative Thinking
Leading concern about proxy decision making were those related to life support in the context of a coma or brain damage	Altered confidence/Leading to a change in behavior/AD's Viability	Social acceptability/Negative Thinking/Revocability

RAW DATAS	SUB THEME	OPEN CODES
For the majority of services users, hospital admission was problematic. Many described how hospitalization did not help them, they felt bored heavily medicated and trapped	Altered confidence/AD's Viability	Negative Thinking/Concept of Death
Crainte d'être mal perçus par les médecins ou d'être punis par une mise en isolement ou autre, s'ils parlent de leur DA	Altered confidence	Evolution of Illness/Negative Thinking/Experience/Concept of Death
Sentiment de ne pas se sentir accueilli et respecté	Altered confidence	Social acceptability
They often did not share volunteerly information about their PAD when in crisis () how difficult it was to remember the PAD once in crisis	AD's Viability	Negative Thinking/access to AD
Feared that executing a directive could actually invite the situation it was designated to manage	Altered confidence	Negative Thinking/access to AD
Not thinking advance instructions will make a difference was a concern	Altered confidence/AD's Viability	Negative Thinking
6% believed that having a PAD would not affect treatment	Altered confidence/AD's Viability	Negative Thinking
Current clinical management was viewed to be crisis driven. If a consumer is clinically managed, they are assumed to be fairly unwell, and may not be viewed as at a suitable stage for an Advance Agreement	Altered confidence/AD's Viability/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Revocability
Prepared PAD with help: yes for 21 (70%)	AD's Viability	Social acceptability/access to AD
Some clients said that is difficult to formulate a correct description	AD's Viability	access to AD
The documents were viewed as to cumbersome by 79% of the clients	AD's Viability	access to AD
Clients were less likely to think they should consult their clinician about what to write in the PAD	AD's Viability/Altered confidence	Access to AD/Non consensual Making of
It's easier to explain themselves to someone who know by experience what are they going through	Altered confidence	Lack of experience
Reason for not completing: relapse of illness; process too confronting	Altered confidence/AD's Viability	Negative Thinking/Evolution of Illness
Elderly patients who had suicidal ideation were significantly less likely to ask for CPR than those who did not have suicidal ideation	AD's Viability	Evolution of Illness/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Difficulties communicating PADs to Inpatient Staff	AD's Viability	access to AD
Just over half of those who made a refusal made a refusal about medication (in a pre established list)	Altered confidence	Standardization/access to AD/ Lack of experience
Importance of a correct description of the moment of intervention	Altered confidence	Standardization/access to AD
Depression therapy did alter the preference of 26% subjects in the direction of desiring more life sustaining treatment	AD's Viability/Leading to a change in behavior	Access to AD/Evolution of Illness
Subjects who had an increase in desire for life sustaining therapy wanted twice as many interventions after depression treatment as before	AD's Viability/Leading to a change in behavior	Non consensual Making of/ access to AD/Evolution of Illness
Providers' lack of knowledge of or overall inertia to PADs/clinicians were unaware of what a PAD was	Altered confidence	Access to AD/Lack of experience
Providers themselves had not been adequately educated about PADs, might ignore PAD in crisis situation	Altered confidence	Lack of experience/access to AD
84%wanted to appoint a nominated representative	Altered confidence/AD's Viability/Leading to a change in behavior	Social acceptability/access to AD
Wanted both an PAD and health care agent	AD's Viability	Social acceptability/access to AD
Not knowing what to include	AD's Viability	access to AD
Importance of having things writing down	Altered confidence	Standardization/access to AD
Wanted their directive to be irrevocable during periods of incapacity	Leading to a change in behavior/Altered confidence/	Evolution of Illness/ Revocability/Responsibility
Changing one's mind when ill (irrevocability)	Leading to a change in behavior/Altered confidence/ AD's Viability	Evolution of Illness/ Revocability/Responsibility
Perhaps it will make me feel very unhappy or frustrated to think: Yeah I agreed to this but now I disagree completely »	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Ambivalent about whether individuals should be allowed to change their PADs	Altered confidence/AD's Viability	Evolution of Illness/Revocability
Preferences may change over time, but students would not take steps to change their PADs »	AD's Viability	Evolution of Illness/ Revocability/access to AD

RAW DATAS	SUB THEME	OPEN CODES
Many participants asked how much control the consumer actually holds	Leading to a change in behavior/Altered confidence	Negative Thinking/ Responsibility
Otherwise they might be put in the hospital against their will »	Leading to a change in behavior/Altered confidence/	Evolution of Illness/Non consensual Making of
Many participants remarked on the limited options for future treatment and difficulty assessing services	AD's Viability/Altered confidence	Access to AD/Standardization
A good number of patients wondered how the PAD would be used in their treatment	Altered confidence//AD's Viability	Negative Thinking/access to AD
Some contents may not always be achievable in routine care	Altered confidence/AD's Viability/Leading to a change in behavior	Experience
Participate communicated the potential for clinicians to intimidate them during a psychiatric crisis, thus deterring them introducing their PAD	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Leading to a change in behaviorMore paperwork, more hassles »	AD's Viability/Leading to a change in behavior	access to AD
Concerns that the directive might not stand up in court or would be overridden in practice	Altered confidence	Responsibility
They were unaware of it in one case because a patient was admitted in another part of the country without showing his JCP	AD's Viability/Altered confidence	access to AD
No attempt was made to inform the inpatient clinicians because the social worker who knew about the PAD doesn't work here anymore	AD's Viability/Altered confidence	access to AD
Misunderstanings PADs	AD's Viability	access to AD
Lack of information	AD's Viability	access to AD
Not knowing what to include	AD's Viability	Access to AD/Lack of experience/Non consensual Making of
Not understanding PAD	AD's Viability	Access to AD/Lack of experience
Clients often stressed the importance of a doctor who knows the client well	Altered confidence	Standardization/access to AD/ Lack of experience
Users generally asked for more equality in their relationship with health providers	Altered confidence	Social acceptability/ Responsibility

RAW DATAS	SUB THEME	OPEN CODES
The desire to be treated with dignity and respect	Altered confidence	Social acceptability
Treat me with respect	Altered confidence	Negative Thinking/Social acceptability
Wish for making the development of the crisis card a standard part of care	Leading to a change in behavior/AD's Viability	Standardization/access to AD
Fear that PADs would be ignored	Altered confidence	access to AD
When the PAD was relieved by providers no attempt was made to follow the specified request	Leading to a change in behavior/Altered confidence/	Social acceptability/Negative Thinking/Revocability/ Responsibility
The (caregivers) team believed that they had followed PAD but the holder disagreed	AD's Viability	Access to AD/Negative Thinking
Lack of consensus among providers	AD's Viability/Altered confidence	Non consensual Making of
Statements were not followed, usually because staff felt it was not in the patients interest to follow the plan	Leading to a change in behavior/AD's Viability	Experience
PAD was ignored	Altered confidence	Negative Thinking/access to AD/Experience
Nominee (person I wish to be contacted in event of crisis) 83%	AD's Viability	access to AD
A large majority reporting wanting to complete PADs if given assistance in doing so	AD's Viability	access to AD
Help needed for completing	AD's Viability	access to AD
80% wanted help from their mental health case manager to complete PAD	AD's Viability/	access to AD
Over 90% indicated they could not have completed the PAD without intervention	AD's Viability	access to AD
The importance of having a trusted person	AD's Viability	Social acceptability/access to AD/Non consensual Making of
Clients ranked 7 factors for importance () having a family member or friend support them when completing a directive	AD's Viability	access to AD
Nearly all PAD completer indicated an immediate family member as their nominate representative	AD's Viability	access to AD

Appendix 5: I HEMATIC ANALYSIS (CONFLICT ANXIETY)				
RAW DATAS	SUB THEME	OPEN CODES		
% de patients désignant un substitut dans leurs directives est élevé mais varie d'une etude à l'autre	AD's Viability	access to AD		
Designation of a proxy with surrogate decision making capacities during the period of incompetence	AD's Viability	access to AD		
46% appointed a surrogate decision maker	AD's Viability	access to AD		
Clients ranked 7 factors for importance () surrogate decision making	AD's Viability	access to AD		
43% indicated not having anyone to trust	Altered confidence/AD's Viability	Access to AD		
6) POISSON F. What are the difficulties of general practitioners to introduce and discuss advance directives with their patients? Qualitative study by individual interview Th. : Méd : BREST 2019				
Pas le temps sujet non prioritaire	Leading to a change in behavior	Access to AD/Experience		
Oubli	Leading to a change in behavior	Lack of experience/Experience		
Pas de projection des patients	Altered confidence/AD's Viability	Social acceptability/Evolution of Illness/Negative Thinking		
Les patients se dirigent plutôt vers leur famille	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death		
Apprehension chez les patients en bonne santé	AD's Viability/Leading to a change in behavior	Negative Thinking		
Peur des patients d'une décision précipitée	Leading to a change in behavior/Altered confidence/ AD's Viability	Negative Thinking/ Revocability/Lack of experience		
Le médecin n'y pense pas	Leading to a change in behavior	Lack of experience/Experience		
Difficulté de parler de la fin de vie	Leading to a change in behavior	Negative Thinking/Concept of Death		
Pas frequent, oubli	Leading to a change in behavior	Lack of experience		
Proposition plus frequente si registre national	Leading to a change in behavior	Access to AD/Lack of experience		
Pas de coordination avec l'hôpital	Leading to a change in behavior/Altered confidence/ AD's Viability	Access to AD/Non consensual Making of		
Caractere opposable contraignant	Leading to a change in behavior/Altered confidence	Revocability/Responsibility		
Tabou de parler de fin de vie quand patient en bonne santé	Leading to a change in behavior	Concept of Death/Negative Thinking/Social acceptability		

RAW DATAS	SUB THEME	OPEN CODES
Patient venu pour autre motif	Leading to a change in behavior/	Negative Thinking
Le médecin n'y pense pas	Leading to a change in behavior/	Lack of experience
Plusieurs motifs de consultation	Leading to a change in behavior/	access to AD
Les patients n'y pensent pas et ne veulent pas y penser	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Sujet non abordé	Leading to a change in behavior/	access to AD
Peur de heurter le patient, en ne lui laissant pas d'espoir	Leading to a change in behavior	Negative Thinking
Difficulté émotionnelle, sujet sensible	Leading to a change in behavior/Altered confidence	Negative Thinking
N'y pense pas car non quotidien	Leading to a change in behavior	Lack of experience
Fin de vie difficilement anticipable	Altered confidence/AD's Viability	Concept of Death/Evolution of Illness/
DA pas assez détaillées pour toutes les situations de fin de vie	Altered confidence	Standardization/access to AD
Difficulté à aborder le sujet	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Peur de heurter le patient, en ne lui laissant pas d'espoir	Altered confidence/Leading to a change in behavior	Negative Thinking
Difficulté à aborder le sujet	Altered confidence/Leading to a change in behavior	Negative Thinking/Social acceptability
Peur de heurter le patient, en ne lui laissant pas d'espoir	Altered confidence/Leading to a change in behavior	Negative Thinking
Difficulté à savoir ce que veut réellement le patient	AD's Viability	Concept of Death/access to AD
Difficulté à savoir en détail ce que souhaite le patient	AD's Viability/Altered confidence	Standardization/access to AD
Difficulté à rédiger car termes techniques	AD's Viability	Access to AD/Lack of experience/Standardization
Difficulté pour les rédiger	AD's Viability	access to AD
Difficulté à répondre aux questions techniques	AD's Viability/Altered confidence	Negative Thinking/access to AD/Lack of experience
Volontés non transmises au médecin traitant	AD's Viability/Altered confidence	Non consensual Making of
Difficulté à les faire connaitre	AD's Viability/Leading to a change in behavior	Access to AD/Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
A quel moment de la vie en discuter avec le patient	AD's Viability	Evolution of Illness
Pas de fichier national	AD's Viability	access to AD
Nécessité de standardisation	AD's Viability	Standardization/access to AD
Difficulté pour les trouver	AD's Viability	access to AD
Perte de temps car pas de fichier national	AD's Viability/Altered confidence	access to AD
Intérêt du DMP pour faire connaitre les DA	AD's Viability	Access to AD/Non consensual Making of
Difficulté à en parler chez des patients en bonne santé	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
Difficulté à en parler chez le patient jeune	AD's Viability	Social acceptability/Evolution of Illness/Concept of Death
Difficulté vis à vis de la validité des DA	AD's Viability	Evolution of Illness/ Responsibility/Revocability
+ facile chez patient en bonne santé	AD's Viability	Evolution of Illness/Lack of experience
Difficulté car existence d'une DA non connue du médecin	AD's Viability/Altered confidence	access to AD
Pas de référence nationale	AD's Viability	Access to AD

#### 7) KRURIEN E. 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

Older individuals may come to view the AD with some suspicion and skepticism	Altered confidence	Negative Thinking/Social acceptability
The high cost of Healthcare let the people suspicious	Altered confidence	Social acceptability/Negative Thinking
There is a cost containment issue of treatments	Altered confidence	Social acceptability
There is a cost containment issue of treatments	Altered confidence	Social acceptability
Nursing students claim that he care of the older people is « uninteresting »	Altered confidence/	Social acceptability/Negative Thinking/Lack of experience
AD shift the burden of medical decision making on to patients	Altered confidence/	Social acceptability/Negative Thinking/Responsibility
Directives may be based on bad information	Altered confidence//AD's Viability	Access to AD/Revocability

RAW DATAS	SUB THEME	OPEN CODES
There is an uncertainty about the influence and the quality of the information	Altered confidence/AD's Viability	Negative Thinking/access to AD/Responsibility
Proxy directives do not represent a true tension of patient autonomy	Altered confidence//AD's Viability/	Social acceptability/Concept of Death
The concept of precedent autonomy has a controversial degree	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
Some people believes that the future life has no intrinsic value	AD's Viability	Social acceptability/Concept of Death
An AD spare family from the financial hardship	Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking
The previously competent person's wishes prevail	Leading to a change in Behavior/AD's Viability	Concept of Death/Evolution of Illness
Continuity,liability, completeness ans interpretation are a practical and ethical problem of AD	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Evolution of Illness/Negative Thinking/ access to AD/Revocability/ Responsibility
There is a fear of abuse by physicians	/Altered confidence	Social acceptability/Negative Thinking
Concrete decisions depends on specific experience	Altered confidence/Leading to a change in behavior	Standardization/Lack of experience
Thinking of death and illness may have negative impacts on psyche	AD's Viability/Leading to a change in behavior	Negative Thinking
Proxies, doctors and lawyers often must interpret these documents	Altered confidence/	Social acceptability/ Standardization/Negative Thinking
Applicability is problematic when there is a cognitive disorder	/AD's Viability	Evolution of Illness/Social acceptability
Third persons will interpret the document and act on behalf of their interpretation	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Evolution of Illness/Standardization/ Experience
This process is a dialectic process of interpretation and action	AD's Viability	Social acceptability/Negative Thinking/Experience/Lack of experience
Does a « right to die » exist	Altered confidence	Social acceptability/Concept of Death
Qualité of life justifies AD	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Negative Thinking/ Experience
The cost benefits calculation changes the consideration of the quality of life	/Altered confidence/	Social acceptability/Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
The subject is master of the doctor's conscience	/Leading to a change in Behavior/Altered confidence/	Experience/Responsibility/ Negative Thinking
The living will is not a private agreement	/Leading to a change in Behavior	Access to AD/Revocability/ Responsibility
The right to die distort the traditional deontological Hippocratic duty	Leading to a change in behavior	Negative Thinking/Experience
The Wills are interpreted	Altered confidence	Access to AD/Standardization/ Lack of experience/Experience/ Social acceptability
Pressures surrounding the person may exist	/Altered confidence	Negative Thinking/access to AD/Revocability/ Responsibility/Social acceptability
The Will Can change	Leading to a change in Behavior/AD's Viability	Evolution of Illness/Revocability
There is legal consequences when there is misinterpreting	AD's Viability	Negative Thinking/ Responsibility
The physician judge the indications of the directives	/Leading to a change in Behavior/	Social acceptability/Experience/ Concept of Death
Choices may be idiosyncratic or mistaken	Leading to a change in Behavior	Standardization/Evolution of Illness/Experience
Respect for whatever choice the patient makes, including choices that are idiosyncratic mistaken or self- destructive	Leading to a change in Behavior/AD's Viability	Negative Thinking/ Standardization/Responsibility/ Revocability/Experience
Emotions and the social embeddedness of the individual are underevalued	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
If the content of the AD is opaque there is interpretation	/AD's Viability	Access to AD/Revocability/ Responsibility
A balance has to be established between autonomy and the behavior turning to the welfare	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Evolution of Illness/ Experience
Fear of abuse limit their employment	Altered confidence	Social acceptability/ Responsibility
Death is an unpleasant subject	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking
Prospective orders are very risky	/Leading to a change in Behavior/Altered confidence	Negative Thinking/access to AD/Responsibility
A patient's preference for decision making varies with illness experience	Altered confidence//Leading to a change in Behavior	Experience/Evolution of Illness/ Revocability

RAW DATAS	SUB THEME	OPEN CODES
There are fears of worsening of care in end of life situations	/Altered confidence	Lack of experience/Negative Thinking/Evolution of Illness
Decisions that have an economic impact might lead to under treatment	Altered confidence/	Social acceptability/Negative Thinking
The autonomy of the patient might lead to indifference of physicians towards patients	Altered confidence//	Social acceptability/Concept of Death/Evolution of Illness/ Experience/Revocability/ Responsibility
There are fears that a patient's autonomy can turn to social expectation of suicide	/Leading to a change in Behavior/	Social acceptability/Negative Thinking
Surrogates tended to make prediction errors of overtreatment	/Altered confidence/	Social acceptability/Lack of experience/Non consensual Making of/Revocability
Autonomy can be placed above the doctor's duty to save life	/Leading to a change in Behavior//	Negative Thinking/Experience/ Responsibility
We will never be able to know what decision a currently incompetent person would make in a concrete situation	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Responsibility
The two imperatives are the respect of autonomy and welfare/protection of life	/Leading to a change in Behavior/	Social acceptability/Concept of Death
The authority of ADs: risk that physicians lose their sense of responsibility	/Leading to a change in Behavior/	Standardization/Revocability/ Responsibility/Experience
The people fear misinterpretation	Altered confidence	Social acceptability/Negative Thinking/access to AD
Physicians will be reduced to executors of patient's wishes	Altered confidence//Leading to a change in Behavior	Standardization/Negative Thinking/Experience
Physicians could abandon their patients and discharge them of their duty to care for them	/Leading to a change in Behavior/Altered confidence	Social acceptability/ Standardization/Negative Thinking
It may weaken both the family and physician's sense of responsibility	Leading to a change in Behavior/Altered confidence/	Social acceptability/ Standardization/Negative Thinking/Responsibility
The duty to respect patient autonomy seems to be overridden by the principle of beneficence	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Evolution of Illness/ Experience/Responsibility/ Revocability
The patients could be overwhelmed with too much information	Altered confidence/AD's Viability	Negative Thinking/access to AD
The is tension between autonomy and the other principle	/Leading to a change in Behavior/	Negative Thinking/Lack of experience/Experience

RAW DATAS	SUB THEME	OPEN CODES
There need no conflict between the moral principles	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Negative Thinking
Autonomy overrides the sanctity of life	Altered confidence//Leading to a change in Behavior/	Social acceptability/Concept of Death/Negative Thinking
Clinical freedom is constraint	Altered confidence//Leading to a change in Behavior/	Negative Thinking/ Responsibility/Standardization/ Experience
Physicians leave the decision maker in the dark at the most critical juncture	Leading to a change in Behavior//	Social acceptability/access to AD/Lack of experience/ Responsibility
It is important to consider the patient's quality of life values without imposing one's own	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death/Evolution of Illness
A significant number of people legally incompetent have a decision making capacity	Altered confidence/Altered confidence/AD's Viability	Social acceptability/Evolution of Illness/access to AD/ Revocability
Care providers should accept unusual practices	Leading to a change in Behavior//	Concept of Death/Lack of experience/Experience
Physicians care about their moral conscience	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Experience/Negative Thinking
Care providers may not agree	Leading to a change in Behavior/	Experience/Negative Thinking/ Non consensual Making of
Patients with DNR are not admitted in intensive care unit	Leading to a change in Behavior//	Social acceptability/Concept of Death/Evolution of Illness/ Experience
Should the physician lies, to benefit their patients?	/Leading to a change in Behavior/	Negative Thinking/Experience/ Social acceptability
Lying undermine the system	/Leading to a change in Behavior/	Social acceptability/Negative Thinking
Care providers think that it is too painful for the patients	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking
Thinking about death may be scary	Leading to a change in behavior	Negative Thinking/Concept of Death
Some people distrust the care providers	Altered confidence	Social acceptability/Negative Thinking
Some care providers pressure patients	Leading to a change in Behavior//	Experience/Social acceptability/ Negative Thinking
Discussing AD can be traumatic	Leading to a change in behavior/Altered confidence	Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
An Ad must be followed, even if family and friends don't agree	Leading to a change in Behavior///	Social acceptability/Concept of Death/Revocability/ Responsibility/Experience
Incorrect informations or assumions are not applicable	Altered confidence//AD's Viability	access to AD
There are conflicting interests between personal autonomy and sanctity of life	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Negative Thinking
Autonomy should prevail over the sanctity of life	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Experience
A directive inconsistent with good medical practice may not be follow	/Leading to a change in Behavior/	Experience/Negative Thinking/ Concept of Death
Imposition of medical treatment is against liberty and autonomy	Leading to a change in Behavior/Altered confidence/	Social acceptability/Evolution of Illness/Revocability/ Responsibility
Paternalistic position must be justified	/Leading to a change in Behavior/	Experience/Negative Thinking/ Non consensual Making of
There are conflicts with the principles of beneficence and non maleficence	AD's Viability/Altered confidence	Negative Thinking/ Revocability/Responsibility
An autonomous decision may disagree with the notion of a person's wellbeing	/Leading to a change in Behavior/	Negative Thinking/Experience/ Social acceptability/Concept of Death/Evolution of Illness
Lack of information may not represent the autonomous choice	Altered confidence///AD's Viability	Access to AD/Responsibility/ Lack of experience
There is a lack of information when people are not concerned by the illness	Altered confidence/AD's Viability	Evolution of Illness/Social acceptability/Lack of experience
Some people may not take steps to ensure their decision in an informed one	Altered confidence//AD's Viability	Social acceptability/access to AD/Lack of experience
The treatment choice change when the person is hospitalized	Altered confidence//AD's Viability	Evolution of Illness/Lack of experience
Doctor's haven't confidence in AD	Altered confidence/AD's Viability	Social acceptability/Experience/ Lack of experience
Directive depends on how is given the information	Altered confidence//AD's Viability	Access to AD/Lack of experience/Social acceptability
The principle of autonomy and sanctity of life are brought into conflict	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Negative Thinking
There is reluctance of medical profession to discontinue treatment	/Altered confidence	Experience/Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
Medical professionals can be reluctant to adhere to an AD	/Leading to a change in Behavior/	Negative Thinking/Experience/ Responsibility
The medical professional may not be satisfied that an individual has requisite capacity	Leading to a change in Behavior/Altered confidence/ AD's Viability	Social acceptability/Negative Thinking/Revocability/ Responsibility
The directives may be estimated as contrary to good medical practice	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Experience
Directives are valid too without relevant information	Altered confidence/Altered confidence/AD's Viability	Social acceptability/access to AD
When the directive is uninformed, the professional may feel uncomfortable	/Altered confidence	Standardization/access to AD/ Non consensual Making of/ Responsibility/Lack of experience
Correct informations may change choice	/Altered confidence//AD's Viability	access to AD
AD prevent financial hardship	Leading to a change in behavior/Altered confidence	Social acceptability/Negative Thinking
There is a possible conflict between a future oriented autonomy and her welfare as an incompetent individual	/AD's Viability	Social acceptability/Evolution of Illness/Negative Thinking/Lack of experience
When there is a loss of personal identity the person is not the same as the creator of advance directive	Altered confidence/AD's Viability	Evolution of Illness
Autonomy does not always coincide with welfare	Leading to a change in Behavior/AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
Interpretation by physician is subjective	AD's Viability/Altered confidence	Standardization/Social acceptability/Experience/Lack of experience
To judge the validity of DA belongs to paternalism	Leading to a change in Behavior/	Social acceptability/Experience
Family members may want to interfere with the patience preferences	Altered confidence	Social acceptability/Negative Thinking/Responsibility
Directives help against conflict of interest with the family	Altered confidence/	Social acceptability/ Revocability/Responsibility/ Negative Thinking/Non consensual Making of
Discussing the possibility of death may be seen as against the beneficence based role	/Leading to a change in Behavior	Social acceptability/Concept of Death/Negative Thinking
Physicians may feel discomfortable	Altered confidence/Leading to a change in behavior	Negative Thinking
A family member may try to ignore the patient's AD	Altered confidence/	Social acceptability/Negative Thinking/Revocability

RAW DATAS	SUB THEME	OPEN CODES
A family member needs to be educated about AD	AD's Viability/Altered confidence	Lack of experience/Negative Thinking
The person holding the durable power of attorney may fail to follow the patient's prior autonomous directives	Altered confidence//AD's Viability/	Lack of experience/ Revocability/Responsibility/ Non consensual Making of
Professionals attitudes are ingrained	Leading to a change in Behavior/	Experience
There is a personal reluctance to employ the AD	Altered confidence	Negative Thinking
The is a fear of liability	Altered confidence/AD's Viability	Negative Thinking/ Responsibility
There is resentment on the part of physicians and hospital personnel	Altered confidence/Leading to a change in behavior	Negative Thinking/ Responsibility/Experience
Physicians are reluctant to follow even applicable advance directive because of insufficient medical information	/Leading to a change in Behavior//	Access to AD/Lack of experience
In case of doubt the preservation of life is favored	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
The next of kin's predictions of patients preferences are disappointingly poor	Altered confidence/AD's Viability/	Social acceptability/access to AD/Lack of experience
Broad terms make it difficult to evaluate directives	Altered confidence//AD's Viability	access to AD
An error about the judgement of the validity is against autonomous choices	Altered confidence//	access to AD
The law's approach is based on two distinct principles	/Leading to a change in Behavior/	Negative Thinking/ Responsibility/Experience/ Social acceptability
Directives are interpreted	Leading to a change in behavior/Altered confidence/ AD's Viability	Lack of experience/Experience/ Responsibility/Revocability/ Social acceptability
To protect the present interests of a patient is problematic	/AD's Viability	Negative Thinking/ Responsibility/Evolution of Illness
Autonomy is less important than the current interests	/AD's Viability	Evolution of Illness/Negative Thinking/Responsibility
AD may be irrational	AD's Viability/Altered confidence	Social acceptability/Negative Thinking/Concept of Death/ Experience
The judge may find that a life is worthwhile	Altered confidence	Social acceptability/ Responsibility

RAW DATAS	SUB THEME	OPEN CODES
The courts are prepared to protect a person right to self determination	/Leading to a change in Behavior//	Social acceptability/ Responsibility
This is contrary to the principle that treatment may be refused for irrational reasons	/Leading to a change in Behavior//	Negative Thinking/Lack of experience/Experience/ Responsibility
AD must not be influenced	Altered confidence/AD's Viability/	Access to AD/Social acceptability
AD must not be influenced	Altered confidence/AD's Viability/	Social acceptability/access to AD
There is a risk of interpretation by allowing AD to be revoked	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Responsibility
Change of mind may be a non autonomous choice	Leading to a change in Behavior/Altered confidence/ AD's Viability	Evolution of Illness/Social acceptability/access to AD
There is no formal requirements to be sufficiently well informed	Altered confidence//AD's Viability	Access to AD/Non consensual Making of/Lack of experience
Competent people tend to underestimate the quality of life incompetent people	/AD's Viability/	Social acceptability/Concept of Death/Lack of experience
The author may have procrastinated	Altered confidence//AD's Viability	Access to AD/Negative Thinking
These two principles do not sit together comfortably	/Leading to a change in Behavior/	Negative Thinking/Social acceptability/Experience
A bias that some lives are worth preserving may exist	AD's Viability/Altered confidence	Social acceptability/Concept of Death/Responsibility
Judges have a moral emotional reluctance to reach a decision that will result in the death of a vulnerable individual	Altered confidence/Leading to a change in behavior	Negative Thinking
The principle of autonomy prevails over that sanctity of life	/Leading to a change in Behavior/	Social acceptability/Concept of Death/Evolution of Illness/ Negative Thinking/Experience
The laws accept that the decision can be made in the absence of informations	Altered confidence///	Social acceptability/access to AD/Responsibility
The decision can be made without relevant information	Altered confidence/AD's Viability	Standardization/Negative Thinking/access to AD
To disregards an AD because it is based on insufficient information is unacceptable	Altered confidence/Leading to a change in Behavior/AD's Viability/	Social acceptability/access to AD/Responsibility/Lack of experience
A decision overbone by the influence is not legally effective	Leading to a change in Behavior//	Social acceptability/Negative Thinking/access to AD

RAW DATAS	SUB THEME	OPEN CODES
The judiciary talk about lack of capacity when the choice is unacceptable	Altered confidence/AD's Viability	Negative Thinking/Evolution of Illness/Revocability/ Responsibility/Standardization
Judges are anxious to decide cases	/Leading to a change in Behavior	Negative Thinking/Lack of experience
People procrastinate	Altered confidence//	Negative Thinking/access to AD
People hesitate to broach the topic to their doctors	Altered confidence	Negative Thinking
There is a suspicion that living wills not change the treatments	Altered confidence	Social acceptability/Negative Thinking
Even contemporary decisions about contemporary illnesses are difficult	/Leading to a change in Behavior	Negative Thinking/Lack of experience/Evolution of Illness
Illness and hospitalization change people's preferences	Altered confidence/AD's Viability	Social acceptability/Evolution of Illness/Lack of experience
Someone must decide what the living will commands	/Leading to a change in Behavior/	Social acceptability/Negative Thinking/Responsibility/ Revocability
The imprecision wills stymies interpreters	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking/ Responsibility
It was never considered the time to invoke the AD	Altered confidence/Leading to a change in Behavior/	Access to AD/Lack of experience
The living wills without adequate reflection not lead surrogates to make the choices	Altered confidence//AD's Viability	Access to AD/Revocability/Lack of experience
The patient's relatives and caregivers may feel that an AD may not be in the best interests	/Leading to a change in Behavior/	Social acceptability/Evolution of Illness/Negative Thinking
The patient may miss out on new advances on medical care	Altered confidence/AD's Viability/	Evolution of Illness/access to AD
The self gradually evolves and changes	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Interpretation is restricted to the explicit guidance	//AD's Viability/	access to AD/Revocability
Informations may be given with a degree of persuasion	//AD's Viability/	Social acceptability/Negative Thinking/access to AD
The conversations are ordinary short, vague, and tendencious	//AD's Viability	access to AD
It is difficult to inform about a lot o situation of decision making	//AD's Viability	Standardization/access to AD/ Lack of experience
Future treatment may be discovered	/AD's Viability	Evolution of Illness

RAW DATAS	SUB THEME	OPEN CODES
The personal and cultural dimensions of identity are situationally decoupled	/AD's Viability/	Social acceptability/Concept of Death/Lack of experience
The wills may expressed contrasting and incompatible wishes	//AD's Viability/	Access to AD/Negative Thinking
Some situations deemed incurable can be modified because of the progress in biomedical knowledge	/AD's Viability	Evolution of Illness/Negative Thinking
The imagination of future situations is vague	/AD's Viability	Evolution of Illness/Lack of experience
A medical professional may have concerns about its validity or applicability	/AD's Viability	Access to AD/Experience/ Responsibility/Revocability
Some people may be unaware the threat to her future welfare	/AD's Viability	Access to AD/Evolution of Illness
There is a need for a functional test of competence	//AD's Viability	Responsibility/Revocability/ Non consensual Making of
To believe to know without being aware of the possibilities	//AD's Viability	Access to AD/Revocability/ Responsibility/Lack of experience
Doubt about vague decisions may exist	//AD's Viability	Lack of experience/Negative Thinking/access to AD
It is difficult to make an unambiguous directive	//AD's Viability	access to AD
Without information individuals may be less able to predict the future	/AD's Viability	Evolution of Illness/access to AD/Lack of experience
An AD may be self determining but not autonomous	/AD's Viability	Social acceptability/access to AD/Revocability/Responsibility
A qualitative identity also presupposes certain abilities and continuities	AD's Viability/	Social acceptability/Concept of Death
Choices may change in time	AD's Viability/	Evolution of Illness/access to AD/Lack of experience
It may be hard to project his will into a completely different context	AD's Viability/	Social acceptability/Lack of experience
Avoiding therapeutic obstinacy is implicit in the very meaning of deontological duty	AD's Viability/	Experience/Negative Thinking
Autonomy places too much weight on the self as independent and rationally controlling	/AD's Viability/	Social acceptability/Negative Thinking/Revocability/ Responsibility/Non consensual Making of

RAW DATAS	SUB THEME	OPEN CODES
There is a risk of interpretation	/AD's Viability/	Access to AD/Non consensual Making of/Experience
Conflict arises between the wishes of a patient and the views of the legal representative	AD's Viability//	Revocability/Responsibility/ Negative Thinking/Social acceptability
An AD will be invalid if there is no sufficient information	/AD's Viability/	Access to AD/Responsibility
As capacity is not a static concept a bias in favor of preserving life might arise	AD's Viability//	Evolution of Illness/Social acceptability/Revocability
When there is no interpretation the patient autonomy is undermined by the views of medical profession and/ or society	AD's Viability/	Social acceptability/Concept of Death
Unsubstantiated doubts might be sufficient to invalidate the AD	/AD's Viability/	Negative Thinking/access to AD
Is the weight of autonomy fair?	AD's Viability/	Social acceptability/Concept of Death
The couts avoid the issue by finding the patients incompetent	AD's Viability/	Social acceptability/Evolution of Illness/Revocability
Any undue influence affect the validity the advance directive	AD's Viability/	Social acceptability/Negative Thinking/Responsibility
The later desires of the incompetent individual are not accurate reflections of these core interests	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/ Responsibility/Revocability
The loss of competence entails that the relevance and value of the core interest are diminished	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
The future is opaque	AD's Viability	Evolution of Illness
Beliefs ans values may change	AD's Viability	Social acceptability/Evolution of Illness/Lack of experience
Is the antecedent consent sufficiently informed	AD's Viability	Access to AD/Responsibility/ Revocability
Interests may change	AD's Viability	Evolution of Illness/Social acceptability
Is the consent about the future really informed	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
The same identity of the individual when there is a loss of consciousness?	AD's Viability	Evolution of Illness
Question concerning the scope of AD	AD's Viability/	Standardization/access to AD

RAW DATAS	SUB THEME	OPEN CODES
If the content of the AD is opaque there is interpretation	/AD's Viability	Standardization/access to AD
Language in AD was too non specific to provide clear instruction	/AD's Viability	Social acceptability/ Standardization/access to AD
A patient's preference for decision making varies with age	Altered confidence/AD's Viability/	Evolution of Illness/Lack of experience
A patient's preference for decision making varies with gravity of the decision	AD's Viability	Social acceptability/Evolution of Illness/Negative Thinking
People are not able to foresee situations	AD's Viability	Access to AD/Evolution of Illness/Revocability
The interest of people are changing	AD's Viability	Social acceptability/Evolution of Illness/Lack of experience
Doubts may exist that the patient changed in faith	/AD's Viability	Revocability
A patient may change their mind over the years	AD's Viability	Revocability/Social acceptability/Evolution of Illness
Medical techniques and treatment opportunities may develop	AD's Viability	Evolution of Illness/Lack of experience
Preferences change between healthy people and ill people	AD's Viability	Evolution of Illness/Concept of Death
Mind may change	AD's Viability	Evolution of Illness/Social acceptability/Lack of experience
There is ambiguity in the wording of the directive	/AD's Viability	access to AD
The art in therapeutic is changing	AD's Viability	Evolution of Illness/Revocability
It is not possible for the author to imagine all future exigencies	AD's Viability	Lack of experience
The attempt to achieve specificity and comprehensiveness is at the expense of simplicity and clarity	/AD's Viability	Social acceptability/access to AD/Lack of experience
Directives are complex because of the medical technology progresses	/AD's Viability	Standardization/access to AD
Criticaly ill patients commonly have severe depressions	AD's Viability	Evolution of Illness
With more time, mind is changing	AD's Viability	Evolution of Illness/Social acceptability/Revocability
Requests may be based on panic	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Close to death mind is changing	AD's Viability	Revocability/Evolution of Illness

Directive may be influencedAD's ViabilitySocial accept RevocabilityThe circumstances may changeAD's ViabilityEvolution of Social accept RevocabilityIndividuals with degenerative disease will changeAD's ViabilitySocial accept Social accept Social accept RevocabilityThere is no connection between the competent and the incompetent personAD's ViabilityEvolution of Social accept Social	y/Responsibility f Illness otability/Evolution of ative Thinking/ y f Illness/Revocability f Illness/Lack of
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may change experience	
Person view change with maturity Altered confidence/AD's Lack of expe	erience
and experience Viability	
The same person's treatment choice AD's Viability Evolution of experience	f Illness/Lack of
	f Illness/Lack of /Revocability
No undue influence or any other vitiating factor is required AD's Viability Social acception Death/Resp	otability/Concept of consibility
There is uncertainty about a change AD's Viability Evolution of circumstances	f Illness
Without information about when an AD was given, there is legitimate concerns about whether the individual retains the views previously articulated	f Illness/access to AD
The circumstances may change AD's Viability Evolution of	f Illness/Revocability
There is doubts about the validity of the projection of autonomous choice into the future Evolution of AD's Viability	f Illness/Revocability
People may be mistaken about their future interests AD's Viability Evolution of	f Illness/Revocability
The person may no longer be the same personAD's ViabilityEvolution of Revocability	f Illness/ y/Social acceptability
The personal identity and welfare problems are presentAD's ViabilityEvolution of Death	f Illness/Concept of
Doctors cannot assume that AD's Viability access to AI insufficient information was given	D/Lack of experience
It is impossible to anticipate all the future AD's Viability Evolution of	f Illness/Revocability

RAW DATAS	SUB THEME	OPEN CODES
There is a subjective interpretation	/AD's Viability	Lack of experience/Experience/ Social acceptability/Concept of Death
It is difficult to predict all eventualities	AD's Viability	Access to AD/Evolution of Illness/Revocability
General terms leave room for ambiguity	/AD's Viability	access to AD
Relevant circumstances may changed between the making of the directive and the moment of its implementation	AD's Viability	Evolution of Illness
An incurable illness may become curable	AD's Viability	Evolution of Illness/Lack of experience
patient's interest are changing with dementia	AD's Viability	Evolution of Illness
Are AD binding when the patient does not have the capacity to perceive the violation of past autonomous decision?	AD's Viability	Evolution of Illness/ Revocability/Responsibility
There is a lack of psychological relationship between the competent and incompetent person	AD's Viability	Evolution of Illness/Revocability
The courts will assess the patient's competence	AD's Viability	Social acceptability/Evolution of Illness/Responsibility
There may be change of mind at the last minute	AD's Viability	Evolution of Illness/Negative Thinking
Changes may not be communicated to the relevant healthcare professional	/AD's Viability	access to AD
To be sufficiently specific is hard	/AD's Viability	access to AD
It is difficult to anticipate the exact circumstances	AD's Viability	Evolution of Illness/access to AD/Revocability
The use of newly developed but unanticipated treatment is possible	AD's Viability	Evolution of Illness/Lack of experience
There is an onus about the Leading to a change in behaviorcontinuing validity »	AD's Viability	Evolution of Illness/Revocability
Is there a continuing validity?	AD's Viability	Evolution of Illness/Revocability
Some people falter in gathering information	/AD's Viability	Access to AD/Negative Thinking
Future is unspecified and unidentified, diseases may have unpredictable treatments	AD's Viability	Evolution of Illness/Revocability

RAW DATAS	SUB THEME	OPEN CODES
Preferences are labile and people have trouble recognizing that their views have changed	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
People makes inconsistant instructions in living wills	/AD's Viability	access to AD
The imprecision exacerbates their tendency to read documents in light of their own preferences	/AD's Viability	Access to AD/Social acceptability/Concept of Death
Future circumstances are prone to misjudgment	AD's Viability	Evolution of Illness
Such decisions are subject to a greater risk of error	AD's Viability	Evolution of Illness/ Revocability/Lack of experience
8) PANCHER J. What are the barriers Qualitative study	about applying the advance directi by collective interviews Th. : Méd :	
L'état de douleur du patient	Leading to a change in behavior	Evolution of Illness/Negative Thinking
L'application des DA confine à l'acharnement thérapeutique	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
L'application des DA confine à l'acharnement thérapeutique	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking/ Experience
Lorsque les DA ne sont pas adaptées à la situation du patient	AD's Viability	Negative Thinking/access to AD/Revocability
Le médecin pense que les DA ne s'appliquent pas à la situation clinique du patient	Altered confidence/Leading to a change in behavior	Experience
Les DA ne sont pas adaptées à la situation clinique du patient	Altered confidence/Leading to a change in behavior	Evolution of Illness/Experience
Les thérapeutiques antalgiques peuvent mener à abréger la vie du patient et ainsi aller à l'encontre des DA	Altered confidence/AD's Viability	Negative Thinking/Lack of experience/Responsibility
Appliquer les DA d'un proche si on n'est pas en accord avec celles ci	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking/Non consensual Making of
Etre médecin et appliquer les DA d'un proche	Altered confidence	Negative Thinking/Experience
Avoir des biais parce qu'on est médecin	Leading to a change in behavior	Lack of experience/Experience/ Responsibility
Ne pas être d'accord avec le contenu des DA	Leading to a change in behavior/Altered confidence/ AD's Viability	Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Être medecin traitant et personne de confiance en meme temps	Leading to a change in behavior/Altered confidence	Negative Thinking
Application influencée par l'experience vécue du médecin	/Leading to a change in behavior	Negative Thinking/Lack of experience/Experience
Le réflexe d'un médecin dans l'urgence est de tenter de sauver son patient quand un moyen simple est à disposition	/Leading to a change in behavior/	Experience
Le format figé des DA manque d'adaptabilité	Altered confidence/AD's Viability	Access to AD/Standardization
Appréciation clinique du médecin vis à vis de la situation	Altered confidence//	Lack of experience/Experience/ Negative Thinking/ Responsibility
Les DA sont un concept	Leading to a change in behavior/	Access to AD/Lack of experience
Difficulté pour le médecin d'aborder le thème des DA avec les patients	Leading to a change in behavior	Negative Thinking/Lack of experience
Difficulté pour le médecin d'aborder le thème des DA avec les patients au « bon » moment	AD's Viability	Negative Thinking/Evolution of Illness/Lack of experience
Role du médecin pour évoquer les DA	Altered confidence/Leading to a change in behavior	Social acceptability/Evolution of Illness/Revocability
Role du médecin pour évoquer les DA	Leading to a change in behavior/	Lack of experience
Difficulté à aborder les DA avec certains patients	/AD's Viability/	Negative Thinking/Evolution of Illness/Social acceptability/ Concept of Death
Prendre une decision dans le cas d'une situation d'urgence	Leading to a change in behavior	Evolution of Illness/ Responsibility/Experience
Prendre une décision en l'absence d'une directive anticipée écrite	Leading to a change in behavior/	Access to AD/Experience
Danger d'avoir des DA finalement pas en adéquation avec la situation actuelle du patient	/Leading to a change in behavior/Altered confidence/ AD's Viability	Evolution of Illness/Negative Thinking/access to AD
l'émotion de l'entourage peut interférer dans la transmission de la parole du patient	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Adhésion au concept de DA	Altered confidence//	Social acceptability/ Responsibility
Adhésion au concept de DA	Altered confidence//	Social acceptability/ Responsibility
Difficulté pour le patient de se représenter la réalité de la situation avant qu'elle ne se produise	Altered confidence//	Evolution of Illness/Revocability
	Dago 90	

RAW DATAS	SUB THEME	OPEN CODES
Le médecin pense que les DA ne s'appliquent pas à la situation clinique du patient	Leading to a change in behavior	Evolution of Illness/Negative Thinking/Experience
La souffrance du patient rend difficile l'application des DA pour les équipes soignantes	/Leading to a change in behavior/	Social acceptability/Negative Thinking/Experience
Difficultés des équipes soignantes paramédicales qui sont au quotidien auprès des patients	/Leading to a change in behavior	Negative Thinking/Experience/ Social acceptability
Le vécu du médecin influence l'application des DA	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking/ Experience
Le médecin a peur de rompre l'alliance thérapeutique en évoquant la fin de vie	Altered confidence	Negative Thinking
Évoquer les DA avec un patient jeune	AD's Viability	Negative Thinking/Evolution of Illness/Social acceptability/ Concept of Death
Trouver le bon moment pour discuter des DA	Altered confidence//AD's Viability	Social acceptability/Evolution of Illness
Que le médecin soit la personne appropriée pour discuter des DA avec le patient	Altered confidence/Leading to a change in behavior/	Responsibility/Lack of experience
Difficulté pour le patient d'aborder les DA avec ses proches	Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking/Concept of Death
Le médecin refuse de devoir aborder les DA	Leading to a change in behavior/	Responsibility/Negative Thinking/Experience
Difficulté à aborder les DA avec le patient	Altered confidence/Leading to a change in behavior	Negative Thinking/Lack of experience
Difficulté à appliquer les DA si elles ne sont pas raisonnables	/Leading to a change in behavior/AD's Viability	Access to AD/Negative Thinking/Experience
Définir les limites thérapeutiques	Altered confidence/Altered confidence/AD's Viability	Evolution of Illness/ Standardization/access to AD/ Non consensual Making of
Définir les limites thérapeutiques	Altered confidence/Leading to a change in behavior/AD's Viability/	Evolution of Illness/Experience/ Social acceptability/Concept of Death
Difficultés des équipes soignantes paramédicales, notamment en EHPAD à gérer les fins de vie	Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking
Singularité de toute fin de vie qui rend difficile parfois l'application à la lettre des DA	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
Limites du caractère obligatoire auquel le médecin n'adhere pas	Altered confidence//Leading to a change in behavior	Social acceptability/ Revocability/Responsibility
Limite du caractère strict de l'application	AD's Viability/Altered confidence	Standardization/access to AD/ Responsibility
Difficulté à aborder des DA avec le patient atteint d'une pathologie grave	AD's Viability	Concept of Death/Negative Thinking/Evolution of Illness
Difficulté à aborder le sujet de la mort avec le patient	Leading to a change in behavior/Altered confidence	Concept of Death/Negative Thinking
Le vécu et les angoisses du médecin influencent l'application des DA	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking/Experience
Difficulté pour le MG d'aborder les directives anticipées	AD's Viability/Leading to a change in behavior	Negative Thinking/access to AD/Lack of experience
Difficulté d'anticiper les situations auxquelles le patient sera confronté dans plusieurs années	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Absence de DA écrite pour leur application	AD's Viability	access to AD
Appliquer les DA d'un proche si l'on est pas d'accord avec celles ci	/Leading to a change in behavior/	Social acceptability/Negative Thinking/Experience
La souffrance du patient rend difficile l'application des DA pour les équipes soignantes	Leading to a change in behavior/Altered confidence	Negative Thinking
Ne pas pouvoir respecter les DA d'un patient car la famille s'y oppose	/AD's Viability/	Social acceptability/ Responsibility/Revocability/ Non consensual Making of
Difficulté à aborder les DA quand la personne est atteinte d'une pathologie rapidement évolutive	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking
DA rédigées avant d'être dans la situation de maladie grave ou incurable	Altered confidence/AD's Viability	Evolution of Illness/Revocability
Évoquer les DA avec un patient en bonne santé	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Lack of experience
Appliquer les volontés d'un patient avec des troubles cognitifs	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Social acceptability
Difficulté de faire des DA en cas de troubles cognitifs	Altered confidence//AD's Viability/	Evolution of Illness/ Standardization/access to AD
Acceptabilité des DA par l'entourage, sa capacité à supporter la fin de vie (type phase agonique)	/AD's Viability/	Social acceptability/Concept of Death/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Difficulté pour anticiper toutes les situations qui vont se présenter	Altered confidence/AD's Viability	Evolution of Illness/ Standardization
Peur de la part du médecin de choquer le patient en évoquant les DA	Altered confidence/Leading to a change in behavior	Negative Thinking/Social acceptability/Concept of Death
Le role du médecin est plutôt d'être dans le soin	Leading to a change in behavior/	Experience
Difficulté pour le patient de s'imaginer dans sa fin de Vie	Altered confidence/	Lack of experience/Evolution of Illness/Negative Thinking
Application des DA orale et refus de la famille de les appliquer en évinçant le médecin	/Leading to a change in behavior//	Social acceptability/Concept of Death/Revocability/ Responsibility
Importance d'expliquer clairement au patient les tenants et les aboutissants	AD's Viability/Altered confidence	Negative Thinking/access to AD
Difficultés pour les proches d'entendre des volontés de limitation de soin	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Difficulté à appliquer les DA d'un proche quand on est pas en accord avec celles-ci	Leading to a change in behavior/	Social acceptability/Evolution of Illness/Negative Thinking/Non consensual Making of
Difficulté à appliquer des DA qui semblent déraisonnables	Altered confidence//Leading to a change in behavior	Negative Thinking/access to AD/Non consensual Making of/ experience
Des directives dites ou écrites discordantes pour l'entourage	/AD's Viability/	Social acceptability/Concept of Death/Revocability/ Responsibility
Absnece de DA écrites	/Altered confidence	access to AD
Définir ce que l'on considère comme un acharnement	/Leading to a change in behavior/	Concept of Death/Social acceptability/Lack of experience/Experience
Etre médecin traitant et personne de confiance d'un même patient	AD's Viability/Altered confidence/Leading to a change in behavior	Responsibility/Negative Thinking
Difficulté à aborder les DA car Tabou	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Le médecin a peur que le patient se sente agressépar une discussion autour des DA	/Altered confidence/	Negative Thinking/Social acceptability/Concept of Death
Difficulté à aborder des DA au moment du diagnostic d'une maladie grave	/AD's Viability	Social acceptability/Evolution of Illness/Negative Thinking

		-
RAW DATAS	SUB THEME	OPEN CODES
Évolution de la clinique du patient qui modifie la perception du pronostic par l'entourage	/AD's Viability/	Social acceptability/Concept of Death/Evolution of Illness
Etat clinique du patient	Altered confidence/AD's Viability	Evolution of Illness
Difficulté à appliquer les DA dans le contexte de soins aigus uniquement	Altered confidence/AD's Viability	Evolution of Illness/access to AD
Évolution des peurs/du vécu du patient avec l'évolution de son état de santé	Altered confidence/AD's Viability	Evolution of Illness/Social acceptability/Concept of Death
Caractère figé de l'ecrit	Altered confidence//AD's Viability	Access to AD/Revocability
Da écrite mais à un age bien antérieur et évolution des volontés du patient	Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Lack of experience
DA en inadéquation avec les possibilités thérapeutiques	Leading to a change in behavior/AD's Viability/	Evolution of Illness/access to AD/Experience
Adapter les DA en fonction de la situation aigue	Leading to a change in behavior/AD's Viability/	Evolution of Illness
Savoir déterminer où se situe les limites du soins, le caractère déraisonnable	Altered confidence/AD's Viability	Social acceptability/Concept of Death/Negative Thinking/Lack of experience/Experience
Singularité des situations menant à adapter les DA pour les appliquer/ interpréter/rediscuter avec le patient	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Quand l'hôpital n'appelle pas pour connaitre les DA du patient	Altered confidence	Non consensual Making of
DA rédigées mais non accessibles pour les équipes soignante de l'hôpital	Altered confidence/AD's Viability	Access to AD/Non consensual Making of
Le manque de comprehension au sein des équipes soignantes peut rendre difficile l'application des volontés des patients	Altered confidence/Leading to a change in behavior/AD's Viability	Social acceptability/Concept of Death/Lack of experience
Difficultés de s'appuyer sur des DA orales, manques de DA écrites	AD's Viability	access to AD
Définir les termes d'acharnement et de soins palliatifs/soin de fin de vie	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
Difficulté à avoir des discussions autour des DA avec l'entourage pour harmoniser les choses	Altered confidence/AD's Viability	Non consensual Making of
Importance d'utiliser un vocabulaire adapté au patient	AD's Viability	access to AD

RAW DATAS	SUB THEME	OPEN CODES
Définir ce qui releve de la reanimation ou des soins de confort	/AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/ Revocability/Responsibility
Le médecin ne connait pas bien le texte de loi	/AD's Viability	Access to AD/Responsibility/ Lack of experience
Le médecin ne connait pas bien le texte de loi	/AD's Viability	Access to AD/Responsibility/ Lack of experience
Difficulté d'anticiper les situations auxquelles vont être confrontés le patient	/AD's Viability	Evolution of Illness/Lack of experience
Le patient ne réalise pas ce qu'implique la maladie	/AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/Lack of experience
Définir ce que l'on entend par soins de fin de vie et les thérapeutiques associées	//AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/Lack of experience
Evenement aigu chez un patient qui n'a pas rédigé ses DA	AD's Viability/	Social acceptability/Concept of Death
Absence de DA aboutissant à une situation déraisonnable	AD's Viability/	Social acceptability/Concept of Death
absence de DA écrite et donc l'avis de la famille prévaut par rapport aux paroles rapportées de la personne	/AD's Viability/	Social acceptability/Concept of Death/Revocability/ Responsibility
Évolution clinique du patient mais pas de DA écrite	AD's Viability/	Evolution of Illness
Discussion avec le patient en cas de pathologie curable bien que les DA soient en faveur d'un arrêt de traitement	AD's Viability/	Evolution of Illness/Negative Thinking/Experience
Format écrit des DA peu compatible avec l'évolutivité et la multiplicité des situations	/AD's Viability	access to AD
Appliquer des DA quand elles ne sont pas rédigées	AD's Viability/Altered confidence	Access to AD/Responsibility
Appliquer des DA quand elles ne sont pas écrites	AD's Viability/Altered confidence	Access to AD/Responsibility
Séquelles potentielles en cas de reanimation	AD's Viability	Evolution of Illness/Negative Thinking
Contenu des DA inadapté à la situation clinique du patient	AD's Viability	Evolution of Illness/access to AD/Revocability
Inadéquation entre l'idée philosophique des DA et sa réalisation	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death/Evolution of Illness

RAW DATAS	SUB THEME	OPEN CODES
Caractère imprévisible des situations amenant à appliquer des DA	AD's Viability/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Lack of experience
Évolution des pronostics en lien avec les thérapeutiques	AD's Viability	Evolution of Illness
Le caractère écrit des DA les rendent moins adaptables	/AD's Viability	Standardization/access to AD
La transmission orale peut ne pas correspondre exactement aux souhaits du patient	Altered confidence	access to AD
DA écrites longtemps avant l'application	AD's Viability	Concept of Death/Evolution of Illness/access to AD
Difficulté d'appliquer les DA face à des situations aiguës	AD's Viability	Evolution of Illness/access to AD/Lack of experience/ Experience
Éventail des situations possibles trop large	AD's Viability	Evolution of Illness/access to AD
Évolution des thérapeutiques et donc des pronostics de certaines maladies	AD's Viability	Evolution of Illness/access to AD/Lack of experience
Éventail des situations possibles trop large	AD's Viability	Evolution of Illness/access to AD
Le médecin pense que le formulaire est trop simplifié comparé aux multiples situations possibles	AD's Viability/Altered confidence	Standardization/access to AD
Les DA évoluent en fonction de l'état clinique du patienter doivent être réactualisés	AD's Viability	Evolution of Illness
Aborder les DA avec un patient jeune en bonne santé	AD's Viability/Altered confidence	Evolution of Illness/Social acceptability/Lack of experience
Adapter les DA à la situation clinique	AD's Viability	Evolution of Illness/access to AD
Les DA ne peuvent pas anticiper toutes les situations qui vont se présenter en réalité	AD's Viability	Evolution of Illness/ Standardization/access to AD
Manque d'accessibilité des fiches SAMU pallia	AD's Viability	access to AD
Format papier des DA pour le SAMU	AD's Viability	access to AD
Le patient a pu exprimer oralement une volonté qui diffère de celle écrite dans ses DA	AD's Viability	Social acceptability/Evolution of Illness/Revocability
LES DA écrites ne sont pas en accord avec ce que le patient a pu exprimer de son vivant plus récemment	AD's Viability	Access to AD/Revocability/ Standardization

RAW DATAS	SUB THEME	OPEN CODES
DA écrite mais non accessible au médecin lors du moment aigu	AD's Viability	access to AD
Complexité et multitudes des situations potentielles	AD's Viability	Evolution of Illness/access to AD
Il est trop difficile d'anticiper toutes les situations possibles	AD's Viability	Evolution of Illness/access to AD
Evolution de la volonté des patients au fil du temps	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
Difficulté à appliquer les DA écrites lorsqu'elles ne sont pas en accord avec des paroles du patient rapportées par oral ou connue par le médecin	Altered confidence/AD's Viability	Responsibility/Revocability/ access to AD
Des directives dites ou écrites à des moments différents donc avec une finalité différentes	AD's Viability	Evolution of Illness/Revocability
Évoquer les DA dépend de la pathologie du patient	AD's Viability	Evolution of Illness
Évoquer les DA au moment du diagnostic d'une pathologie grave	AD's Viability	Evolution of Illness/Negative Thinking/Concept of Death
Absence de DA écrite pour un patient	AD's Viability	access to AD
Évolution des DA en fonction de l'état clinique du patient en parallèle de l'évolution de la pathologie	AD's Viability	Evolution of Illness/Lack of experience
Évolution des thérapeutiques et donc des pronostics	AD's Viability	Evolution of Illness
Évolution de la situation du patient entre le moment de la rédaction et celui de l'application	AD's Viability	Social acceptability/Evolution of Illness/Concept of Death
Importance d'utiliser un vocabulaire adapté au patient	Altered confidence/AD's Viability	access to AD
Singularité des situations menant à adapter les DA pour les appliquer/ interpréter/rediscuter avec le patient	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/Lack of experience/Experience
Singularité des situations menant à adapter les DA pour les appliquer/ interpréter/rediscuter avec le patient	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/Lack of experience/Experience
La situation clinique du patient varie dans des contextes aigus pr exemple	AD's Viability	Evolution of Illness

Appendix 5: THEMATIC ANALYSIS (CONFLICT ANXIETY)		
RAW DATAS	SUB THEME	OPEN CODES
Évolution des envies du patients en parallèle de l'evolution de la pathologie	AD's Viability	Social acceptability/Evolution of Illness
	tors that hinder the drafting of adv ionship? Qualitative focus group s ners in Brittany Th.: Med : BREST (	tudy carried out with general
Le sujet des DA n'est pas un sujet calibré	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking/Standardization
Sujet difficile à aborder pour le médecin	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Médecin n'est pas à l'aise avec le concept de DA	Altered confidence/	Social acceptability/Concept of Death/Lack of experience
Difficile por le MG de parler des DA	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death/Negative Thinking
Medecin mal à l'aise pour aborder le sujet des DA	Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking
Difficile d'amener le sujet des DA au centre de la conversation	Altered confidence//AD's Viability	Lack of experience/Negative Thinking
Le plus dur est d'amener le sujet des DA	AD's Viability/Altered confidence	Concept of Death/Negative Thinking/Lack of experience/ access to AD
Difficile d'amener le sujet des DA	AD's Viability/Altered confidence	Social acceptability/Negative Thinking
Médecin a peur d'aborder les DA	AD's Viability/Altered confidence/Leading to a change in behavior	Concept of Death/Negative Thinking
Parler des DA reveille des choses pas agréables	Altered confidence/Leading to a change in behavior	Negative Thinking
La mort est un sujet tabou	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death
Il est difficile pour le médecin de se projeter comme futur malade et d'écrire ses DA	Altered confidence/AD's Viability	Concept of Death/Evolution of Illness/Lack of experience
Le médecin reconnait avoir des freins psychologiques vis à vis des DA	AD's Viability/Altered confidence	Negative Thinking/Concept of Death
Le MG est freiné par ses propres peurs	Leading to a change in behavior/Altered confidence	Negative Thinking
Le médecin puise dans son experience personnelle et son vécu	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Médecin freiné par sa volonté de mettre les formes	/Altered confidence	Social acceptability/Negative Thinking
Peur de pousser le patient dans ses retranchements	Altered confidence	Negative Thinking
Médecin a peur que le patient malade perde espoir s'il lui parle des DA	Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking
Les MG a peur qu'en parlant des DA, le patient pense qu'il va bientôt mourir	AD's Viability/	Evolution of Illness/Negative Thinking
Le médecin a peur d'être responsable d'une mauvaise décision en cas de problème	/Altered confidence	Evolution of Illness/Negative Thinking/Responsibility
Culpabilité médecine car DA non respectées	Altered confidence	Revocability/Responsibility
Médecin refuse sa propre fin	AD's Viability/Leading to a change in behavior	Concept of Death/Negative Thinking
Etre médecin conjure la notion de mort pour soi meme	/Leading to a change in behavior/	Experience
Le médecin se pense immortel du fait de sa fonction	/Leading to a change in behavior	Experience/Negative Thinking/ Concept of Death
Difficulté de se projeter en tant que médecin car se croit tout puissant	Leading to a change in behavior/Altered confidence	Concept of Death/Negative Thinking/Experience
Dur de se projeter avec un handicap	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Le médecin n'arrive pas à se projeter donc préfère ne pas écrire ses DA	Leading to a change in behavior/AD's Viability	Evolution of Illness/Lack of experience
Les medecins sont des guérisseurs, ils ne sont pas sensés parler de la mort	Leading to a change in behavior/	Experience
Sujet qui met le médecin face à la mort	Leading to a change in behavior/Altered confidence	Concept of Death/Negative Thinking
Parler de la mort renvoie au patient une mauvaise image du médecin	Altered confidence	Negative Thinking/Social acceptability
La mort n'est pas le premier sujet auquel pense le médecin dans une consultation	Leading to a change in behavior/AD's Viability	Lack of experience/Experience
Le médecin ne parle pas facilement des DA	Leading to a change in behavior	Lack of experience/Experience
Le MG ne pense pas parler des DA aux patients	Leading to a change in behavior	Lack of experience/ Standardization
Le médecin ne parle pas spontanément des DA	Leading to a change in behavior	Lack of experience

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RAW DATAS	SUB THEME	OPEN CODES
Le MG n'a jamais posé la question des DA à ses patients	Leading to a change in behavior/	Lack of experience
Le médecin n'initie jamais la discussion sur les DA	Leading to a change in behavior	Lack of experience/Experience
Médecin pense que la discussion doit venir du patient	Leading to a change in behavior	Experience/access to AD
Médecin élude la question par facilité	Altered confidence/	Social acceptability/Negative Thinking
sujet difficile car oblige à se projeter sur la fin de vie	Leading to a change in behavior/Altered confidence	Concept of Death/Negative Thinking
Difficulté pour le patient de se projeter sur sa fin de vie	Leading to a change in behavior/Altered confidence	Evolution of Illness/Negative Thinking
Les patients n'ont pas envie de se projeter sur la fin de vie	Leading to a change in behavior/Altered confidence/ AD's Viability	Evolution of Illness/Negative Thinking/Social acceptability/ Concept of Death
Difficulté pour le patient de se projeter dans un état futur	AD's Viability	Evolution of Illness/Negative Thinking
Les gens ne veulent pas se projeter	Leading to a change in behavior	Evolution of Illness/Negative Thinking/Concept of Death
Les gens ne sont pas prêt à faire la démarche des DA	Altered confidence	access to AD
Les patients atteints d'une maladie grave n'arrivent pas à se projeter	Altered confidence//AD's Viability	Evolution of Illness/Negative Thinking
Les patients cancéreux n'ont pas envie de penser à leur DA	/Altered confidence	Evolution of Illness/Negative Thinking
Les gens ne veulent pas envisager leur mort ni celles de leurs proches	Leading to a change in behavior/Altered confidence	Concept of Death/Negative Thinking
Les patients abordent leur mort timidement	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Toutes les personnes ne sont pas prêtes à réfléchir à leur mort	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death
On ne peut pas parler de mort à la premiere consultation	Altered confidence/AD's Viability	Lack of experience
Difficile de demander aux gens de prendre rendez vous pour parler de la mort	/AD's Viability/	Negative Thinking/access to AD
Le patient n'attend pas de son médecin qu'il lui parle de la mort	Leading to a change in behavior	Social acceptability/Negative Thinking
Parler de la mort renvoie au patient une mauvaise image du médecin	Leading to a change in behavior/Altered confidence	Negative Thinking/Social acceptability
Sujet qui met le patient face à la mort	AD's Viability	Concept of Death/Evolution of Illness/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Les patients n'ont pas envie de mourir	Altered confidence/	Concept of Death
Les médecins n'ont pas besoin des DA dans leur pratique quotidienne	Altered confidence/Leading to a change in behavior	Social acceptability/Lack of experience
Le MG n'a pas besoin des DA	Altered confidence/Leading to a change in behavior	Social acceptability/Lack of experience/Experience
Le MG trouve que ce n'est pas son travail de rédiger les DA avec les patients	Leading to a change in behavior/	Social acceptability/Experience
Médecin doute du role du médecin traitant dans les DA	Leading to a change in behavior	Social acceptability/Lack of experience
Trop d'importance donnée au MG dans le processus des DA	Leading to a change in behavior/Altered confidence	Social acceptability/ Responsibility
LE MT doit rester à sa place	Leading to a change in behavior	Social acceptability/ Responsibility
Le patient demande trop au MT concernant les DA	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking/ Responsibility
Les MG sont sensés demander aux patients de faire leur DA mais eux meme ne les écrivent pas	/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
DA abordées brièvement à l'oral, pas à l'écrit	Altered confidence/AD's Viability/AD's Viability	access to AD
Recueil des DA informel, par oral	Leading to a change in behavior	access to AD
Le médecin n'ose pas aborder le sujet, de peur de ne pas savoir orienter les patients	Altered confidence/	Negative Thinking/access to AD/Lack of experience
Le médecin a peur de ne pas savoir se servir des DA que leurs patients lui donne	Altered confidence//AD's Viability	Negative Thinking/access to AD/Lack of experience
Les patients n'ont pas assez de connaissance médicale pour savoir ce qu'ils écrivent	Altered confidence/AD's Viability/AD's Viability	Access to AD/Lack of experience
Dans la fin de vie d'un patient, c'est au médecin de prendre ses responsabilités	Leading to a change in behavior/	Social acceptability/Experience/ Responsibility
Le patient attend du médecin qu'il sache prendre les bonnes décisions pour lui du fait de son bagage de connaissance	Altered confidence/Leading to a change in behavior/	Social acceptability/Experience/ Responsibility
Les gens viennent avec un motif précis, pas pour parler de la mort	Leading to a change in behavior/Altered confidence/ AD's Viability	Social acceptability/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Peur que le moment ne soit pas approprié	AD's Viability/Altered confidence	Access to AD/Negative Thinking/Evolution of Illness
Difficile de trouve le bon moment pour parler des DA	/AD's Viability	Evolution of Illness/Negative Thinking/access to AD/Lack of experience
Pas le bon moment pour parler des DA quad le patient est déjà stressé vis à vis d'une intervention	/AD's Viability/	Evolution of Illness/Negative Thinking
Démence = top tard pour parler des DA	/AD's Viability	Evolution of Illness/Revocability
Compliqué d'aborder les DA si diagnostic de démence	AD's Viability	Evolution of Illness/Revocability
Il est trop tard pour parler des DA quad les troubles cognitifs commencent	Altered confidence/AD's Viability	Evolution of Illness/Revocability
En EHPAD difficile de poser la question des DA car entrée en structure déjà dure pour les patients	AD's Viability	Negative Thinking/Evolution of Illness
Médecin mal à l'aise de demander les DA à un patient malade	AD's Viability/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Difficile de poser la question des DA au moment de l'annonce de la maladie	/AD's Viability	Evolution of Illness/Negative Thinking/access to AD
L'annonce de la maladie grave n'est pas le bon moment pour parler des DA	AD's Viability/Leading to a change in behavior	Negative Thinking/Evolution of Illness
Pas le moment pour parler des DA au moment d'une annonce diagnostique	/AD's Viability	Social acceptability/Evolution of Illness/Negative Thinking
Difficile de parler des DA lors de l'aggravation d'une maladie	/AD's Viability	Evolution of Illness/Negative Thinking
Pas le bon moment pour parler des DA quad le patient est déjà stressé vis à vis d'une intervention	AD's Viability/Leading to a change in behavior	Negative Thinking
Les gens ne demandent plus à écrire leur DA lors de l'aggravation de leur maladie	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Il ne faut pas parler des DA quand les patients ont encore un espoir de guérison	AD's Viability/Altered confidence	Concept of Death/Negative Thinking
Il ne faut pas parler des DA quand les gens sont encore combatif par rapport à la maladie	AD's Viability/Leading to a change in behavior	Concept of Death/Evolution of Illness/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Les patients malades viennent voir leur médecin pour qu'il les encourage, pas pour qu'il leur parle de mort	Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Difficile pour le médecin de parler de fi de vie à quelque'un de tres malade	Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking
Mauvais moment si fin de vie non acceptée par le patient	/Altered confidence/	Social acceptability/Negative Thinking
Trop tard pour parler de DA si maladie neuro dégénérative avancée	Altered confidence/AD's Viability	Evolution of Illness
Chaque situation est particuliere, tout depend du contexte	Altered confidence/AD's Viability	Evolution of Illness/access to AD/Revocability
Peur que la famille interprète mal les DA écrites	Altered confidence/	Social acceptability/Negative Thinking/Non consensual Making of
DA ne sont pas adaptées aux pathologies aigues	Altered confidence/AD's Viability	Evolution of Illness/access to AD/Revocability
Médecin mal à l'aise avec un patient tres jeune pour parler des DA	Altered confidence/	Evolution of Illness/Lack of experience
Toutes les DA se ressemblent et manquent de précision	Altered confidence/AD's Viability	Standardization
Le médecin ne sait pas quoi faire des DA une fois écrites	Leading to a change in behavior/	Lack of experience/access to AD
Les DA sont compliquées à respecter à domicile	/AD's Viability/	Evolution of Illness/access to AD
Les patients atteints d'une maladie grave n'arrivent pas à se projeter	Altered confidence//AD's Viability	Concept of Death/Evolution of Illness
Probleme pour ouvrir la discussion sur les DA	AD's Viability/Leading to a change in behavior	Social acceptability/access to AD
Difficile d'aborder les DA pour les médecins	/AD's Viability	Concept of Death/Negative Thinking/Lack of experience
Difficile de parler de la mort pour les médecins	Leading to a change in behavior	Concept of Death/Social acceptability/Negative Thinking/Lack of experience
Le médecin n'est pas associé à la mort dans la tête des gens	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death
Sujet qui touche à la philosophie	AD's Viability	Social acceptability/Concept of Death
Parler de la mort est tabou dans notre société actuelle	AD's Viability	Social acceptability/Concept of Death
La mort est encore plus taboue que le sexe dans notre société	AD's Viability	Social acceptability/Concept of Death

		OPEN CODES
RAW DATAS	SUB THEME	OPEN CODES
Pas dans notre culture de parler de la mort	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
Dans la société actuelle, les gens n'envisagent pas de mourir	AD's Viability	Social acceptability/Concept of Death
La mort est un sujet tabou en France	AD's Viability	Social acceptability/Concept of Death
La religion peut être un frein	AD's Viability	Social acceptability/Concept of Death
Les médecins sont influencés par leur morale et éducation	AD's Viability/Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Experience
Médecin freiné par sa volonté de mettre les formes	Altered confidence	Social acceptability/Negative Thinking/Experience
Le soignant est là pour aider, pas pour parler de la mort	AD's Viability	Social acceptability/Experience
Difficile de parler de la mort	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
Nous sommes dans un mode qui n'accepte pas de mourir	AD's Viability	Social acceptability/Concept of Death
Les patients viennent souvent pour un autre motif	AD's Viability/	Evolution of Illness/Negative Thinking
Le médecin a l'impression que les écrits engagent les gens	AD's Viability/	Revocability/Responsibility
Le médecin est limité par l'impression que l'écrit bloque les potentielles discussions futures	AD's Viability/	Standardization/access to AD/ Revocability
Probleme de la définition de l'acharnement thérapeutique selon les patients	AD's Viability/	Social acceptability/Non consensual Making of/Lack of experience
La notion d'acharnement thérapeutique est tres subjective	AD's Viability/	Social acceptability/Evolution of Illness/Revocability/ Responsibility
Le médecin n'a pas rédigé ses propres DA	AD's Viability	Social acceptability/Concept of Death/Negative Thinking
Le médecin a peur de se tromper dans la rédaction	AD's Viability	access to AD
La rise de décision est dure meme pour les médecins malgré leurs études	AD's Viability	Negative Thinking/Experience/ Lack of experience
Lorsque'il reste du temps de consultation, les médecins sont plutôt tourner vers la prevention que vers les DA	Leading to a change in behavior/AD's Viability	Experience

RAW DATAS	SUB THEME	OPEN CODES
La trame téléchargeable sur Internent n'est pa satisfaisante	AD's Viability	access to AD
Impossible d'avoir une bonne trame car trop de paramètres rentrent en compte	AD's Viability	Access to AD/Standardization
Une trame trop précise nécessite de détailler les volontés de chaque patients selon chaque situation possible	AD's Viability	Access to AD/Standardization
Une trame trop large n'apporte pas de réponse dans les situations singulieres	AD's Viability	Standardization/access to AD
Chaque situation est tellement singulière qu'il est difficile d'avoir un formulaire adapté	AD's Viability	Evolution of Illness/ Standardization
DA parfois trop précise	AD's Viability	Standardization/access to AD
Trame trop large=imprecise	AD's Viability	Standardization/access to AD
Sujet pour lequel il n'est pas facile de répondre par oui ou par non	AD's Viability	Evolution of Illness/Social acceptability/access to AD/ Standardization
Pas facile de recueillir des DA claires	AD's Viability	access to AD
Le médecin ne trouve pas le bon moment pour aborder le sujet des DA	AD's Viability	Social acceptability/Evolution of Illness/access to AD
Il n'y a pas de bon moment pour aborder les DA	AD's Viability	Evolution of Illness/Negative Thinking/access to AD
La consultation est rarement à propos pour aborder les DA	AD's Viability	Social acceptability/Lack of experience
Pas le bon moment pour parler des DA quand le patient est tres anxieux vis à vis d'une intervention	AD's Viability	Evolution of Illness/Negative Thinking
Les troubles cognitifs installés sont un frein à la réduction des DA	AD's Viability	Evolution of Illness/Non consensual Making of/ Revocability
Les patients ne sont souvent plus en état de signer leur DA en arrivant en EHPAD	AD's Viability	Evolution of Illness
Quand le patient ne peut plus s'exprimer, il est trop tard	AD's Viability	Evolution of Illness/ Revocability/Responsibility
Patients déments à leur arrivée en EHPAD, complique le recueil des DA	AD's Viability	Evolution of Illness/access to AD/Revocability
Difficile de recueillir les DA en EHPAD	AD's Viability	Evolution of Illness/ Revocability/Social acceptability

RAW DATAS	SUB THEME	OPEN CODES
Une aggravation clinique d'une maladie grave n'est pas le bon moment pour parler des DA	AD's Viability	Evolution of Illness/Revocability
Mauvais moment si fin de vie non acceptée par le patient	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness
Fin de vie = trop tard pour parler des DA	AD's Viability	Evolution of Illness/Negative Thinking
Difficulté à anticiper les volontés du patient	AD's Viability	Access to AD/Evolution of Illness/Revocability
Difficile d'anticiper les volontés d'un patient en bonne santé	AD's Viability	Social acceptability/Evolution of Illness/Revocability
Difficile d'anticiper toutes les possibilités	AD's Viability	Social acceptability/Evolution of Illness/Revocability/access to AD
Impossible d'anticiper toutes les situations possibles et de les exposer au patient	AD's Viability	Evolution of Illness/ Standardization/access to AD
Situations souvent complexes, difficile de tout prévoir dans les DA écrites	AD's Viability	Evolution of Illness/ Standardization/access to AD
Impression qu'écrire les DA empêche de changer d'avis	AD's Viability	Revocability/Responsibility
Les DA représentent un avis à un moment T donné	AD's Viability	Evolution of Illness
Peur que les DA ne reflète plus sa pensée actuelle et ne pas pouvoir les modifier	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Peur que les DA soient fixées et ne plus pouvoir changer d'avis une fois grabataire	AD's Viability	Evolution of Illness/ Responsibility/Revocability
Les gens changent d'avis une fois grabataire	AD's Viability	Evolution of Illness/ Revocability/Responsibility
Les gens changent d'avis quand ils apprennent être malade	AD's Viability	Evolution of Illness/Revocability
Les patients changent d'avis lorsque'ils sont faces à la maladie	AD's Viability	Evolution of Illness/Revocability
Discours tres fluctuant dans le temps pour un meme patient	AD's Viability	Evolution of Illness/Revocability
En dix ans, on a plus les memes envies	AD's Viability	Evolution of Illness/Revocability

RAW DATAS	SUB THEME	OPEN CODES
Raisonnement variable dans le temps, comment savoir si ce qu'il a écrit il y a deux ans est toujours valable?	AD's Viability	Evolution of Illness/ Revocability/Concept of Death
En six mois les patients peuvent avoir changé d'avis concernant leurs volontés en fin de vie	AD's Viability	Concept of Death/Evolution of Illness/Revocability
Le patient peut avoir changé d'avis entre le moment où il écrit ses DA et le moment où elles sont utilisées	AD's Viability	Evolution of Illness/access to AD/Revocability
Discours fluctuant des patients selon age/maladie	AD's Viability	Evolution of Illness
Décision différente selon le type de maladie	AD's Viability	Evolution of Illness/ Standardization
Da inutile dans le cadre de l'urgence chez le sujet jeune	AD's Viability	Evolution of Illness/Revocability
Les gens disent souvent qu'ils ne veulent pas finir legume, ce qui ne correspond pas à grand chose	AD's Viability	Standardization/access to AD
Sur la phase initiale, compliqué d'évaluer ce qui est de l'acharnement ou non	AD's Viability	Evolution of Illness/Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
10) Zambonino M;, What are the factors that have hindered the achievement of the anticipated guidelines for the community since the Claeys-Leonetti Act? A thematic analysis based on the grey literature review Th.: Med : BREST 2019		
Le format des DA ne peuvent illustrer la vision de la vie	AD's Viability	Standardization/Concept of Death
Les DA sont considérés comme une Norme juridique	AD's Viability/Leading to a change in behavior	Social acceptability/ Standardization
Manque d'intérêt des DA: trop compliquée	Altered confidence/	Access to AD
Refus d'anticiper ou de parler des DA	Altered confidence//AD's Viability	Negative Thinking/Lack of experience/Concept of Death
Risque de réduire l'identité d'une personne en une simple procedure	Altered confidence/	Standardization
Dimension spirituelle rendant difficile de s'ouvrir à autrui et de rédiger ses directives	Altered confidence/	Social acceptability/Concept of Death/Standardization/ Negative Thinking
Absence d'interlocuteur privilégié empêchera le récit de vie	AD's Viability	Non consensual Making of/ Social acceptability/Concept of Death/access to AD
Biais de temporalité des DA: nos désirs, nos avis fluctuent dans le temps. On ne peut figer nos désirs sur notre mort	AD's Viability	Evolution of Illness/ Revocability
L'imminence de la mort modifie nos jugements et nos certitudes	AD's Viability	Evolution of Illness/ Revocability/Experience
Dangers de la valorisation trop exclusive de l'autodétermination dans le cadre de la vulnérabilité induite par une maladie grave	Altered confidence/AD's Viability	Evolution of Illness/Negative Thinking/Responsibility
l'autodetermination et le libre arbitre peuvent induire une forme de solitude	/AD's Viability/	Social acceptability/Non consensual Making of/ Revocability/Responsibility
l'autodetermination pourrait ne pas être conforme à la volonté exprimée	/AD's Viability	Standardization/access to AD
Importance de l'élaboration conjointe avec l'équipe soignante des DA	Altered confidence/	Non consensual Making of
Danger des DA de rester figés et de ne pas prendre en compte la temporalité	AD's Viability	Evolution of Illness/ Revocability
L'anticipation est à différencier de la prévision, cela pourrait être réducteur	/AD's Viability	Evolution of Illness/ Standardization/Lack of experience
L'anticipation est à différencier de la maîtrise, l'anticipation donne l'illusion d'une maîtrise	Leading to a change in behavior/Altered confidence/AD's Viability	Evolution of Illness/ Revocability/Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
Dangers de l'acharnement herméneutique(se fier coute que coute aux DA sans prendre en compte l'evolution du psychique)	/AD's Viability/	Concept of Death/Evolution of Illness/Revocability/ Responsibility/Social acceptability
Danger de la derive institutionnelle des DA	Leading to a change in behavior/	Standardization/ Responsibility
Caracteres contraignants des DA au travers es incitations répétées	Leading to a change in behavior/AD's Viability/	Social acceptability/Concept of Death/Responsibility
Caractère contraignant et déviance vers l'obligation à leur réalisation	Leading to a change in behavior/	Social acceptability/ Standardization/ Revocability/Responsibility
Injonction à l'autonomie	/AD's Viability	Standardization/Evolution of Illness/Social acceptability
Les exceptions au respect des DA complexifient la prise de decision médicale	Altered confidence/AD's Viability	Lack of experience/ Experience/Standardization/ Revocability
Difficultés de projection en fin de vie	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Difficultés de collaboration entre différents acteurs du soin	Leading to a change in behavior/AD's Viability/	Non consensual Making of/ Lack of experience
Le type de pathologie influences propositions de soins palliatifs	AD's Viability/	Evolution of Illness
Accessibilité des DA difficile	AD's Viability/Altered confidence	Access to AD
DA sont souvent médicalement inappropriées	Altered confidence/AD's Viability	Experience/access to AD
Crainte d'une perte de chance en faisant ses DA	Altered confidence/AD's Viability	Social acceptability/Concept of Death/Negative Thinking
Il est impossible d'élaborer un projet de vie rationnel et détaillé sur le long terme	AD's Viability	Standardization/Social acceptability/Concept of Death
Il peut exister un décalage veritable entre un désir sincere à un moment donné et l'intérêt veritable	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Probleme de la temporalité des DA, de l'evolution dans le temps des désirs concernant sa fin de vie	AD's Viability	Evolution of Illness/ Revocability/Concept of Death
Danger de l'ambivalence du patient vulnérable qui exprime ses DA ne traduisant pas son intérêt profond (ex: patient suicidaire)	AD's Viability	Social acceptability/Concept of Death/Evolution of Illness/Negative Thinking/ Responsibility
Dangers des DA trop précises: risque d'impertinence	/AD's Viability	Access to AD/ Standardization

RAW DATAS	SUB THEME	OPEN CODES
L'application des DA risque d'être herméneutique	Leading to a change in behavior/	Standardization/Lack of experience/Experience
L'interpretation du médecin peut differer de celle du sens voulu par le patient	/AD's Viability/	Access to AD/Concept of Death
Difficulté de projection en état de dépendance mais finalement les patients peuvent s'y adapter	AD's Viability	Evolution of Illness/Lack of experience/Concept of Death
Le patient peut avoir des difficultés de projection en état de perte d'autonomie	AD's Viability	Evolution of Illness/Negative Thinking
Dérive de l'autonomie des DA, conçue comme une satisfaction de tous les besoins	Altered confidence/AD's Viability/	Social acceptability/Concept of Death/Revocability
Les DA d'un refus peuvent traduite une depression qui est à dépister	AD's Viability	Evolution of Illness/Negative Thinking/Revocability
Valeur relative du testament de vie: volontés changeantes du patient en fonction de l'évolution de la pathologie	AD's Viability	Evolution of Illness
Ambivalence du patient, dont les demandes peuvent être contradictoires	Altered confidence/AD's Viability	Concept of Death/Negative Thinking
Le patient selon le temps qui le separe de la mort n'aura pas la meme identité sur le plan philosophique	AD's Viability	Evolution of Illness/ Revocability/Concept of Death
Les DA se limitent en l'etat de droit au refus de soins déraisonnables	AD's Viability/Altered confidence	Standardization/access to AD
Risque de culpabilisation de l'entourage dans le respect inconditionnel des DA	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
Difficulté de se confronter à la notion de souffrance selon différentes voies (psychiques, religieuses, somatiques existentielle)	Leading to a change in behavior	Social acceptability/Concept of Death/Lack of experience
Tabous de la mort	Leading to a change in behavior	Concept of Death/Social acceptability
On demande aux individus de décider pour eux meme dans un champ de competence dont ils sont ignorants	Altered confidence/	Lack of experience/access to AD
Les recommendations cliniques (formation) ne considèrent pas l'abstention thérapeutique mais sont seulement « dans l'action »	Leading to a change in behavior/	Experience
Les patients ont une méconnaissance des soins palliatifs qu'ils assimilent au fait de « baisser les bras » de la part des médecins	Altered confidence/	Social acceptability/ Responsibility
La dépersonnalisation liée à la spécialisation de la médecine est un frein à l'éthique médicale	Leading to a change in behavior/	Experience/Social acceptability/Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
Inconvénients des droits renforcés du patient: exigence irréaliste du patient, investigations déraisonnables	Altered confidence/Leading to a change in behavior/	Social acceptability/ Revocability/Responsibility/ Experience
Manque d'interet des DA: trop tot	Altered confidence/	Evolution of Illness/ Revocability
Manque d'interet des DA: deja confiés aux proches	Altered confidence/	Social acceptability/Concept of Death
Les DA sont considéres comme inutile ou dangereuse	Altered confidence	Negative Thinking/ Revocability
Approche negative dans la démarche d'indiquer les situations dans lesquelles le patient ne veut pas se retrouver	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking
Peur de perdre sa capacité de décision	Leading to a change in behavior	Negative Thinking/ Revocability/Responsibility
Necessite le courage de s'ouvrir aux questions du sens de la vie	Leading to a change in behavior	Negative Thinking
Caractère opposable des DA est discutable	Altered confidence/Leading to a change in behavior/	Revocability/Responsibility
Caractère indispensable des DA est discutable	AD's Viability	Social acceptability
Crainte de faire violence aux patients	Altered confidence/Leading to a change in behavior	Negative Thinking/Lack of experience
passivité du patient dans les échanges avec le médecin	Altered confidence/Leading to a change in behavior/	Social acceptability/Negative Thinking
Danger d'instrumentalisation des DA	/Leading to a change in behavior	Social acceptability/ Revocability/Responsibility
Danger de la judiciarisation commedéresponsabilisation des soignants	/Leading to a change in behavior	Social acceptability/Negative Thinking/Revocability/ Responsibility
Individus ne souhaitent pas forcement se positionner sur ces questions	Altered confidence	Concept of Death/Negative Thinking/Lack of experience
Faible recours aux DA: réticences « naturelles » à rédiger de telles DA	Leading to a change in behavior/Altered confidence	Social acceptability/Negative Thinking
Déresponsabilisation du médecin	Leading to a change in behavior	Standardization/ Revocability/Responsibility
Tabou de la mort	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking
Traiter sans guérir est considéré comme un échec par les médecins	/Leading to a change in behavior/	Experience
Réticences des proches à évoquer la fin de vie	Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death/Negative Thinking

RAW DATAS	SUB THEME	OPEN CODES
Réticences du patient à évoquer la fin de vie	Leading to a change in behavior/Altered confidence/AD's Viability	Social acceptability/Concept of Death/Negative Thinking
La mort et son approche renvoie à une problématique de confiance à l'autre, en l'avenir, et de confiance en soi	Altered confidence	Social acceptability/Concept of Death/Negative Thinking
La volonté illusoire de contrôler sa fin de vie traduit une perte de confiance entre les hommes	Altered confidence	Social acceptability/Negative Thinking
Plutôt que de chercher à anticiper la mort, nous devrions retrouver l'humilité d'accepter l'incertitude et notre finitude	Altered confidence/	Social acceptability/Concept of Death/Experience
Le respect de la volonté du patient entre en contradiction avec le respect de la vie du point de vue du médecin	/Leading to a change in behavior/	Negative Thinking/ Experience
Dilemme éthique à respecter un refus de soin que le patient pense être bénéfique	/Leading to a change in behavior/Altered confidence	Negative Thinking/ Experience
Le respect du refus de soin peut procurer un sentiment de culpabilité au médecin	AD's Viability/Altered confidence	Negative Thinking
La projection dans une situation médicale future est souvent ressentie comme une violence psychique	Altered confidence	Negative Thinking/Lack of experience
Les DA entrent en contradiction avec une philosophie de vie de l'instant présent chez les personnes âgées	Leading to a change in behavior/AD's Viability	Social acceptability/Negative Thinking
Crainte d'une deresponsabilisation des médecins	Leading to a change in behavior	Standardization/ Revocability/Responsibility
La judiciarisation de la relation soignant soigné est un frein à l'ethique médicale	AD's Viability/Leading to a change in behavior	Responsibility/Negative Thinking
Danger du choix « souverain »du patient qui s'opposerait à la bienfaisance du médecin et au souci du malade	Leading to a change in behavior/	Social acceptability/ Experience/Negative Thinking
Les DA peuvent être biaisés par la vision utilitariste de la société, le patient se voyant comme une charge pour l'entourage	Altered confidence	Social acceptability/Negative Thinking/Concept of Death
Danger de la déresponsabilisation médicale devant une Leading to a change in behaviorhypertrophie de l'autonomie »	Leading to a change in behavior/	Social acceptability/Concept of Death/Experience
Selon Axel Kahn, la tendance est au respect aveugle de l'autonomie, ce qui induit une déresponsabilisation de l'acte médical	Leading to a change in behavior	Social acceptability/Concept of Death/Responsibility
Reconnaitre la liberté du patient, c'est reconnaître la liberté d'éviter toute contrainte, comme celle de faire des choix anticipées	Altered confidence/	Social acceptability/Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
Inconvénients des droits renforcés du patient: risque de nomadisme médical	Leading to a change in behavior/Altered confidence	Revocability/Responsibility/ Social acceptability
Inconvénients des droits renforcés du patient: risque de judiciarisation croissante	AD's Viability	Social acceptability/Concept of Death/Responsibility
Danger du déséquilibre responsabilité entre le médecin et le patient	Leading to a change in behavior/	Responsibility/Experience
Refoulement de la mort dans la société	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
Il n'est pas normal pour la société d'accepter la maladie et la fin	AD's Viability	Social acceptability/Concept of Death
Les differences culturelles complexifient les rapports à la mort	Leading to a change in behavior/Altered confidence	Social acceptability
Les differences religieuses complexifient les rapports à la mort	Leading to a change in behavior/AD's Viability	Social acceptability
La mort est un tabou social	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
	AD's Viability/Leading to a	

# <u>11) LEBRUN A. What factors limiting advance directives writing highlighted in patients? A systematic literature review Th. : Méd. : Brest 2020</u>

Young age is a brake on writing	AD's Viability/Altered confidence	Social acceptability/Concept of Death/Lack of experience
Being young is a barrier to writing	AD's Viability/Altered confidence	Social acceptability/Concept of Death/Lack of experience
Age factor influencing writing of ADs	AD's Viability/Altered confidence	Social acceptability/Concept of Death/Lack of experience
Young people don't think about AD because death is too far away	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Deathc/Lack of experience
Afro Americans are less comfortable discussing death	Altered confidence	Social acceptability/Concept of Death
Superstition in Chinese culture, talking about death could lead to a curse	AD's Viability/Altered confidence	Social acceptability/Concept of Death
Superstitions around death (asian culture)	AD's Viability/Altered confidence	Social acceptability/Concept of Death
Mexicans in America think it may be harmful for the patient to discuss death and die	AD's Viability/Altered confidence	Social acceptability/Concept of Death
Cultural superstitions around the onset of illness and death if the topic is brought up	AD's Viability/Altered confidence	Social acceptability/Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
For Afro-Americans AD is considered as a death sentence and not as a freedom of choice	Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
The family makes choices regarding the end of a patient's life is not an option, the weight of their choices being stronger than that of the caregiver	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Concept of Death
End-of-life decisions fall under a family centered model	Leading to a change in behavior	Social acceptability/Concept of Death
The family has a major influence on end of life decisions	Leading to a change in behavior	Social acceptability/Concept of Death
Traditional cultural values, such as family obligation can influence decisions about a patient's end of life care	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
End-of-life decisions fall under a family centered model	Leading to a change in behavior/AD's Viability	Social acceptability/Concept of Death
In Asian Culture, family functioning influences the writing of AD	AD's Viability/Leading to a change in behavior	Social acceptability/Concept of Death
Afro Americans prefer invasive treatments so they don't write ADs	Leading to a change in behavior	Social acceptability
A beautiful death as define in literature is not the same for African Americans point of view	Altered confidence/	Social acceptability/Concept of Death/Experience
End-of-life decisions fall under a family centered model	Altered confidence/	Social acceptability/Concept of Death
Do not plan the unknown, cultural value of Afro Americans	AD's Viability/Leading to a change in behavior/Altered confidence	Social acceptability/Concept of Death
Afro Americans are less comfortable discussing death	Altered confidence	Concept of Death/Negative Thinking
Discriminations facts within the health system make afro Americans suspicious	Altered confidence	Social acceptability/ Experience
Feeling of being treated differently because being black	/Altered confidence/	Social acceptability/ Experience/Negative Thinking
Altered confidence in the medical profession due to the cultural history of Afro Americans	Altered confidence/	Social acceptability/Negative Thinking/Experience
Experiences of racism and discrimination influences Afro Americans decision making on end of life care	Altered confidence	Negative Thinking/Social acceptability
Fear of dying prematurely from negligence in AD	/Altered confidence/	Social acceptability/Negative Thinking/Responsibility

RAW DATAS	SUB THEME	OPEN CODES
Reluctance to write ADs for Altered confidence/historical facts of racism and deep seated discrimination	Altered confidence/	Social acceptability/Negative Thinking/Experience
Racial differences in writing ADcan be explained by mistrust following discriminatory experiences	Altered confidence	Social acceptability/Negative Thinking
Historical trauma such as segregation remains anchored	Altered confidence	Social acceptability/Negative Thinking
Lack of trust in caregivers due to a history of discrimination against Afro Americans	Altered confidence/	Social acceptability/Negative Thinking
Past medical mistreatment of black men has led to mistrust of health professionals	Altered confidence//	Social acceptability/Negative Thinking
The sometimes tragic history of its people in terms of health can lea to fears/false beliefs	Altered confidence	Social acceptability/Negative Thinking
Distrust of the medical profession following historical facts of racism (afroamericans)	Altered confidence/	Social acceptability/Negative Thinking
Afro-Americans' mistrust of the system can keep them away from AD's	Altered confidence/	Social acceptability/Negative Thinking/Experience
Low literacy is a barrier to writing ADs	AD's Viability	Access to AD
There is a link between low educational attainment and low AD completion rate	AD's Viability	Access to AD
Completion of ADs associated with level of education	AD's Viability	Access to AD
The language barrier is a major obstacle to writing ADs	/AD's Viability/	Access to AD
Patient's origin is important (race/cultural values)	AD's Viability	Social acceptability
Afro Americans are less supportive of AD and palliative care	AD's Viability/Altered confidence	Social acceptability
Culture helps explain differences in attitude, writing and completion of AD, which vary according to ethnic origin	AD's Viability	Social acceptability
Living in isolation limits exchange around AD	AD's Viability/Altered confidence	Social acceptability/access to AD
Married people do not write their AD because they can rely on their husbands/ wives	Altered confidence/	Social acceptability/Concept of Death/Responsibility
Death is the fate of God	AD's Viability/Leading to a change in behavior	Concept of Death

RAW DATAS	SUB THEME	OPEN CODES
Superstitions around death (talking about it would precipitate its arrival)	AD's Viability/Altered confidence/Leading to a change in behavior	Concept of Death
Believers don't need to plan their end of life	Altered confidence/	Social acceptability/Concept of Death
Do not feel concerned about the subject, don't want to deal with it	Altered confidence/	Social acceptability/Negative Thinking/Lack of experience
Postpone	Altered confidence//AD's Viability	Negative Thinking/Lack of experience
Unpleasant subject	Altered confidence/Leading to a change in behavior	Negative Thinking
Fear of the end-of-life	Altered confidence/Leading to a change in behavior	Concept of Death/Negative Thinking
Fear of under treatment	/Leading to a change in behavior/Altered confidence	Negative Thinking/ Revocability/Responsibility
Hypothetical development and complexity of an intensive care situation for a non medically trained person	/AD's Viability	Access to AD/Lack of experience
Patients who consider themselves to be in a good health do not feel the need to discuss AD	Altered confidence	Evolution of Illness/ Revocability
To protect loved ones from difficult subjects	Leading to a change in behavior	Social acceptability/Negative Thinking
Denial of terminal illness	Altered confidence/	Evolution of Illness/Negative Thinking
Fear of losing luck	/Altered confidence/	Negative Thinking/ Revocability/Responsibility
Fear of Losing luck	/Altered confidence/	Negative Thinking/ Revocability/Responsibility
Doubts about the efficiency of ADs	Altered confidence	Access to AD/Revocability/ Responsibility
Lack of time	Altered confidence/AD's Viability	access to AD
Lack of knowledge (not aware of), negative perception of AD	AD's Viability/Altered confidence	Lack of experience/Negative Thinking
Anxiety about facing one's own death	Altered confidence/Leading to a change in behavior	Negative Thinking
Denial of old age, refusal of death	Altered confidence/	Concept of Death/Negative Thinking
Lack of physicians communication (due to lack of knowledge/investment of doctors)	Altered confidence//	Lack of experience

RAW DATAS	SUB THEME	OPEN CODES
Difficulty in talking about death, taboo subject	AD's Viability/Altered confidence/Leading to a change in behavior	Concept of Death/Negative Thinking
Some elderly people, fearful of death, are not aware of these documents and remain passive	Leading to a change in behavior/AD's Viability	Concept of Death/Negative Thinking/access to AD
Intensive care hospitalization experiences increase awareness of AD compared to those who have never experience it	Altered confidence	Lack of experience
Anxiety/discomfort around death and discussion about death	AD's Viability/Altered confidence/Leading to a change in behavior	Negative Thinking
Fear of a poorer quality of care if no insurance (USA)	Altered confidence/	Social acceptability
Fear of loss of luck and acute care if AD	/Altered confidence	Social acceptability/ Revocability
AD considered to be useless or even harmful	Altered confidence	Social acceptability
Doctor anxiety negatively felt by the patient	Leading to a change in behavior/Altered confidence	Negative Thinking
Not wanting to think about negative things such as the end of life	Altered confidence/Leading to a change in behavior	Negative Thinking/Concept of Death
Refusal to anticipate what may happen in the future	Altered confidence/	Concept of Death/Negative Thinking/Lack of experience
Patients don't want to be more involved in medical decisions	Altered confidence/	Social acceptability
Very few have discussed AD with their doctor	AD's Viability	Access to AD/Lack of experience
The doctor will only follow his wishes without taking into account the patient's ones	Altered confidence/Leading to a change in behavior	Social acceptability/ Experience
Health status influences ADs writing	Altered confidence/AD's Viability	Evolution of Illness
Lack of <b>staff</b> = less time with the patient= less communication around ADs	Altered confidence//AD's Viability	Non consensual Making of
Experiences in contact with relatives at the end of their life sometimes perceived negatively	Altered confidence/Leading to a change in behavior	Negative Thinking/ Experience
Not believing the doctor will follow the written AD	Altered confidence	Revocability/Responsibility
Doubts that their Ads are being followed	Altered confidence	Revocability/Responsibility

RAW DATAS	SUB THEME	OPEN CODES
As long as I am able I want to stay independent as late as possible	Altered confidence/Leading to a change in behavior	Evolution of Illness/Concept of Death/Negative Thinking
Being uncomfortable with discussions about end of life care	AD's Viability/Altered confidence/Leading to a change in behavior	Social acceptability/Negative Thinking/Concept of Death
Preoccuation about medical heroism, the doctor playing gods	Leading to a change in behavior/Altered confidence	Social acceptability/ Revocability/Responsibility
Fear that AD will be interpreted as euthanasia	Altered confidence/AD's Viability	Social acceptability/Concept of Death/Revocability/ Responsibility
Difficulting making choices and projecting oneself into a situation that has not taken place yet	Altered confidence/AD's Viability	Evolution of Illness/Lack of experience
Difficulty bringing up the subject with loved ones and worrying about raising it	AD's Viability/Leading to a change in behavior	Negative Thinking/Non consensual Making of
Concern about emotional distress around the end of life discussion	Altered confidence/Leading to a change in behavior	Evolution of Illness/Negative Thinking/Concept of Death
Forced to stop talking about it because embarrassing the other	Altered confidence/Leading to a change in behavior	Concept of Death/Negative Thinking/Social acceptability
Not want to talk about it	Altered confidence	Negative Thinking/Concept of Death
Lack of respect from health professional	Altered confidence	Social acceptability
Doubt that AD will not be applied despite the legal appearance of the document	Altered confidence	Revocability/Responsibility/ Standardization
Medical heroism	Altered confidence	Responsibility/Social acceptability
Fear that ADs could harm	AD's Viability	Social acceptability/Concept of Death/Lack of experience
The health system control treatments, unnecessary AD	Altered confidence	Negative Thinking/ Experience
Discomfort discussing end of life care	AD's Viability/Altered confidence	Concept of Death/Negative Thinking
Negative experiences of perceveided racism in healthcare leading to mistrust the healthcare system	Altered confidence	Experience/Social acceptability
Not wanting to talk about anything that could be related to death	Altered confidence/Leading to a change in behavior	Concept of Death/Negative Thinking
Mistrust and negative experiences with health care lead to prefer agressive care than ADs	Altered confidence	Experience
Fear of limiting care and loss of chance in active care if ADs written	Altered confidence/	Social acceptability/ Experience/Standardization

RAW DATAS	SUB THEME	OPEN CODES
Fear of being treated differently if Writing ADs (Afro Americans population study)	Altered confidence/	Social acceptability/ Experience
Not wanting to disturb loved ones	Altered confidence/Leading to a change in behavior	Negative Thinking/Social acceptability
Patients with less severe illnesses still think they can be cured	AD's Viability	Evolution of Illness/Lack of experience
Patients with terminal illnesses still think they can be cured	/AD's Viability	Concept of Death/Evolution of Illness
Be comfortable discussing AD	Altered confidence/Leading to a change in behavior	Negative Thinking/Lack of experience
Patient does not want to be the one raising the issue	Leading to a change in behavior/	Access to AD/Negative Thinking
Not being sure of your preferences in terms of care	AD's Viability	Access to AD/Lack of experience
Did not want to place the burden of the decision on a specific person	AD's Viability/Altered confidence	Social acceptability/Negative Thinking/Concept of Death
Difficulty in choosing a single person to trust more than another	Altered confidence	Non consensual Making of/ Negative Thinking/Social acceptability
False beliefs about writing formality (where to obtain?)	AD's Viability	access to AD
Lack of knowledge regarding the details of the document completion process	AD's Viability	Standardization/access to AD
How to formulate directives and to whom to write them remains unclear	AD's Viability	access to AD
Confusion around the legality of ADs	AD's Viability/Altered confidence	Revocability/Responsibility
Confusion around the contents and purpose of ADs	AD's Viability	Access to AD/Revocability/ Responsibility
Lack of knowledge around the legal frameworks of ADs (ethical/legal/ treatment decision making)	AD's Viability/Altered confidence	Revocability/Responsibility/ access to AD

#### 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

#### LE GUEN Victor – DOES ANY TRANSVERSE AND INVARIABLE BARRIER FOR WRITING AND CARRYING OUT AN ADVANCE DIRECTIVE EXIST ? Th. : Méd. : Brest 2021

**<u>RESUME</u>** : Les directives anticipées sont un sujet de débat sociétal prégnant, et améliorer son taux de complétion un sujet d'intérêt. Suite à l'identification de freins spécifiques à certaines populations réalisée par le groupe d'études EA 7479 SPURBO, une question s'imposait: existe t'il des freins invariants et transversaux à l'écriture et l'application de directives anticipées?

Afin de résoudre la question, une approche pragmatique inspirée de la théorie ancrée a été choisie. Elle s'appuyait sur les revues de littératures systématiques et études qualitatives précédemment réalisées par l'EA-7479-SPURBO comme source de données. Apres synthèse de ces travaux, un modèle conceptuel a été proposé afin de répondre à la question de recherche.

Onze codes ouverts, trois sous thèmes ont été relevés, s'agglomérant autour d'un theme invariant et transversal: l'anxiété conflictuelle, qui représentait le frein transversal recherché. Afin de comprendre les mécanismes de ce frein, un modèle conceptuel a été établi. Onze notions accessibles et empiriques agissaient en synergie pour irriguer trois concepts théoriques (confiance altérée, Viabilité des directives anticipées; Impliquant un changement de comportement), augmentant l'incertitude. Se faisant, ces trois concepts donnaient accès au coeur du modèle, l'anxiété conflictuelle.

En proposant cela, le modele permet une vision élargie du concept de directives anticipées et pourrait participer à une meilleure comprehension de ce frein s'opposant à l'application des directives anticipées, et ce pour toute personne impliquée.

MOTS CLES : Directives anticipées, incertitude, anxiété conflictuelle

#### <u>JURY</u>

Mr le Professeur Bernard LE FLOC'H <u>Mr le Docteur Patrice NABBE</u> Mme le Docteur Morgane GUILLOU Mr le Docteur Cyril HAZIF THOMAS

#### DATE DE SOUTENANCE :

06 Mai 2021