End-of-life patients' rights and general practice: advance directives, healthcare proxy, continuous and deep sedation until death

Clément Guineberteau[1,2,3], Marie-Pierre Ombredane[2,3,4,5], Marc Noujaïm[1,2], Véronique Rachet-Darfeuille[6,7], Marie Petit[8], Edmond Desmoulins[1], Aude Pignon[2,8]

1.Département de médecine générale, Faculté de Santé d'Angers, rue Haute de Reculée, 49045 Angers, France.
2.Coordination de l'accompagnement en soins palliatifs du Maine-et-Loire (CASSPA 49), Angers, France.
3.Comité d'éthique et consultation d'éthique clinique du CHU d'Angers, Angers, France.
4.Département de soins longue durée-gérontologie au centre des Capucins, Angers, France.
5.Équipe mobile de soins palliatifs du CHU d'Angers, Angers, France.
6.Consultation d'éthique clinique du CHU de Nantes, Nantes, France.
7.Docteur en droit, avocat au barreau de Nantes, Cabinet Orior, Nantes, France.
8.Unité de soins palliatifs « Laroque » et Fédération de soins de support et palliatifs du CHU d'Angers, Angers, France.

Clement.guineberteau@gmail.com
exercer 2019;158:464-70.

INTRODUCTION

When the rights of end-of-life patients are mentioned, it is mainly with regard to application of the 2005 Leonetti law and the 2016 Claeys-Leonetti law, both of which stem from a dynamic propelled by the 4 March 2002 law. Two major principles are promulgated in these texts: combating unreasonable obstinacy (article L.1110-5-1 of the French public health code [CSP]) and favoring self-determination (article L.1111-4 of the CSP). Given that the legal framework is specific to the French context, in this article the rights of end-of-life patients will be examined from a French perspective.

Given their position as first-line interface between the general population and the health care system, general practitioners (GPs) are often considered by the health authorities as care pathway "pivots". This is definitely the case as concerns the support they provide for end-of-life patients. Moreover, the 2016 law reinforces the role of GPs by creating a "duty to inform" on the rights of end-of-life patients. Health professionals (including GPs) are often unfamiliar with the relevant provisions, and their lack of knowledge constitutes an obstacle to their role as information transmitters.

The objective of this article was to provide GPs with food for thought on how to optimally support patients wishing to exercise their newly acquired rights.

Knowing the provisions in view of informing

Prior to becoming a political choice, the 26 August 1986 "Laroque circular" (DGS/275/3D) highlighted social interest in support for terminally ill patients; its objectives were close to those of associations and health professionals. The Senate report n° 207 1998-1999 led to enactment of the first French law guaranteeing the right to access to palliative care (law n°99-477 of 9 June 1999). This law established rights not only for the patient ("to receive palliative care at home or in institution, to refuse any investigation or treatment"), but also for kith and kin : the right for any employee to "benefit from end-of-life support leave" (ascendant, descendant or person sharing his/her home). A 2002 nationwide situational analysis showed that the palliative approach was not sufficiently developed; that access to palliative care was unequal, varying according to region; and that patients' choices concerning the conditions and site of their final days were not taken into adequate consideration[1]. One aim of the laws enacted subsequent to this analysis was to reinforce patient self-determination.

The 4 mars 2002 law n° 2002-303, (the "Kouchner law") on patients' rights and the quality of the French health care system recalled the fundamental rights to health protection, to respect for dignity, privacy and the confidentiality of patient information. The law established a new framework, built around the "support person" (personne de confiance, in French), which was reinforced by the 2 February 2016 law rendering mandatory the co-signature of the designation document (health care proxy: HCP) by the patient and the support person. The support person is apprised of the patient's wishes, which he is statutorily compelled to respect and transmit. Sidebar 1 details the current framework, particularly as regards the role, responsibilities and designation of the support person.

Enacted on 22 April 2005, law n° 2005-370 (the Leonetti law) established new rights for the patient: he/she can refuse unreasonable obstinacy and call upon a doctor to ensure symptom management at

the risk of shortening his/her life. This is commonly known as the "dual effect theory"; while relief from suffering is provided, it entails the risk of shortening a patient's life. The 2005 law reinforced the rights of patients no longer in a position to declare their will by establishing a framework built around advance directives (AD). As for the 2 February 2016 law (Claeys -Leonetti law), it reinforced the previous measures by rendering them binding and having them harmonized with existing European legislation. The wishes expressed by the patient in his/her AD are henceforth imposed on physicians, except in two specific situations. Sidebar 2 details present-day AD functioning.

Legislative modifications pertaining to end-of-life situations have enabled advances by developing palliative care and by affirming the decision-making role of the patient as regards his/her treatment modalities. Application of these rights is part and parcel of shared physician -patient approach in which listening and dialogue are essential. Their exchanges facilitate identification of patients' diversified expectations and compel the doctor to follow a necessarily peculiar pathway, taking into full account the circumstances in which the end-of-life question is evoked.

What do the patients think?

From the patients' standpoint, several years after publication of the applicable law, the articles regularly confirms how little they still know about their rights, even though some progress has been noted in the most recent studies[2]. When questioned on the measures adopted, particularly AD, patients are apparently of two minds. While they find AD interesting in principle, they have doubts about its efficiency, fearing that their instructions will not be respected[3]. With that in mind, the strengthening of AD by the Claeys-Leonetti law (the directives are now binding) seems to favor intentions to put them in writing[2]. Broadly speaking, patients state that they have been requesting information and assistance in drawing up their directives[4]. That much said, they seldom explicitly ask to avail themselves of these rights[5]. More often, they initially show interest in a listening ear, and express a wish for relief from their suffering and the right to decide for themselves, particularly the right to refuse treatment[6].

In general medicine: highly diversified situations

GPs receive patients in highly variable contexts. Several types of situations may appear: patients suffering from a chronic pathology, young patients in good health without a chronic pathology, very elderly patients with cognitive disorders, patients who return following an acute event during which a limitation of life-sustaining care was decided upon in an emergency or a medical reanimation unit, very elderly patients without cognitive disorder who "have had it" and are requesting an end to their travails.

According to the situation, introduction of reflection on patients' end-of-life rights - and the contents of discussion - can markedly differ from one another. Quite often, the initiative of the discussion is correspondingly modified. When confronted with illness, the doctor frequently broaches the subject with a pragmatic objective in mind; he needs to obtain details enabling him to make decisions in accordance with the patient's wishes. If, on the other hand, the patient is not ill, taking the initiative can be difficult, insofar as the doctor may be reluctant to offend or otherwise cause harm to the patient[7].

In other, far less frequent cases, patients explicitly initiate discussion. These situations are likely to raise questions in doctors' minds about the motivations for evocation of their rights. They often occur following a brutal confrontation with death, either directly or by proxy (traumatic experience of the death of a close friend or relative)[7].

A predicament specific to general medicine: How to render accessible the informal data gathered during consultation

GPs regularly collect relevant information from patients as regards their end-of-life wishes. That said, in a non-negligible proportion of cases, gathering of this information does not result in the writing of AD. The reasons for inaction are

What is the role of the support person (SP)?

The SP is consulted if the patient cannot express his willingness and/or in the absence of advance directives (AD): His role is to function as a point of reference for the medical team, to receive information on the treatment strategy, to vouch for the patient's will and to maintain a connection with his/her kith and kin. The doctor has the right to consult the SP, even after the ADs have been written. While the ADs take precedence over the testimony of the SP, to the extent that these instructions are unclear, which is often the case, interpretation of a patient's willingness can be deepened through discussions with the designated SP.

If the patient is capable of expressing him/herself, the SP can provide accompaniment and support in that person's actions.

Who can designate the support person?

Any adult person.

For persons under guardianship : Designation (or confirmation of designation; if the SP was designated previous to the guardianship measure) necessitates the authorization of a judge or a family council.

Who can be a support person?

Any adult person (family, friends, attending physician).

When is he/she to be designated?

At any moment, whether it not the patient be ill. Designation is revocable.

In cases of hospitalization, the proposal must be made by the caregivers on the patient's admission. Designation remains valid from admission through discharge from the hospital, and may be prolonged by the patient. The "support person" must not be conflated with the "person to notify"; while the SP can receive the same information as the patient on the health of the latter, the person to notify does not receive information covered by medical and professional confidentiality.

How is he/she to be designated?

By writing on a separate sheet of paper or form (HAS), mentioning the date, last name, first name, the SP's contact information and the two signatures (patient and SP).

In the event of difficulties in writing, two deponents will testify in writing that the designated SP indeed represents the free and informed expression of the patient (HAS form).

How can the document be made known and conserved?

By conserving the document in the patient's medical files (attending physician, hospital, site of accommodations).

By asking the patient to inform his/her kith and kin about the designated SP and the place where the document will be conserved.
By asking the patient to conserve a copy and keep it in his/her possession

Sidebar 1 - The support person

What is the role of advance directives (AD)?

Make known one's wishes as to how to be treated, and the conditions for limitation, cessation or pursuit of end-of-life treatment. Once the patient is no longer able to express him/herself, they prevail over all other depositions: the support person's (SP), friends' or close relatives'.

Who can write them?

Any adult person.

For persons under guardianship: prior authorization of a judge or family council.

When can they be written?

At any time, whether or not the patient be ill.

While remaining valid without any time limit, they are revisable and revocable at any moment and by any available means.

How?

By writing on a separate sheet of paper or form (HAS), dated and signed.

In the event of difficulties in writing, the document is written by two deponents, one of whom is the SP.

What information should be included?

All elements that the patient deems necessary in view of enabling the doctor to make decisions in the closest possible agreement with his wishes.

The elements can be not only wishes relative to treatment, care and support, but also attestations to the patient's values or convictions.

How can the document be made known and conserved?

By conserving the document in the patient's medical files (attending physician, hospital, site of accommodations).

By asking the patient to associate the designation of an SP depositary of the AD.

By asking the patient to inform his/her kith and kin about the existence of the AD and the place where the document will be conserved.

By asking the patient to conserve a copy and keep it in his/her possession.

How can advance directives be used?

They are sought out prior to any operation, treatment or investigation in the event that the patient is unable to express him/herself.

They impose an obligation to the doctor, except in two situations:

- in cases of life-threatening emergency, for as long as to takes to provide a comprehensive assessment of the situation;
- if, following a collegial procedure, they are deemed inappropriate or incompatible with the medical situation.

Sidebar 2 - Advance directives

multiple and complex: reluctance to discuss, difficulty of setting things in writing or uneasiness over the idea of ossifying a thought that might eventually cause prejudice. Transcription of the information in the patient's medical file is far from systematic and can raise questions, especially in an epoch where general medicine is evolving toward group practice, frequently on a part-time basis[8].

That much said, several ways of maintaining patients' rights to self-determination remain open:

- indicating to the patient that relevant informal information is being collected: "I sense something important in the elements you are giving me today";
- obtaining his/her agreement to render the information traceable in the person's medical file, while specifying in which contexts it could eventually be used: "I believe it important that I include these elements in your records, so that in my absence, a colleague of mine could have them transmitted";
- proposing assistance in the writing of advance directives, if the patient so wishes, in view of "reinforcing" the weight of the relevant information;
- thinking in terms of regular reassessment of the patient's wishes;
- getting to better know one another, given that active involvement constitutes a choice of practice.

Advance directives and support person, two indissociable elements: pretexts for anticipated discussion and openness to dialogue

The experience of palliative care professionals has shown that often, a discussion on illness, risks incurred and the way they are and apprehended by the patient leads to discussion about death and may eventually allow a medical team to propose AD and/or designation of an SP. Even though this situation can occur in general medicine, more often than not the dynamic works the other way around. More precisely, introduction of reflection on the rights of end-of-life patients is what leads to talk about death, a subject with regard to which, each party is prone to wait for the other party to take the initiative[9].

In this respect, the recent creation of a GP "duty" to inform is ambiguous. Several works have shown that doctors have difficulty informing patients who are not ill and do not spontaneously request information. As a result, existing practices are highly variable. Should patients be directly informed or indirectly addressed by means of posters or flyers installed in waiting rooms, as is proposed in a nationwide information campaign? Should patients be informed systematically or on certain "occasions" conducive to projection toward illness and possible death, for example following hospitalization after an acute event, or at the age of 50 parallel to the transmission of information on organized cancer screening?

Secondarily, there is the question of the minimum content relevant to the patient. Other ongoing studies attempt to address these questions.

In any case, experience has shown that patients can find these questions problematic, to say the least, and that they can be reassured when they are informed that ADs and SPs represent "only" a right, and not a duty. It is also important to consider the writing of advance directives not as an issue per se, but rather as a tool, an opportunity for dialogue allowing the patient to move forward and express his wishes as faithfully as possible.

The specific case of institutionalized, very elderly patients

Few residents arrive in dependent care facilities for the elderly (EHPAD) with written ADs and notwithstanding the information they systematically receive on admission in a written document explaining SP and AD functioning, they seldom follow up. Elderly persons nonetheless have something to say when discussion is opened on end-of-life situations. An unpublished internal survey carried out during the 1990s by the geriatrics unit of the Paul-Brousse hospital showed that EHPAD admission was the moment when "dying" was the most pronouncedly dreaded by elderly patients; at that time, "not suffering" and "not being kept artificially alive" were viewed as imperative. Hospitalization at the moment of death was most frequently feared, and having chosen an establishment offering medical services

1. Collegial procedure: Dialogue between the physician in charge, the patient's care team and a 2nd physician outside of the team, who is called on as a consultant: analysis of the request, assessment of the refractory character of the suffering, of the prognosis, of the patient's capacity for judgment in decision-making concerning his care and treatment; if he is no longer able to express his wishes, his AD or what he has said, which is reported by his SP will be taken into account.

2. Decision by the physician in charge, indication in the patient's medical files of the reasons for recourse to or refusal of CDSUD.

3. Decision of the site of CDSUD application according to available resources: home, EHPAD, hospital.

4. Prescription of CDSUD by the physician.

5. Administration by the nurse in the physician's presence: either midazolam titration, or a progressively increased maintenance dose.

6. Surveillance every 15 minutes during the first hour, and then 3 times a day: depth of the sedation (Richmond scale), degree of relief, adverse effects, respiratory rhythm, pulse.

7. CDSUD is associated with analgesia and cessation of treatments not aimed at maintaining the patient's comfort.

8. Pursuit of comfort care and family support.

9. Anticipation of a respite bed in the event of CDSUD complication.

Sidebar 3 - Procedure for establishment of continuous and deep sedation maintained until death (CDSUD in English, SPCMD in French)[14]

was often associated with being eligible for treatment that would avoid end-of-life hospitalization. The words pronounced by residents during visits or, more particularly, during acute health events, are noted and appear in medical files as indications of "caregiving atmosphere", otherwise known as "level of medical intervention (NIM, in French)[10]. NIM is a tool drawn from the guide by the Collège des médecins du Québec on long-term care[11]. Aimed at facilitating communication between patient and physician on health care objectives, it can lead to the writing of advance directives. These indications are dated and serve as guides for on-call doctors in cases demanding emergency decision-making. The existence of these indications in no way precludes listening and dialogue when possible, as is strongly recommended in the article of the "age, rights and freedom commission" published in 2015[12]. This article underlines the importance of reflection and discussion on what is occurring at the moment when a medical emergency occurs.

A person's way of thinking may evolve. For example, a resident suffering from cardiac insufficiency had repeatedly indicated that in the event of aggravation, he did not wish to be hospitalized. During each of two critical episodes, he changed his mind and was hospitalized. During a third episode, on the other hand, he indicated that he would rather stay at the EHPAD, and his wish was respected.

In the event of severe cognitive disorders, dialogue is more difficult to establish, and it becomes that much harder to make appropriate decisions. In this context, the questions of the Sebag-Lanoë grid can constructively contribute to the decision-making process[13]. Consent – and, if possible, agreement – should be sought out. It becomes necessary to strive to decode not only verbal language, but also behavior indicating adherence or, in the contrary, refusal of proposals for care and treatment. More precisely, it becomes necessary to sense refusal of care, even and perhaps especially if it emanates from someone who can no longer construct phrases or sentences, like the man who hid in his closet when ambulance drivers came to pick him up for his dialysis sessions.

While preliminarily formulated wishes such as written ADs represent indications for decision-making, they hardly guarantee the application of what has been decided on. Confrontation with reality may modify one's way of looking at things. Some persons experience their time as dependent institutionalized residents with equanimity, even though they had previously emphasized the extent to which they dreaded falling ill and having to live in an institution. What ADs would they have written if they could have done so – or wished to do so?

How does deep and continuous sedation maintained until death work?

The Claeys-Leonetti law has established a new right for patients suffering from a severe and incurable condition; they may request continuous and deep sedation until death (CDSUD in English, SPCMD in French).

This practice is authorized in three situations:
- when "the vital prognosis is engaged in the short term" and the patient "presents refractory symptoms";
- when "the patient's decision to stop treatment impairs his/her short-term prognosis and is likely to cause unbearable suffering";
- and finally, in the event that a patient is unable to express his/her willingness, "the physician applies CDSUD on cessation of life-maintaining treatment stemming from refusal of unreasonable obstinacy".

A collegial procedure is required by law prior to any implementation of CDSUD. The objective of this interdisciplinary and multiprofessional assessment is to verify that the conditions established by law have been met, namely the refractory character of the patient's suffering and engagement of his/her short-term prognosis due to illness severity or to possible cessation of life-maintaining treatment decided on by the patient[14]. Involvement of teams specialized in palliative care is conducive to the required collegiality in analysis of the request, and also to the support provided for the patient and his/her family through CDSUD implementation. The teams will make sure that organizational exigencies are effectively fulfilled (doctor and nurse contactable 24h/24, family members remaining one after the other on alert) and provide advice for a prescription aimed at maintaining deep sedation over a certain time. When the intention to undergo sedation seems unclear or when opinions among team members diverge, it may be of interest to think things over while consulting the SEDAPALL typology developed by the SFAP. Sidebar 3 details the procedure provided for by law.

In primary care, recourse to

The key messages

- To have clear ideas on the applicable legislation and consequently be able to adequately inform.
- To be able to identify optimal times for providing relevant information.
- To dispose of resource teams suited to exceptional situations.
- To develop a culture of collegiality.
- And, especially, to keep a vigilant eye on how a patient's wishes may evolve.

The toolbox

What are the best supports for productive discussion?

- The French health authority (HAD) guide and models for the writing of advance directives[18]
- The web site of the *Société française d'accompagnement et de soins palliatifs*[19]
- The website of CASSPA 49, particularly its regional guide (now being distributed in other regions)[20]

CDSUD is exceptional, even though relevant French laws recommend home care by calling upon health professionals to inform patients about CDSUD as an option. According to a 2016 study, as of that year 18% of French GPs had organized CDSUD in a home setting[15]. Request from patients seem to have remained rare, and physicians' proposals may be limited by the difficulties seemingly inherent to this type of organization, which may justify the presence of a doctor and/or a nurse several hours a day. In addition, surveillance, management of complications (awakening, agitation, respiratory disorders and family attendance represent a sizable burden and investment that is not always compatible with the practice of general medicine. Given these difficulties, home hospitalization (HAD) seems all but inevitable.

Patients' newly granted right to request CDSUD consequently raises questions specific to the home setting: How can the conditions allowing for collegiality be constructively reconsidered? Are home resources reassuring and comforting for the patient, family and caregivers? How can sufficient value be attached to the caregiver time necessitated for analysis of the patient's request, for listening and discussion, for collegiality, for providing the family with information and, last but not least, for CDSUD surveillance? Is systematic recourse to midazolam and its protocol, which was drawn up for the hospital and has received market authorization (MA) for hospital use (retrocession is allowable in the framework of palliative care) adapted to primary care, do any viable alternatives exist?

Even though their limitations should compel caution in the analysis of results, recently conducted studies in primary care shed some light on existing practices. When carried out in primary care, CDSUD seems to fulfill most of the conditions set forth by law[16,17]. This is in all likelihood explained by the virtually systematic involvement of adequately trained and experienced resource teams. That much said, two "gray areas" remain. The first has to do with definitional vagueness; in these studies, it is often difficult to distinguish CDSUD from other forms of sedation; extrapolation from their results is consequently problematic. The second difficulty resides in the notion of collegiality, of which practitioners may not possess a clear representation. The "collegiality" they describe is often informal and seldom documented in medical files. Its compliance with applicable legislation and relevance for patients remain uncertain.

As a result, it would seem imperative for GPs:

- To detect situations in which this right could be applied, as much at the patient's request as subsequent to care team proposals;
- To identify the legal framework in which this right is applicable;
- To be acquainted with the modalities and resources available for organization
- Given the rarity of application, to possibly deemphasize the technical aspects, knowing that in any event, CDSUD organization imposes collegiality and, quite often, the technical assistance of resource teams with more experience of CDSUD practices than GPs.

Summary

French society, associations, healthcare providers and politicians rally around end-of life patients' rights. Since 1999, many laws arised from the government to promote patient's autonomy. The law of March 4, 2002 created the healthcare proxy status and the 2005 Leonetti's law define advance directives. Both were revised and increased by the Claeys-Leonetti law in 2016. These measures allow patient to express their living wills, especially for future situation where they will not be able to express it themselves. The Claeys-Leonetti law also enables patients to request a deep continuous sedation. Since their enactment, these measures had remained insufficiently known by both patients and healthcare providers. The aim of this expert overview was to provide information for general practitioner (GP) in order to help them to guide their patients staking their claim. The GP is the pivotal point in the healthcare pathway of each patient. He plays an important part in patient support, enhanced by Claeys-Leonetti law proclaiming a "information duty" for the GP. This "information duty" brings many interrogations: inform every patients? Only those who suffer from a disease? On which occasion? What this information must be about? There is no single answer to all these interrogations. Given how varied and singular could be each patient case in primary care, GP must adjust their speech to each patient. Several tools can make these advance discussions easier. The purpose is not the use of the tools but to request progressive living wills.

Keywords: primary health care; advance directives; healthcare proxy; deep sedation.

References

1. Circulaire DHOS/O 2/DGS/SD 5 D n° 2002-98 du 19 février 2002 relative à l'organisation des soins palliatifs et de l'accompagnement, en application de la loi n° 99-477 du 9 juin 1999, visant à garantir le droit à l'accès aux soins palliatifs.

2. Senelle C. Loi Claeys-Leonetti : l'opposabilité des directives anticipées a-t-elle un impact sur l'intention des patients à les rédiger ? Thèse de médecine : Université d'Angers, 2019.

3. Gordiani C. Directives anticipées : vécu et représentations des patients en phase palliative. Thèse de médecine : Université Bretagne Loire, 2016.

4. Valsevia AC, Paternostre B, Crouzet C. Directives anticipées dans la relation médecin-malade : points de vue de patients. Médecine palliative 2018;17:177-85.

5. Fournier V, Berthiau D, Kempf E, d'Haussy J. Quelle utilité des directives anticipées pour les médecins ? Presse Med 2013;42:e159-69.

6. Guineberteau C, Merlet C, Pignon A, Huez J, Angoulvant C. Des patients parlent de la mort : un souvenir ancré dans l'histoire de vie et de soin, un atout pour le médecin généraliste. exercer 2018;140:63-9.

7. Champion P. Recueillir les directives anticipées : expériences de médecins généralistes. Thèse de médecine : Université d'Angers, 2019.

8. Lefebvre M. Contribution des médecins généralistes (MG) dans les décisions de limitation et d'arrêt des thérapeutiques actives (LATA) en réanimation ? Enquête à partir du service de médecine intensive et réanimation du CHU d'Angers. Thèse de médecine : Université d'Angers, 2018.

9. Mondo A. Opinions des médecins généralistes et des patients consultant en médecine générale sur les modalités et les obstacles de la discussion à propos des directives anticipées et de la fin de vie. Thèse de médecine : Université de Versailles- Saint-Quentin-en-Yvelines, 2008.

10. Le Geay F. Les décisions de soins anticipés en EHPAD et en SLD : l'utilisation d'un outil forma-

lisé (le NIM) est-elle possible ? Thèse de médecine : Université d'Angers, 2009.
11. Collège des médecins du Québec. Guide sur la pratique médicale en soins de longue durée. Montréal : CMQ, 2015. Disponible sur : http://www. cmq.org/nouvelle/fr/guide-pratique-medicale-soins-longue-duree.aspx [consulté le 19 août 2019].
12. Moulias R, Abbad J, Bille M. Les directives anticipées peuvent-elles devenir contraignantes ? Une impossibilité pratique et éthique. Revue Geriatr 2015;40:69-72.
13. Sebag-Lanoë R. Soigner le grand âge. Paris : Desclée de Brouwer, 1992.
14. Haute Autorité de santé. Comment mettre en oeuvre une sédation profonde et continue maintenue jusqu'au décès ? Saint-Denis : HAS, 2018.
15. Urbain J. La pratique de la sédation profonde et continue jusqu'au décès à domicile par les médecins généralistes en France. Thèse de médecine : Université Pierre-et-Marie-Curie, 2017.
16. Pardenaud R. Recours à la sédation profonde et continue maintenue jusqu'au décès en soins primaires : étude à partir de dossiers des services d'hospitalisation à domicile du Maine-et-Loire sur l'année 2017. Thèse de médecine : Université d'Angers, 2018.
17. Le Gall-Grimaux C, Guineberteau C, Bec M, Pignon A, Gutierrez D. Sédation profonde et continue maintenue jusqu'au décès à domicile : état des lieux des pratiques des médecins généralistes du Maine-et-Loire. Médecine palliative 2019;18:116-25.
18. Haute Autorité de santé. Pourquoi et comment rédiger mes directives anticipées ? Guide pour le grand public. Saint-Denis : HAS, 2016.
19. Société française d'accompagnement et de soins palliatifs. Vos droits. Paris : SFAP, 20149. Disponible sur : http://www.sfap.org/rubrique/vos-droits [consulté le 19 août 2019].
20. Coordination de l'accompagnement en soins palliatifs angevine. Guide de soins palliatifs des Pays de la Loire. Angers : CASSPA49, 2015. Disponible sur : http://www.casspa49.fr/publications-cd6.html [consulté le 19 août 2019].