Orchestrating death in contemporary France: When the juridico-medical scansion at the end of life produces new ontologies

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ABSTRACT
How does a state codify temporalities at the end of life? This article explores the ways in which French medico-administrative, institutional and legal dispositions are creating new timeframes for the end of life, new categories of patients and new frontiers between life and death. In particular, a gradual increase in formalizing the terminal phase of patients’ lives, partly distinct from the terminal stage of their illness, leads to identifying specific forms of “bare lives” around which the medical practices of biopower come to be recreated as thanatopower. The article concludes by highlighting the specific features of French governmentality of dying and how it uniquely attempts to overcome the contradictions facing all Western states involved in developing policies for prolonging life.

Have the state and the law lost interest in death? Far from it, according to Iacub, who, in a 1999 article, identified the key stages characterizing the French legal definition of death (Iacub 1999). The 1889 Civil Code initially set a single definition for it (as the cessation of heartbeats) as well as a time threshold authorizing the implementation of inheritance laws. The primacy of cardiac activity in the definition was reaffirmed by a 1947 decree and remained in force until 1996, when the legal system was faced with the new challenge of organ transplants and set the new criterion of cerebral activity. Whether focusing on the heart or the brain, this first type of codification sought to associate the time of medically defined death with that of its legal recognition; it used medical knowledge (clinical definitions of death, ways in which it could be measured) to legitimize a political definition. From this standpoint, a process of medicalizing death, familiar to sociologists and actively fostered by the French state, was already underway. Yet this first type of state intervention obscured another, pertaining to how the state, through law and public policies, could actually organize the interruption of some lives. Of course, state “killings” have gradually disappeared over the 20th century, particularly since the end of World War II, which saw an unprecedented “lay sacralization” of human life. The emergence of palliative care in the late 20th century may be seen as a symptom of this evolution (Memmi, 1996). However, while Western states may be highly involved in developing policies for prolonging human life, they continue to legitimize some forms of interrupting human life—although they have done away with death as a punitive measure, as in the case in France since 1981. This article thus aims to provide an analysis of the forms this thanatopower has taken.

To this end, we will examine the types of political vision and legal framing of medical interventions related to the existential transitions of human life, since they reveal the policies of “fostering life” and “letting one die” of the current French state. Memmi (2003) has clearly demonstrated this in the context of the national medico-political framing of births. However, few works have attempted to examine how the state frames death at other stages of human life, such as during an “end-of-life” period extended by transformations in medical technology, a time more often analyzed from the standpoint of “fostering life” rather than “interrupting life” or “letting one die” (Castra, 2003; Hintermeyer, 2004; Long, 2004; Schepens, 2013; Seale, 1998). Have policies for “interrupting life” forsaken that stage of the human life cycle? After a quick overview of the literature highlighting the theoretical underpinnings of the
analysis of the institutional, legal and medical rules governing medical interruption of life at the "end-of-life," we will show, by contrast, how the French state institutes thresholds, whereby biopower turns into thanatopower through a requalification of the timing and techniques used to intervene on the body of patients in their "terminal phase." We will then conclude by pinpointing the specific features of this French mode of governmentality of death.

A close interweaving of biopower and thanatopower in Western states

In France, study of the ways in which the State authorizes killing—or ending life—is marginal and is generally restricted to the work of political scientists interested in the transformations of the instruments of power-knowledge through which human life and death have been codified (Ferrarese, 2015; Memmi & Taleb, 2009). One discussion point specifically concerns where death fits within Foucault's (1976) analysis of the biopower apparatus: Has it disappeared with the transition from sovereign power to biopower? Or does it persist within it? This is, in any event, the position taken by Agamben (1997) for whom the power to end life constitutes a fundamental underpinning of state sovereign power, ever since Aristotle, who specifically used the concept of biological life to distinguish between the domestic space in charge of individual life and the political space, which focuses on public office and decisions. A triple inversion is thus derived from such a perspective. First, it leads us to consider that some specific forms of "interrupting life" persist at the heart of states involved in developing policies for prolonging human life. Moreover, Agamben encourages us to see this not as a failing of biopower, but rather as one of its paradoxical consequences. Finally, these state-mandated interruptions of human life take on a multiplicity of forms that go beyond the figures of torture or of public executions described by Foucault in *Discipline and Punish* (Foucault, 1975). Agamben, in particular, draws our attention to what he calls "bare lives."

Forms of the production of bare life

For Agamben, state “thanatopower” is based on the ability to legitimately discriminate between forms of human life through the production of *homo sacri—lives that can be taken without breaking legal codes and without bringing about religious or moral oppro- brium. This “bare life” can take two forms. First, it can take the form of “Muslims” from Nazi concentration camps, whose lives are “bare” because they are “banished,” that is, politically neglected and abandoned to the whims of other humans (the deadly games of camp wardens). Since concentration camps hold great importance in Agamben’s work, this first meaning will be granted significant attention. Yet this author also mentions another form of bare life: the “neo-dead.” This figure is of interest to us for two reasons. A pure product of biopower and its resuscitation and physiological assistance technologies, it enables us to analyze the ways in which biopower and thanatopower are interwoven and “the threshold beyond which, by ceasing to be politically relevant, life is no more a ‘sacred life’ and can, as such, be helplessly suppressed” (Agamben, 1997, p. 150). Moreover, in the case of the neo-dead, bare life is no longer produced by an abandonment to the marginal spaces that are left to arbitrary rule (the camps). It is derived from the blurred boundaries into which medicalized bodies fall. Neither alive nor dead, these bodies are maintained in a liminal space, where the moral and legal values that protect the rights of humans are not suspended, but rather inverted to help justify ending life, without this type of death being categorized as murder, euthanasia or suicide—all forms of death still sanctioned by moral or legal prohibitions. Like Agamben, we think that analytical work conducted on the types of thanatopower that have developed at the very heart of biopower must seek to understand the tipping points at which a sacred life, to be preserved at all costs, becomes a life that can be taken, precisely in the name of the sacred character of human life.

A focus on legal and medical controversies

To explore the boundary that the French state draws between biopower and thanatopower, we have examined the legal and policy categories of medically assisted dying. This is not only because they arise within the state structures of biopower (involvement of opposition political parties and the government, echoes in the media, official positions taken by the highest legal and medical institutions—the French National Authority on Health, the Council of State, the health ministry, medical corporate leaders, etc.), but also because they determine a priori the specific situations in which human lives can be maintained or interrupted. France is characterized by a strong state framing of “interrupting life” as well as “letting one die” at the end of life: legal rules exist stipulating the cases that may receive assistance in dying by
continuous deep sedation until death, national directives, rules and best-practice guidelines issued by the French National Authority on Health, ethics committees in all health institutions charged with relaying national norms, etc., institutional responsibility over and above individual responsibility of medical staff, etc.

To grasp the terms of this issue, we assembled two distinct corpora. The first consisted of legal and institutional documents, chosen because of their prescriptive status (laws), their political nature and public echo (breadth of debate these documents generated in the political, parliamentary, medical, media, and association realms) as well as their impact on internal rules and directives (changes in public health codes, position papers of scholarly societies and medical institutions, publication of best-practice guides, etc.). Then, insofar as the legal documents systematically refer to medical data, we have created a second corpus of medico-administrative data (it contains, for the most part, documents issued by medical institutions charged with regulating palliative practices).

In both cases, we started our data collection at the beginning of the 2000s, a time when the issue of assistance to dying patients in hospital had entered both the public and the political spheres. Adopting a sociohistorical perspective that involves questioning the past on the basis of present-day categories in order to retrace its genesis, we have used keywords drawn from the analysis of the current legal corpus that have become hot-button terms—such as the notions of “end-of-life,” “artificial life support,” “terminal phase,” “continuous deep sedation until death,” and “limitation and cessation of active therapeutics” (LCAT). This corpus of documents has been analyzed using qualitative methods of anchored theorization, which involves identifying categories around which arguments are structured, rather than applying statistical procedures to lexemes (Balard et al., 2016).

Our analysis shows that a tipping point becomes identifiable on the basis of the 2005 Léonetti law, via the construction of a specific temporal threshold (the “end-of-life”) that transforms the patient’s ontological status, his or her life becoming “bare”—in this case, an “artificial” life, set apart from the social framing that organizes standpoints, practices and affects owed to “natural” lives.

A medico-administrative codification of end of life

In the wake of discussions stemming from the field of palliative care and from media controversies surrounding resuscitation or life-support technologies, the 2005 law does introduce an important concept—unreasonable obstinacy:

When they seem ineffective, disproportionate or without other impact than the artificial prolongation of life, [these actions] may be suspended or need not be undertaken. In this case, the physician preserves the dignity of the dying person and ensures his or her quality of life by dispensing the measures of care specified by article L. 1110-10.

This law thus actually defines a threshold beyond which life-support practices should be modified, although it entrusts the definition of this threshold to the Public Health Code and the national medical consensus positions underpinning it.

Assessing unbearable suffering

To define unreasonable obstinacy, the Public Health Code sets two types of criteria. First, it introduces a hierarchy of pathologies: the 2005 law and the Public Health Code thus mention that assessing the unreasonable character of medical intervention depends on the incurable nature and the severity of the pathology from which the patient suffers. Assessing this incurable nature is left up to doctors, who rely on multiple measurement techniques, organized respectively around population bio-politics and clinical practice. On the one hand, in accordance with the great endeavor of codifying the living that began in the second part of the 20th century, doctors rely on population statistics that determine five-year remission and survival rates according to the types of pathologies and their degree of advancement (the terminal stage of the illness, which should not be confused with the terminal phase of the patient’s life). On the other hand, with respect to the structuring of clinical perception (Foucault, 1963), physicians also rely on knowledge produced at the patient’s bedside—for instance, the feeling that the doctor who regularly sees the patient can forge an opinion of his or her specific chances for survival. The articulation of these two ways of viewing the severity of the illness is complex. The experiences of many oncologists bear witness to this difficulty; they may know the survival statistics associated with certain stages and types of tumors, but they have also developed specific knowledge of their patients’ particular abilities to fight the disease and they sometimes overestimate their chances of survival (Mino et al., 2016). Yet in both cases, arbitration takes place based on knowledge created by the biopower.
apparatus, such as survival rates and illness trajectories.

The process is identical for the second criterion that concerns not the severity and the incurable nature of the illness as assessed by doctors, but the patient’s suffering: it must be unbearable and resistant to medical intervention, pertaining to “symptoms for which treatments provided have failed, or for which no other palliative measure is appropriate in the required timeframe, or for which the risk/benefit ratio is not acceptable for the patient” (Société française d’accompagnement et de soins palliatifs [SFAP], 2009, p. 2). As this definition seems to indicate, the criterion of “unbearable suffering” is directly derived from the palliative approach, which leads us to think that pain alone (in the sense given to it in a palliative context, i.e., total pain) can bring about a desire for death that might disappear when the pain is contained. Here again, the question of the medical assessment of pain must be raised since its “unbearable” character depends not only on available therapeutic measures legitimized by health professionals (unbearable because it is resistant to medical interventions), but also on nationally standardized codifications identifiable in best-practice guides for end-of-life sedation (Société française d’accompagnement et de soins palliatifs, 2009): they demonstrate how suffering has been ranked according to specific medical hierarchies. In this way, suffering due to chronic neuro-degenerative pathologies is viewed as existential moral suffering justifying deep transitory sedation that may precipitate death (that was to be expected in the medium term), while it is acceptable, for patients who have had a stroke or who are in a deep coma, to prolong life long enough for their loved ones to be made aware of the severity of what is taking place (Société française d’accompagnement et de soins palliatifs, 2009, p. 11). Here we see the issue of timing arising in this national medical framing of end-of-life. Finally, although it is significant, the criterion for resistant symptom and unbearable suffering remains secondary, because until 2005, intense suffering due to a severe incurable illness only entitled the patient to intermittent and reversible sedation (medical staff referred to respite or transient sedation in these cases).

From this standpoint, the boundary beyond which the legislator agrees to alter life-support techniques thus presents two characteristics. On the one hand, medical and legal arguments draw upon categories stemming from what Seale (1998) has called the vitalist script (chances of survival, therapeutic relief, ideal of a life lived fully until the very end). This standpoint is so prominent that deaths which do not conform to this script (unaccompanied, silent, characterized by postures of withdrawal) become marginalized. On the other hand, for the most part, criteria defining “unreasonable” measures do not refer to qualitative elements that might make it possible to differentiate between patients by their pathology or the nature of their suffering, but to degrees, that is, to differences in position on a graduated continuum (detailing available therapies, the trajectory of the illness and the level of suffering). In fact, this formulation implies that the qualitative threshold above which biopower becomes thanatopower tends to take the form of a time threshold, as it is not merely a stage along a continuum of decline but rather a tempo that should be respected by occasionally prolonging the life of some patients, without accelerating the demise of others. This “orchestration” of the end-of-life (Le Theule et al., 2020) is further expressed in developing the concept of terminal phase.

From terminal stage of illness to terminal phase of life

The 2005 law does actually allow physicians to provide continuous deep sedation until death in cases of “terminal-stage” illness. As the legislator does not put forward a legal definition of terminal stage, it falls again to medical documents to provide such a definition—particularly in national best-practice guides of the Société française d’accompagnement et de soins palliatifs (2008) and the National Authority on Health (Haute Autorité de Santé, 2018). First, these guides point out that physicians may use sedation as long as it is in pursuit of two goals: a quality of life characterized as free from total suffering and a “natural” death. This “natural” death is not devoid of medical intervention since the doctor must relieve the patient’s suffering until his or her last breath. It implies, however, erasing the connections that may exist between medical interventions and death, since:

Death [must remain] the result of a natural process, predictable in its outcome but not in its course, which lies outside of human control […]. Death must occur “because it is brought about by the natural order of things” and not “because it is brought about by human intervention”. (Haute Autorité de Santé, 2018, p. 9)

To impose a tempo on the process of dying (estimating the time left to live, preparing teams, patients and their families and friends) while simultaneously preserving an appearance of naturalness (keeping
death “non-technicized”), state institutions will thus gradually formalize a singular medico-administrative period during which the guidelines for medical end-of-life support become profoundly altered: it is the terminal phase of the patient’s life, a moment set apart that national medical authorities will attempt to standardize, based on the assessment of patients’ bodily changes. 

**From a clear distinction between pre-agony and agony …**

Unlike the terminal stage of the pathology for determining a vital prognosis, the definition of the terminal phase of the patient’s life derives from an accurate determination of how much longer he or she has to live. This determination is thus closely interwoven, on the one hand, with how physicians define death (Carol, 2004) and, on the other hand, with the technology-based assessment of the human body’s activity (Daston & Galison, 2007). As it turns out, a shift took place in this area between 2007 and 2009, when the SFAP guidelines for sedation in cases of terminal-phase distress were developed.

In the specialized medical literature on palliative care, a first definition of the terminal phase is based on Bichat’s definition of biological life in relation to his famous *vital tripod* (heart, brain, lungs). Within this perspective, the terminal phase of the patient’s life begins when “[…] the evolution of the illness tips over into a stage heralded by the failure of vital functions: cardiovascular, respiratory and cerebral” (Blanchet, 2007, p. 285), apprehended through the measurement of the functional activity of organs. As the expression “tip over” suggests, the deterioration of this vital tripod transforms the status of the patient—at least in the eyes of the medical institution. First, crossing this qualitative threshold necessitates a change in the vision of care to be provided to the patient. While in the “pre-agonal” phase, providing comfort, hydration or oxygen is still prescribed, in the agonal phase, only interventions that cannot actually “hasten the death of the patient” are administered. But more fundamentally, crossing this threshold transforms the medical institution’s gaze on its patients—in terms of their symptoms and, more broadly, their person. For example, signs of death are clearly distinguished from those related to worsening illness, and doctors must learn to tell them apart in order to identify when the agonal phase is reached, which is supposedly universal but through which each patient actually proceeds at a different pace:

[…] During the agonal phase, there is no consciousness, and thus no perception of pain or of respiratory distress. Similarly, tears that may appear are reflex lacrimal hypersecretions, just like bronchial hypersecretions. These tears are not to be viewed as manifestations of suffering. A contrario, during the pre-agonal phase, tears can be interpreted as due to sadness if the patient is conscious. (Blanchet, 2007, p. 287)

In the agonal phase, the *person* has already deserted a body now seen as intertwined physiological and neurological reflexes. Physicians are advised to explain to loved ones the particular status of this body, which no longer cries but which reflexively excretes water through the tear ducts.

This first qualification of the terminal phase echoes another, put forward by the same actors, but which emphasizes a quantitative change that involves a set of clinical manifestations broad enough to warrant determining, ex ante, temporal thresholds calculated on the basis of medical as well as economic and political considerations.

**… To a dying continuum**

The 2009 SFAP guide on “Sedation in cases of patient distress in terminal phase and in specific complex situations: Recommendations for adult patients and for specific situations pertaining to home-based medical care and for geriatric patients” is founded on a very different vision of the terminal phase, defining it from the start as varying from one individual to another and complex to apprehend. This is mainly because the definition no longer rests solely on Bichat’s vital tripod, but also incorporates well-defined medical criteria together with statistically informed temporal criteria.

First, medical experts refer to the annex to the directive of 22 February 2005 on the organization of cancer care to define the terminal phase and distinguish it from the curative and palliative phases:

The term ‘curative’ applies to the phase during which care and treatments are provided with the goal of recovering health and preserving quality of life.

The term ‘palliative’ applies to the phase during which the goals of care and treatments focus on quality of life and, whenever possible, duration of life in cases where tumors may still respond although recovery can no longer be envisaged.

The term ‘terminal’ applies to the phase during which death is inevitable and imminent. The goal of care and treatments is then focused solely on quality of life (Société française d’accompagnement et de soins palliatifs, 2009, p. 7).

As Iacub already pointed out about the first definitions of death in 1889, state institutions adopt
categories developed by physicians in medical contexts and give them a new scope and significance as they become politically legitimate and structure nationwide practices.

More importantly, however, the terminal phase is characterized less by organic deterioration (cf. the assessment of vital tripod failure) than by goals discussed collegially among doctors (deciding that death is inevitable and imminent, no longer aiming for recovery but for quality of life). Moreover, as the spectrum of clinical signs to consider when defining entry into the terminal phase is broadened (organic, functional, metabolic, physiological, phenotypical), implementing the 2017 SFAP recommendations becomes all the more complex:

To best envisage the evaluation of the vital prognosis across the full range of palliative situations, clinical changes should be assessed through clinical arguments based on a cluster of criteria. These include the speed of functional decline; the failure of target (vital) organs [in reference to Bichat’s vital tripod]; the presence of symptoms such as anorexia-cachexia, dysphagia, edema, dyspnea, oligo-anuria or even anuria …; the alteration of vital signs (lowered blood pressure, weak pulse, irregular breathing, desaturation, cold or mottled extremities); a rapid fall in the score on the Palliative Performance Scale—PPS—first dropping from 40 or 30% and then going down to 20% in three days. (Société française d’accompagnement et de soins palliatifs, 2017, p. 2)

Finally, with its reference to the PPS, the 2017 document introduces another central criterion to be taken into account: the speed of decline in terms of mobility, the type of activities the patient can still carry out independently (professional, domestic), autonomy in personal care, feeding and level of consciousness. All these criteria are used to calculate both a “performance level” at time $t$ (with 0% corresponding to death) and the speed of progression along a continuum of involution. The clinical assessment enabling medical staff to measure the crossing of the agonal boundary is accompanied by an approach focused on the acceleration of the decline observed, with reference to a patient’s specific characteristics and to types of “dying trajectories,” developed internationally (Downing et al., 2010; Lau et al., 2009). These standardized trajectories are meant to serve as norms for care staff, who are seen as excessively optimistic when it comes to probable survival time of their patients (Haute Autorité de Santé, 2018, p. 36, 38).

Reliance on these scores based on the speed of involution demonstrates the emphasis that the French governmentality of dying places on tempos and scan- sion, implemented through the establishment of time markers. It also places a higher value on a different medical view of death, one no longer associated with an image of a furrow leading to a change in status (the transition from a pre-agonal to an agonal state), but rather seen as the distribution tail of a progressive continuum of “level of performance.” Life and death are thus interwoven and placed on a single continuum of alteration, along which progression is simultaneously seen as more erratic.

**The transnationalization of the “terminal phase of life”**

The disappearance of a universal and easily identified organic threshold beyond which the physician would view the patient’s life as reduced to biological functions requires that other markers be set—no longer drawn from organic observations but from international statistical data. Thus, the Société française d’accompagnement et de soins palliatifs (2017) directive refers to the various temporal thresholds that enable doctors to use prolonged and constant sedation until death, from a few hours or days in France, but up to two weeks in Quebec:

For the EAPC (European Association of Palliative Care), continuous sedation until death can only be provided to patients whose death is expected to occur within a few hours or days.

For the Quebec directives, continuous deep sedation until death is not recommended when the survival prognosis is longer than two weeks.

Planned continuous sedation should thus be restricted to patients suffering from resistant symptoms whose vital prognosis is around two weeks or less (Société française d’accompagnement et de soins palliatifs, 2017, p. 1).

Under the joint impact of evidence-based medicine on biomedical research and the will to maintain a national political framework for medical practice, the definition of this terminal phase is based to an ever greater extent on knowledge disconnected from the bodies of patients as a source, since it stems from meta-analyses of the international literature and is deemed robust because of its standardized quantification. Mostly, reliance on this repertoire of medical knowledge makes it possible to determine mathematical thresholds, upon which the markers of tipping points along a universalized alteration continuum can be set. We shall now see how, by changing the patient’s ontological status, the invention of a specific medico-administrative time (the terminal phase) also
results in a new approach to the biomedical techniques used in the context of this particular phase.

**Constructing an artificial death**

While medical and legal documents began to shape the terminal phase, the inception of which determined changes in the use of techniques meant to prolong life, they did not explicitly define the moment at which it became legal and legitimate to “cause death to occur.” This shift occurred in 2016, through discussions that no longer pertained solely to the requalification of the time left to live (was the patient in terminal phase or not?), but also to the requalification of molecules and intervention techniques that surrounded it. It was particularly true for two types of interventions—continuous deep sedation until death, and the requalification of feeding and artificial hydration as therapeutic medical interventions.

**The distinction between life molecule and death molecule**

Provisions related to continuous deep sedation until death have primarily been analyzed in light of debates about the standing of patients’ advance directives. However, other controversies have also arisen, though they have received less public attention since they seem more technical. Examining them demonstrates the effect that the invention of the “terminal phase of life” has had on medical techniques impacting patients’ bodies: thus, biotechniques becoming thanatotechniques.

This requalification can be observed in the SFAP guidelines, which, from 2004 onwards (Société française d’accompagnement et de soins palliatifs, 2004), proposed to remove some drugs with analgesic properties from the range of molecules to be used for sedation, in order to “clearly distinguish the two approaches,” a formulation the Haute Autorité de Santé (2018, p. 19) also chose to include in its documents. This is particularly the case for opioids (Agence française de sécurité sanitaire des produits de santé, 2010; Société française d’accompagnement et de soins palliatifs, 2017; Haute Autorité de Santé, 2018) as well as for all other molecules still often used in cases of transitory sedation, where the patient is periodically woken up. Although its sedative impact varies widely among patients and the right dosage may be difficult to find, Midazolam is unanimously recommended. As its impact is short-lived and easily reversible, this molecule does seem particularly appropriate for the French legal framework that promotes flexibility in sedative practices, at least before the terminal phase. Moreover, since it has no simultaneous analgesic properties, it allows for a distinction between palliative practices related to biopower, aimed at relieving pain and promoting life to the end, and practices related to thanatopower, which authorize a medical interruption of life as long as it imitates the “natural” process of dying as closely as possible. Entry into the patient’s terminal phase of life thus leads to redefining the boundaries of those techniques designed to *prolong life* and those intended to *bring on death*, at a time when the two are highly interwoven, and whose goal, unlike the Canadian or Belgian approaches, is to demonstrate clearly that death “should never be the ultimate palliative care measure” (Société française d’accompagnement et de soins palliatifs, 2018). Yet this medico-administrative timeframe not only prompts a renewed approach of biochemical therapeutic measures previously used by medical staff, but it also extends the very boundaries of what is viewed as medical technique.

**The disincorporation of medical feeding and hydration**

The invention of the “terminal phase” does, in fact, set off a process of redefining medical perceptions of feeding and hydration: from a previous “natural” state, they become “artificial,” and may thus be stopped to accelerate the death of the patient. This issue has already been raised in the 2005 law, in article L1111-4 of the Public Health Code as well as in decision 375081 of the Council of State relating to the Vincent Humbert case. Yet it is with the implementation of the 2016 law that “artificial” feeding and hydration fundamentally change status. Until then, medical measures replacing feeding and hydration were seen as “natural” because, even though the devices providing nourishment were physically external, they were still seen as completely incorporated into the patient’s body. Thus, while chemical or medically assisted in nature, these techniques sought to preserve an acceptable quality of life to the end, and not to provide an intervention for controlling pain or prolonging life as such. Once the boundary of the terminal phase has been crossed, they become *disincorporated* in that they are no longer seen as extensions of the human body, but rather as techniques used to inflect biological destiny. They become intrusive measures intended to unreasonably prolong life; stopping them is then considered necessary to preserve the patient’s dignity.
(articles L 1110-5-1 and L 1110-5-2 of the 2016 law). This even implies that suffering derived from the interruption of artificial feeding and hydration is being wholly reconsidered (Pool, 2004). As Léonetti stated in an article in the national daily Le Monde in 2015, “After a general anesthesia, does anyone remember having been thirsty or hungry?”

What do bare lives do to the margins of biopower?

Between 2005 and 2016, intense work on requalifying time and the medical techniques applied to the bodies of some patients (primarily those in the advanced stages of chronic or neurodegenerative diseases) led to establishing new medico-administrative time periods (end-of-life, the terminal phase of the patient’s life) and new ontologies. As a result of inventing these time periods, patients whose lives are considered “vulnerable” are reclassified as persons with “bare lives,” governed by different legal, moral, political and professional norms. These patients then exit the realm of biopower, characterized by placing a high value on life at any cost and upholding the status of “living human being like any other” to the very end; and they enter an unstable zone, where thanatopower reigns: their life now in the terminal phase, at once artificial and erratic, difficult to assess and frame, and liable to be interrupted. However, when these “vulnerable” patients leave the realm of biopower to enter that of thanatopower, the status of all other compromised and biologically contingent lives is called into question. This change of status affects severely handicapped patients for whom there is no hope of improvement, patients in minimally conscious states, or highly fragile elderly people who have multiple pathologies, but who do not fall into the category of terminal phase, according to the medico-administrative definition set out in the 2005 and 2016 laws (Grouille, 2019). In France, current controversies tend to focus on these bodies, as shown in the Humbert affair or in the case of one-year-old Marwa, who had an enterovirus that irretrievably damaged her neurological and cognitive functioning. Do these lives, without communication or socially expressed consciousness, fall within the purview of a law designed to frame the end-of-life phase for patients with incurable chronic diseases who have reached the final stage? Here, we see the extent to which the development of temporal markers for the end-of-life phase of gravely ill patients has given rise to a specific ontology, a new category of living beings, embedded in a moral economy that has yet to be clarified.

Discussion: Situating the French governmentality of death in an international context

To conclude, we wish to emphasize the specific level of analysis on which this article focuses: the political and medico-administrative construction of end-of-life situations. Although it has been developed by multidisciplinary working groups, including representatives from patients’ associations, professional organizations, scholarly societies as well as nurses and doctors from various specialized fields practising in a range of settings (Haute Autorité de Santé, 2018, pp. 43–47), this construction remains deeply embedded in a palliative approach promoted by some figures in the field who are familiar with the areas of expertise and the neocorporatist regulatory mechanisms that stem from them: to wit, the use of participatory methodologies that generate not so much the expression of more diverse views as the hegemony of “discursive coalitions” giving “meaning and coherence to the policies being implemented” and providing “means of interpretation to all and sundry so that everyone’s daily experiences become intelligible” (Lallement & Spurk, 2003, p. 42). This is why this political framing of end-of-life cannot account for the diversity of situated palliative care practices. When such practices are examined from an interactionist perspective, negotiations around a “good death” bring to light a broad range of sedations outside of the framework set by the directives, demonstrate the impact of settings and contexts overlooked in the legal documents and reports we analyzed, and highlight the active participation of other social groups and professionals (nurses, nursing assistants, volunteers from various support associations, sometimes including local religious networks) who promote other ways to support persons at end-of-life, as well as moral dilemmas and role conflicts experienced every day by “front-line” professionals.

However, the documents we studied formalize a grammar that frames, in cultural and organizational terms, the practices of professionals and associations. This framing has a direct impact when care staff and volunteers take on board the idea that a good death is a death that conforms to a specific tempo, when they make a distinction between “the gravely altered living being” whose life should be fostered to the very end, and the “dying person” surrounded by special precautions once the agonal threshold has been crossed—even though the way that this threshold is assessed may differ from that set out in the HAS recommendations (Voléry & Schrecker, 2018). But it may also have
an indirect impact when care staff devise different forms of sedation to get around the rules concerning terminal continuous sedation until death (Blondet, 2019). Analysis of the medico-administrative and political dimensions thus makes comparative perspectives possible, taking into account how these issues come to be framed nationally, which areas are brought to light and which are left in the shadows, while acknowledging the limits derived from each specific scale of observation.

Bearing this caveat in mind, the study of the French governmentality of death, as instituted in the hidden folds of the 2005 and 2016 laws framing end-of-life care, shows both convergent traits with what studies conducted in Switzerland, Belgium, Canada and the US show as well as specific features that we propose to highlight.

How to reconcile thanatopower and biopower? A Western states dilemma

All states that have refined the techniques of bio-power—particularly those aimed at fostering and prolonging human life—find themselves confronted by the same seemingly insurmountable challenges: What can be done about these lives stretched thin at the cost of heavy medicalization? Moreover, how can new boundary markers be set to limit the techniques for manipulating life, which are just as much techniques for manipulating death? Faced with this shared contradiction, some convergent responses emerge.

First among such responses, we observe a shift in the debate on the ways in which medical technology can be used to bring about death. In all these countries, discussions emerge and unfold against resuscitation, pain relief and life-support techniques, as it is there, amid these interventions of biopower, that the political lexicon defining “legitimate death” is elaborated today. In a context where hospitals are both places of preservation for the sacredness of life and where death, for the most part technically supported, takes place, hospital doctors are faced with a major contradiction, which they attempt to overcome by redrawing the boundaries separating “good deaths” and “bad deaths” in a variety of ways: conformity to individualistic values, classified by Rose (2006) through the concept of “neoliberal somatic citizenship,” as in the cases of Switzerland, Canada and the United States, or through the distinction between “natural death” and “artificial death,” as is the case of France.

As a second point of convergence, we can look at the central role played by medical categories. This is especially true in France because of the type of regulation adopted (in national working groups, led by medical personalities from the world of palliative care, who are used to being called upon as medical experts by politicians), as well as because most teams delivering end-of-life medical support are embedded in hospitals or highly medicalized structures. This is not the case in Switzerland, where “assisted suicides” take place at a greater distance from the hospital care sector and where doctors are more frequently called upon ahead of time (sometimes to formally assess the patient’s mental capacity) and after the fact (to provide forensic evidence about the cause of death) (see Hamarat et al. in this issue). However, in France as well as Switzerland and Belgium, medical categories continue to predominate discussions on end-of-life issues. Political debates still revolve around themes drawn from the medical field (the incurable nature of disease, the level of physical alterations and symptoms, the lack of effective therapeutic measures available, uncontrolled pain, etc.). This is also the case for the positions taken by associations in the field as reflected in the stance of the French association for the right to die with dignity (ADMD), which borrows its terminology from palliative care guidelines (emphasizing both relief from suffering and the bio-political imperative to keep living to the very end, taking care to maintain a symbolic and institutional framing around voluntary deaths, which must be protected from the infamous label of suicide). Similarly, in Switzerland, the associations that are tolerated by cantonal authorities place great emphasis on relief from suffering, diagnoses for incurable diseases, the importance of talking about, and being supported during end-of-life, and also drawing on medical technologies to help ensure a good death. Just like in France, a voluntary death that is not socially sanctioned remains scandalous, as arguments about numbers of “good” and “bad” suicides demonstrate (Grouille, 2019).

These points of convergence seem to indicate an ongoing internationalization of the issue, giving rise to new national political challenges (as in the fear of a death-related tourism developing on either side of the border, competition between national laws and regulations, etc.). However, some specific features also come to light.

Time as an instrument of end-of-life government? The French answer

The specific features, first of all, concern the ways that patients’ subjectivities and the collective framing of
access to life-interrupting devices are expressed. How should “mental capacity,” the absence of a “selfish motive” or external pressure brought to bear on those who interrupt life—associations or doctors—or on persons requesting assistance to die, be assessed? Might the elderly who say they are ready to leave this world not actually be incited to do so by relatives who wish to be rid of the decrepit old age of their elders? To what extent might we not be underestimating the incidence of depression and other types of altered cognition in candidates for medical help to die? More broadly, might the very suffering that allows access to these devices not in itself be a factor affecting mental capacity? These discussions take place in many countries (France, Belgium, Switzerland, United States, Canada), but they are not conducted in the same way. Actors contributing to these discussions vary to some extent (associations, individual doctors, patients or, as in France, some medical personalities involved in the political arena, health care and social institutions and doctors’ associations). Arguments are not structured in the same way either: the notion of owning oneself, including the freedom to choose one’s death, is more or less prominent and legitimate. Similarly, the voices of palliative care proponents, who hold the view that no request to die can be “informed,” constant and inflexible, may be more or less authoritative. Moral arguments are drawn from different repertoires, ranging from the grammar of social justice (unequal access to arrangements in Switzerland that are mainly mobilized by the middle and upper classes, or the risk of more easily ending the lives of socially downgraded citizens) to more universalist ethical issues (the impossibility of measuring the quality of life and thus distinguishing between lives “without” quality from those of “lesser” quality). The types of “problematic” situations identified in public debates also fluctuate (the terminal stages of chronic diseases in France, or people who are tired of life and suffering from multiple age-related pathologies in Switzerland). Finally, the nature of political intervention varies.

In particular, the study of French legislative productions demonstrates a framing based on the nationwide legal and institutional specification of a temporal threshold (the “terminal phase”), beyond which a “bare life” is reached, that can be interrupted without disturbing the biopolitical order and overseen according to a predetermined tempo. In this regard, France differs from other countries, which tend to distinguish between types of patients in terms of the nature of their deficiencies, the severity of their pathology, or the intensity of their suffering. The French approach means that even patients at an advanced stage of illness, or who have been diagnosed with a lethal pathology causing them great suffering, may not have access to continuous deep sedation until death if they are not, at the same time, recognized as being in the “terminal phase” of their life.

The French governmentality of end-of-life involves a precise orchestration (in the literal sense of managing a tempo). Its goal is to make the moment of “social” death (the time of slipping into an undifferentiated bare life) coincide with that of “biological” death. This attempt necessitates the prior alignment of the “terminal phase” with scores of the speed of alteration viewed as predictive of biological death, as well as real-time interventions at the moment when “biological” death occurs through LATA and sedations that shape the dying process by acting on its margins. Through this process, the actions taken are legitimized by appealing to the argument of “nature,” whereas other states tend to emphasize respect for individual rights. How should this specific feature be understood? On a short time scale, the profiles of physicians who have influenced public debates, the ways in which palliative approaches have been interpreted in French medical and social spaces (promoting a secular sanctity of life rather than emphasizing the personal and intimate challenges that characterize the end of life), or the type of associations active in the public domain, may constitute a first line of explanation. However, it is also undoubtedly important to place this particular way of managing end-of-life within a longer timeframe to see how French institutions have historically dealt with the inherent contradiction between a formal principle of equality of all human lives, which lies at the heart of republican rhetoric, and the differentiated treatment of these same lives. It is by referring to time—through the notion of degeneracy used in the 18th and 19th centuries (Doron, 2016), or through atypical development trajectories in the 20th century—that this “exclusive inclusion” (Balibar, 2012) is made possible. Lignier (2012) also gives us a wonderful example of this process in his sociohistorical study of the political handling of “giftedness” at the end of the 20th century. To justify separate school treatment for these high-potential children without invoking a category of “gifted” that would suggest a distinct quality of life, the institutions and associations involved relied on psycho-medical data to buttress the view of giftedness as associated with poorly regulated development, causing problems in adaptation and generating suffering. From this standpoint we begin to see the contours of a French-
specific feature that should be further explored in a perspective integrating geographical and temporal focuses, in order to articulate the short timeframe of debates and controversies that weigh upon the political agenda with the long-term processes that govern the production and political management of alterity.

Notes

1. Decree and Ordinance of December 1996 “relating to the pronouncement of death enabling the removal of organs, tissues and cells for therapeutic or scientific purposes”; Articles R. 671-7-1 to R. 671-7-4 and R. 672 of the Public Health Code. Here, legislation follows a more global trend tending to define human life as associated with the brain and its so-called higher functions (receptivity, reactivity, reflection, communication) (Lock, 2013; Steiner, 2006).

2. The focus of the present article is limited to Western states (Belgium, Switzerland, the Netherlands, Canada and the United States) that have developed, since the 18th century, a biopower apparatus aimed at strengthening their subjects and their populations while also benefitting from an increased political legitimacy based on their ability to preserve and maximize biological life. These states thus represent privileged fields for the analysis of the interactions between biopower and thanatopower that we wish to examine. Furthermore, their thanatopolitical-practices (practices pertaining to assistance in dying, euthanasia, palliative care policies, etc.) are beginning to be documented comparatively (Barnikol, 2018; Emanuel et al., 2016).

3. See the four laws (Légifrance, 1999, 2002, 2005, 2016) as well as the evaluation report on the 2016 law issued by the General Inspection of Social Affairs (Barret et al., 2018).

4. This expression is used by Taïeb (2006) to designate state power that uses the interruption of life. In the present article, the term refers less to “direct killing” (e.g., death penalty) than to indirect medical interventions aimed at influencing the temporal, spatial and physiological conditions in which the process of dying and death itself take place. This includes not only practices politically associated with “interrupting life” (assisted suicide, euthanasia) but also those that imply "letting die" persons under medical care (through sedation).

5. According to the French national institute of statistics (Bellamy, 2017), out of 594 000 persons who died in 2016, 60% did so in a medical institution. Death is thus essentially managed by health institutions and doctors.

6. Elisabeth Hirsch Durrett has translated all citations from sources in French into English.

7. Politically abandoned life, left to individual arbitrary power (the “Muslim” in the camp), or lives occupying an unstable position in the political apparatus charged with managing the living (the “neo-dead” in hospital), “bare” lives should not be confused with physical or mental vulnerability (Ferrarese, 2015). One consequence of this theoretical distinction is that a patient hospitalized in a palliative care unit may be viewed as a “vulnerable” life at a given time of his or her trajectory (an altered body, in pain, with a declining quality of life), but still belonging to the shared moral economy and deserving to be treated within the norms of politeness and modesty, following the rites that govern interactions in other social spaces), then as a “bare life” at another time (as soon as he or she enters the unstable zone in which one is seen as not quite alive, but not altogether dead).

8. The place occupied by “suffering” is not specific to France and represents an argument that has become internationalized with the dissemination of the palliative approach.

9. The place taken by the issue of “suffering” in the national apparatus framing end-of-life has been supported by its medicalization: it is assessed by doctors, mostly with regard to the expectations of the medical institution and conceptualized in terms of medical categories (subjected to objective indicators and related to clinically observed symptoms, etc.). This is particularly the case in France, where a preoccupation with the national harmonization of practices has led to the standardization and quantification of suffering, to the detriment of the “intersubjective understanding” of suffering privileged in Switzerland (chapter 6.2 of the 2018 ASSM directives).

10. For an analysis, see Fabian (2006), who shows that confining “primitive people” to timeframes perceived as separate from Western ones did contribute to seeing them as other. For an example of this approach used in the field of palliative care, see Voléry and Schrecker (2018).

11. This qualitative change is, in fact, set forth in medical training and in best-practice guides - instruments of “soft law” that are also present in French medical policies. However, our chosen focus and methodology cannot provide evidence that the patient also changes status in daily medical practice and in the eyes of hospital managers. However, Livne’s research in the USA (Livne, 2014) does provide information on this issue.

12. It is worth noting that this second view of death, found again at the heart of medico-administrative documents after 2009, had been formalized from the early 20th century and has also affected medical conceptions of the aging process (seen as a progression along a continuum of losses). See also Voléry and Julien (2019).

13. Within this conception of scientific objectivity (Daston & Galison, 2007), knowledge production, in fact, must rely on mechanical recording of data since the subjective nature of physicians’ decisions is supposed to negatively affect their rational character. Daston and Galison point out that this view of medical objectivity is not the only one, since the “doctor’s
trained eye” and his or her “experienced judgment” can also be “guarantees” of best practice. Both views are present among French doctors, but the institutional literature we analyzed tends to hold up the first model as the standard.  

14. A contrario, propofol is recommended as a second choice, not only because it can cause drops in blood pressure and is less flexible and easy to use, but also because it is classically used for anesthesia. It is interesting here to see how the side effects of molecules are considered more or less acceptable depending on the ideological approach that underpins the medical framing of dying.

15. See, for instance, the Belgian model of integral end-of-life care and the Quebec Act respecting end-of-life care.

16. In which the Council of State confirms that artificial feeding and hydration represent treatment measures.

17. In the sense of the term given to it by anthropologists of material cultures. For them, incorporation does not necessarily imply crossing the skin barrier (e.g., implanting a device for nutritional assistance); it can also take place through the subjective relation that persons hold with the objects they use on a daily basis (in this case, the care staff’s perception of familiar nutritional assistance, manipulated daily though external to the patient’s body). Yet it also takes on a political dimension, since it also depends on the way in which the law and medical institutions define the connection – continuous or distinct – these devices have with the body of the patient – who is sometimes no longer conscious.

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