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Exploring contemporary forms of aid in dying: An ethnography of euthanasia in Belgium and assisted suicide in Switzerland

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**ABSTRACT**

Drawing on two case studies from large-scale fieldwork carried out on euthanasia in Belgium and assisted suicide in Switzerland, this article focuses on the processes of normalization that structure aid in dying. Normalization takes place through a set of apparatuses only partially derived from current legislation, which underlie the relationships that develop between those requesting aid in dying, healthcare staff, volunteers, and loved ones. The resulting arrangements are specific to each national context, but the empirical data also point to broadly common traits, highlighting new paradigmatic forms of aid in dying in the contemporary era.

**Introduction: choosing one’s own death, providing aid in dying**

“Aid in dying” represents the institutionalization, or socially regulated fulfillment, of a very old idea: being able to choose one’s own death, to decide the end of one’s life according to one’s own plans for existence. This notion has wound its way into the legislative apparatus of several countries and has stirred up political debate in many others (Stark, 2018). It is frequently seen as the emblematic embodiment of the principles of autonomy and self-determination, whose definitions vary from context to context (Horn, 2010). Furthermore, this embodiment cannot be reduced to applying, or submitting to, legal rules, even if such rules offer a broad framework and help define its boundaries. In each context, practices follow a set of specific, differentiated rules, an array of norms that can only be deduced to a very limited extent from laws. In practice, these norms are situated at the intersection of several kinds of rationality (Mol, 2002) taken from medicine, other professional bodies, lay associations, and healthcare organizations. The role of the dying person themself throughout the process also takes on great importance (Berthod et al., 2019; Hamarat & Lebeer, 2019).

Aid in dying is thus an institution, generically speaking. It is framed, bound, and structured by norms. Aid in dying—and, more generally, dying itself—is an object of social control, operating on different levels. It is a political object, one over which power is exerted. Michel Foucault set out to thematize this power, which he felt was primarily a technology that allowed for implementing an apparatus, defined as follows:

What I am trying to pick out with this term is, firstly, a thoroughly heterogeneous ensemble of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral, and philanthropic propositions—in short, the said as much as the unsaid. Such are the elements of the apparatus. The apparatus itself is the system of relations that can be established between these elements (…) I understand by the term ‘apparatus’ a sort of—shall we say—formation which has a major function at a given historical moment, that of responding to an urgent need. The apparatus thus has a dominant strategic function (…) I said that the apparatus is essentially of a strategic nature, which means assuming that it is a matter of a certain manipulation of relations of forces, of a rational and concerted intervention in these relations of forces (…) The apparatus is thus always inscribed in a play of power, but it is also...
linked to certain coordinates of knowledge which issue from it but, to an equal degree, condition it (…) (Foucault, cited in Gordon, 1980, pp. 195–196).

Medicine, for example, has developed such an apparatus, which involves discourses, forms of organizational logic, scientific statements, laws, and moral propositions, which define a time-specific normativity. From this perspective, one needs to take into consideration the role of medicine in aid in dying, whether it be primary as in Belgium or ‘required by default’ as in Switzerland. What place does the medical occupy in ethical controversies? What legitimacy does it hold, and what missions does it have in fulfilling these end-of-life plans? How does the medical come to be articulated around professional and lay actors, and around other apparatuses, those of other professional bodies for example? How do the different apparatuses, in concrete terms, come to configure themselves to bring about, or allow to emerge, a process of aid in dying that may be interpreted as an apparatus of apparatuses?

These questions have taken center stage from around the 1990s, with the arrival of new actors in dying, who have helped change the relationships between different normative registers (Castra, 2003; Déchaux, 2001; Memmi & Taïeb, 2009; Wolf 2012). End-of-life support persons, funeral agents, coroners, healthcare workers “have been propelled, instead of the repressive State, to the forefront of regulation on practices” (Memmi, 2014, p. 261). This trend has been all the more pronounced in a context of “making the experience of death more intimate,” where “the symbolic order is no longer guaranteed by universal and transcendental norms, but rather constructed contingently and intersubjectively” (Déchaux, 2001, p. 93). Individuals are summoned to embark on an introspective quest, where the issue of values and the goal of a ‘good death’ derive to a considerable extent from one’s own subjectivity or, more accurately, from the intersubjectivity that has been constructed around the provision of support and aid in dying.

In truth, the issue of subjectivity is historically anchored. In Foucault’s writings, it is embedded in the time of what he calls “governmentality,” where control is seen as inseparable from subjectivization (Foucault 1997, 2001). Our constitution as subjects is intrinsically tied to contemporary forms of coercion: “Each of us, when we are required to investigate who we are and express the rules we give ourselves, is not only constructing an individual capable of creativity but also, within the very same indivisible movement, creating a subordinated individual, subordinated to that very injunction to work on oneself. It is (…) a mode of governance based on self-surveillance” (Lebeer, 2016, p. 9). In Faire vivre et laisser mourir (Making One Live and Letting One Die), Dominique Memmi shows that the self-control of the patient entails complete “enlightened” awareness, requires adhering to waiting periods for decision-making often imposed by the law, and asks the patient to describe the reasons behind their choice and to talk about their relationship to their body and themself. By contrast, self-control for healthcare workers and support staff entails demonstrating reflexivity to avoid imposing their point of view, while carrying out, with a clear “ethical” conscience, the role of authority conferred upon them by legislators (Memmi, 2003, pp. 49–51).

Taken together, the practical implementation of aid in dying lies at the juncture of many “normalizing” bodies, including the law, medicine, psychology, social work, and associations. We are thus faced with a context where different sets of norms combine and reinforce one another, overlap and occasionally contrast, are discussed and negotiated, and sometimes turn into rules of law. In a generally restrictive normative framework, professionals, volunteers, and loved ones as much as the person they are assisting—through their interactions and an ongoing reflexive stance—take part in transforming and reshaping the contours of the framework while at the same time being transformed by it.

Apparatuses of aid in dying thus seem to be “composite objects” (Dodier & Stavrianakis, 2018), which deserve to be documented and studied as such. The point of view adopted here in no way implies that the apparatus, on the one hand, and the actors’ reflexivity, on the other, should be treated separately (Dodier & Barbot, 2016). The apparatus owes its form of existence and its very implementation to the actors’ positions and, especially, that of the person seeking aid in dying. What is more, the apparatus weighs with all its normative force on these positions which, in turn, may bring about their own unexpected bifurcations (Tsing, 2015). This perspective, deeply rooted in the experience of self-determined, assisted death, opens up a field of research that can account for both the reflexive and political dimensions of these “composite objects.” In so doing, it represents a solid foundation for developing comparative—particularly international—analyses, without succumbing to the temptation of ‘culturalizing’ or ‘psychologizing’ practices of aid in dying.

Following this approach, this article examines two different national contexts – Belgium and Switzerland – while seeking to put their corresponding regulations
Euthanasia in Belgium: adjusting multiple determinations and deeply held beliefs

The legal and political framework is especially important when accounting for the social and political regulatory modes for practices of aid in dying, particularly when considering the roles assigned to different actors and the nature of their expertise in debates surrounding end-of-life plans. In point of fact, unlike the situation in Switzerland where the legal framework for aid in dying falls within a set of norms regulated by positive law (Mauron, 2018), Belgian law, in addition to defining euthanasia as “the act, performed by a third party, which intentionally ends the life of a person on the person’s request” (art. 2), sets out a number of conditions and procedures, and thereby formalizes the relationship between protagonists.

In terms of practices, the act of euthanasia must be performed by a physician, at the request of the patient. The request for euthanasia must be made “voluntarily, in a well-considered manner, and repeatedly,” and must not result from outside pressure. It must come from a “patient who is legally competent and conscious when making the request” (art. 3§1). To ensure these conditions are met, the physician conducts several interviews with the patient “within a reasonable timespan in view of the development of the patient’s condition” (art. 3§2.2). The patient must “be in a medically hopeless condition” and be experiencing “constant and unbearable physical or psychological suffering that cannot be alleviated and results from a serious and incurable condition that is accidental or pathological in nature” (art. 3§1). The physician must inform the patient of their condition and life expectancy, as well as their therapeutic and palliative options and consequences. Following these conversations, the physician and patient, together, must arrive at “the conviction that there is no other reasonable solution” and that the request is indeed voluntary (art. 3§2.1). Regarding the expected time of occurrence of death, one or two physicians unaffiliated with the attending physician and the patient, and knowledgeable of the medical condition in question, will also be consulted (art. 3§2.3). It must also be noted that a conscience-exemption clause ensures the physician’s freedom of therapeutic practice. However, “if the attending physician, on the basis of freedom of conscience, refuses to practise euthanasia, the physician must promptly inform the patient or trusted representative, no later than seven days after the initial request, of the reasons for the refusal and refer the patient or trusted representative to another physician the latter has chosen” (art. 14).

While some might be tempted to see in these procedural conditions an intent to limit the room for maneuver for those individuals directly concerned, it must be noted that the Belgian legal framework, nonetheless, does, as a central tenet, affirm the irreducible nature of the singular doctor-patient relationship (the colloque singulier), specifically “the meeting of conscience and trust,” to quote the often-used phrase from political and practice-oriented debates. For its defenders, the advantage of this relational configuration is that it avoids “turning the way the request is handled into a court proceeding.” Indeed, while all the actors involved are consulted, they do not interfere in the colloque singulier between physician and patient. Thus, the law stipulates that if a healthcare
team is in regular contact with the patient, the attending physician must talk to the team or at least some of its members (art. 3§2.4). If the patient so wishes, the physician should also speak with loved ones designated by the patient (art. 3§2.5).

The colloque singulier, however, does not preclude the generally explicit intervention of conflictual norms and power relations, especially around the task of objectifying the request. Indeed, healthcare staff call upon patients requesting euthanasia and their loved ones to objectivate their situation by locating the request within a coherent, time-bound narrative in light of their experience with severe illness. As a result, patients and their families are expected to reveal publicly, for the most part, the ambivalence inherent in their decision, particularly in the case of emotional conflicts that may arise between the wish for the pain, suffering and illness "to be over" but not necessarily life, or where conflicts of loyalty occur within the family. The professionals, in turn, are called upon to take action in order to facilitate these end-of-life plans, which go beyond the general call of medical duty while reexamining the boundaries of the doctor/patient relationship, professional arrangements, and the contexts in which they take place. By exploring the situation of Annabell, whom we met during a two-year socio-ethnographic study conducted in two Belgian continuing and palliative care hospital units, we will show that these requests—always humanly, relationally, and medically complex—call upon everyone involved not only to debate and deliberate among themselves, but also to grapple with their own moral sentiments, doing away with a harmonious and unequivocal view of deliberation while still striving to reach unique forms of conciliation.

In her fifties and having worked in the financial sector for many years, Annabell told us repeatedly that she had "led a very full life, as if I were 75 years old." However, she has had to "go at a slower pace," more recently. Diagnosed with invasive cervical cancer, she suffered in particular from peritoneal diffusion of the neoplastic mass. In one of our conversations, she spoke of how much pain she had endured after several surgeries, chemotherapy and radiotherapy treatments: "They saw that things did not go well (…). The cells grew a little bit, and now they are very aggressive. I have a lot of problems when I need to go to the bathroom [specifically due to a narrowing of the anal canal (author's note)] (…). They tried to operate on me. But apparently when I need to go to the bathroom [specifically due to a narrowing of the anal canal (author's note)] (…). They tried to operate on me. But apparently... They tried to operate on me. But apparently when I need to go to the bathroom [specifically due to a narrowing of the anal canal (author's note)] (…). They tried to operate on me..." The only feature specific to Annabell's case was that her request, perhaps more than usual, required her to wait anxiously before finding out whether and when the act can be performed. The different stages of the procedure called for the patient to be regularly monitored over a fairly long time, which could represent a considerable obstacle for those living or being treated abroad.

For several months, Annabell met with the Belgian doctor in charge of her case and discussed end-of-life plans. These consultations are offered in several Belgian hospitals and give patients, who are wondering about future provisions, the chance to share their thoughts with a doctor. They may last up to an hour, which is rather long considering the pace of daily hospital activity, and are open to all patients and their loved ones, regardless of their health condition, medical trajectory, or place of treatment. Patients initiating the process of requesting euthanasia often come to these meetings to obtain information about the legalities surrounding their decision or to ask for a second opinion, as required by law. A physician who undertook these consultations summarized his approach in the following way, thus clearly showing how deliberations involving a request for aid in dying are not simply based on a discussion of clinical concerns, but fully engage one's self-conception and the beliefs of those concerned:

When you need to discuss ethical matters, you must have excellent case documentation. You can't simply go on a clinical vignette along the lines of 'a patient of such and such an age, at an advanced stage of cancer, with this or that metastasis, refuses Phase 1, and so requests euthanasia.' You can't give a Reader's Digest version. You have to listen to the patients. (…) If the patient says, 'I'd like you to help me die, but I want it to be as late as possible,' that's how I write it in the file. (…) We ask the patients to tell us about themselves: who they are, whether they...
have children and families, what their beliefs are, things we don’t know much about in medicine. Generally, in a medical case file, it just says for the lifestyle category: alcohol 0 or tobacco 0. Or alcohol ++. If you don’t smoke and don’t drink, your lifestyle is zero (laughs). (excerpt from a field notebook kept during an end-of-life training session for medical staff)

During these consultations, in addition to collecting objective data on the patient’s clinical condition and discussing the unbearable nature of their suffering, the physician offers the patient a socialization to the formal and informal norms governing their request for euthanasia, as well as a potential challenge to these norms. This holds true for the institutional aspect of the request (discussing how the timeframe fits together with the patient’s motives, the healthcare professionals’ motives, and the legislative context) as well as its implications for the relationships with loved ones and respecting the personal choices of the patient (deciding on the date, location, persons in attendance, and so on).

In the course of these meetings, the physician explained to Annabel the sequence of medico-legal stages that she would have to go through, some of which were liable to cause her distress or discomfort. Indeed, although Annabell emphasized the “humanizing” nature of her contact with the Belgian physicians, her physical condition exhausted her and bolstered the urgency of her request. In this kind of situation, the patient and the protagonists involved may hold quite different assessments of the “right” timing for carrying out the request:

It’s a very humane way to die. I think that dying any other way would be dehumanized. (…). The only thing is (…) that you have to see one doctor, then you have to see another. Many doctors saw me before finally making the decision. But I’ve been ready for a long time. I’m ready for tomorrow, but tomorrow, for example, is Saturday, so it can’t happen here8 (…). But I’ve been ready for a long time. (interview excerpt)

While Annabell developed a very strong relationship with her attending physician and also had the opportunity to discuss her situation with other doctors in Belgium specializing in her condition, she never met the members of the healthcare team in the hospital where the euthanasia would be performed some ten days following her admission. During their rounds and clinical meetings in previous days, staff members may have occasionally discussed the difficulties they experienced with these transfers from abroad. However, the following excerpt focuses more on the personability of the patient, who refused the administration of certain analgesics and certain forms of relational support the nurses had offered her. This provides some insight into the issue of late transfers arranged specifically for cases of euthanasia (whose stakes go well beyond the individual situations of patients coming from abroad, since similar discussions also occur in the case of patients transferred from other units or other hospitals within Belgium). It further highlights the tensions surrounding professional cooperation in the care preceding the actual euthanasia. The team complained about not having had the opportunity to “get to know” the patient, at least not for as long as the attending physician, who had met with her on a number of occasions in the preceding months.

Head nurse: This lady, she doesn’t let us in. People don’t all open up in the same way… but she doesn’t open up at all. She’s just here for her euthanasia. She hasn’t come for anything else. You even have to negotiate for her pain relief medication… She’s really got a peculiar personality ["C’est vraiment une personnalité particulière"].

Attending physician: We’re all peculiar, including you and me. Her situation’s been like this for months. It goes on, it gets worse, she has no way out. If we don’t [help her], then who will, in her situation?

Head nurse: So we’re here to do what she wants. She’s a string-puller ["Elle est arrangeuse"].

Attending physician: You don’t have to feel sympathy for her. As a female lawyer friend of mine used to say, ‘If I had to feel sympathy for all the clients I defend, I wouldn’t have very many’ (smiles)…

Another physician from the team: I think this woman, she has no energy left to invest in anything. But it’s true that we have to avoid these kinds of situations from repeating themselves too often, because it’s hard on the team.

Attending physician: It’s exceptional, you know that. These are exceptional situations. Also, nobody’s forced to stay on…

Head nurse (interrupting): We’re still going to have to handle the body!

Another physician on the team: Yes, well, the physicians perform the act itself. You’re lucky to be spared that!

Attending physician: It’s true that cleaning the body after death is, anyway, different from euthanasia…

Head nurse: It’s hard on the team. You can’t do anything for her. She’s just here for her euthanasia.

Attending physician: We’re not going to debate this all over again. It’s exceptional. We’ll talk about it more later at the team meeting. (excerpt from field notebook)
This exchange also shows how these tensions persist through the division of care work, “otherwise people are left with their frustrations, even if I do know that it’s hard on the doctor, it’s hard on everybody,” as the head nurse told us at the end of the meeting. The attending physician would be challenged by the healthcare team about its weak relationship with the patient up until the day before the procedure. For example, some nurses believed that the patient had children, who had not been informed of her decision.

My parents have not been informed. They’re too old. They’ll learn the news when they have to. (…). Fortunately, I’ve got my husband who can make this decision. I don’t know if there are people who come here on their own to make this decision. Are there people on their own here? That must be hard. I feel very protected, it really helps to calm me down. At night he stays here. (…) It helps me to know that he’s here. He’ll be all alone in the end. I also had my in-laws who were going to come, but they [can’t at that time] (…). I said I don’t want to change the date, I’ve got it already. So it’ll just be the two of us (…). It’ll be a good date. (interview excerpt)

The issue of getting the family ready for bereavement is here questioned by the team who had only been able to meet Annabell’s husband: “Euthanasia is never a cheerful time, but it’s easier, so to speak, when you know the family; but here the team was afraid there might be family secrets” (nurse, field notes). For his part, the doctor regretted having to bring this up all over again with the patient and her spouse until the very day of the euthanasia, mostly to avoid there might be family secrets when you know the family; but here the team was afraid there might be family secrets. The psychologist would be present in the room during the euthanasia to support Annabell’s spouse. After carrying through with the gesture, consisting of an anesthetic overdose of barbiturates – and, in some cases, if death had not occurred in a few minutes, the injection of a paralyzing neuromuscular agent to cause a cardio-respiratory arrest,—the nurses then washed Annabell’s body for the last time before it was transported to the hospital morgue. The body would be incinerated thereafter, and the ashes transported to her home country, according to her wishes.

Unlike the Swiss case described below, no coroner’s report is necessary in the case of euthanasia. The usual declaration of death indicates “natural causes” and identifies the pathology justifying the use of euthanasia. A “euthanasia registry document,” comprised of a first confidential report (only to be opened in case of requests for further information) and a second anonymized fact sheet, must be completed by the physician and sent within four working days to the Federal Commission for Control and Evaluation of Euthanasia (CFCEE). The commission is responsible for checking for any irregularities and, if necessary, sending reports to the Crown prosecutor.

This report represents the final act in the relationship between doctor and patient, and brings closure to the deliberations within the healthcare team and the exchanges with family members. Euthanasia has, in fact, been the subject of much debate in that it fully engages one’s conception of self and the innermost convictions of all professionals and nonprofessionals concerned. This debate unfolds in the context of “making the experience of death more intimate,” put forth by Déchaux (2001), where one’s subjective experience is central to achieving a “good” death. However, it can also be viewed from the perspective of Foucault’s analysis of contemporary governmentality, where the patient moves through the expression of subjectivities that are constructed within very active normative apparatuses.

**Assisted suicide in Switzerland: a pedagogical process toward death**

To illustrate how various apparatuses interlock or overlap in carrying out an assisted suicide in Switzerland, we will describe – among a much larger number of possibilities – three moments in a specific request: the first appointment with a volunteer, the preparation of an assisted suicide, and the day on which the act itself takes place. Through this narrative, we aim to highlight a set of normative issues that
underlie these arrangements in order to serve as a basis of comparison with the empirical material presented in the section above on Belgium.

In Switzerland, assisted suicide is generally provided by private nonprofit associations. Asking for such an association to intervene, however, is not required since an attending physician can also offer this assistance on an individual basis. Essentially, the unique character of Swiss assisted suicide, in contrast with direct active euthanasia that is still illegal in doctrine, resides in the fact that it is exempt from criminal prosecution if—and only if—persons requesting assistance carry out the final act themselves and are mentally competent. Therefore, persons or organizations offering assistance should not be motivated for selfish reasons, such as the prospect of financial gain. If any one of these criteria is not met, then Article 115 of the Penal Code states that the person who provided assistance, “should the suicide be committed or attempted, will be liable for a custodial sentence of up to five years or a fine.” This means that requesting assisted suicide is not a right regulated by the federal State, but rather a practice that may be considered illegal under certain circumstances.

While not going into great, formal detail about the medico- and politico-legal context surrounding the practice of assisted suicide in Switzerland, we can nonetheless highlight a few of its salient characteristics useful for comparing the two countries. First, assisted suicide takes place in the vast majority of cases in the intimacy of one’s home. This is the first reason why we have chosen to present a situation occurring outside of an institutional setting. Second, the participation of doctors is indirect and sometimes rather understated throughout the process. It is, however, necessary to issue a certificate of mental competence, to attest to the medical condition of the person and to prescribe the lethal substance. No representative of the medical profession need be present during the preparatory stages leading up to, or at the time of, the suicide itself. Yet, it must be noted that physicians, ethics committees, and healthcare professionals are more directly involved in organizing an assisted suicide when it takes place within the walls of a healthcare institution. This is the second reason that led us to choose the case presented here, since it more strongly reveals the differences between the Belgian and Swiss models in terms of the role played by physicians in voluntary death. To that end, the centrality of a more vertical relationship between physician and patient, which typifies the apparatus of euthanasia in Belgium, is replaced with a more horizontal relationship between the two individuals in Switzerland. This latter case, however, is not devoid of a certain authority exerted by the volunteer, who has in-depth knowledge of the apparatus and, in particular, the protocol for carrying out the assisted suicide. It must be noted that the criteria for access are not completely formalized and—as we will outline below—are left in part to the judgment of volunteers from associations who provide assistance in dying. Also worth emphasizing is that these individuals serve as volunteers and hold no specific qualifications. Depending on their previous professional activity, seniority within the association, and former experience as volunteers, they may display a broad range of sensibilities toward how the practice of assisted suicide should be overseen in Switzerland.

Harboring doubts about the patient’s decision or assuming a conflict exists among family members may be reason enough for a volunteer to refuse to assist or withdraw from the process altogether in the same way as the patient not having an incurable disease or experiencing unbearable suffering. This is why we will illustrate these aspects through a situation that highlights normative adjustments. This process—guided by a horizon of compromise—is part of the construction of the legitimacy of a request, and the assurance that the volition of both patient and volunteer is founded. We will show how the apparatus of assisted suicide brings about ‘soft’ forms of controversy that, in one way or another, must be overcome during the support process for the suicide to be carried through to completion.

Germaine is in her seventies. In addition to undergoing a urinary diversion for a diagnosis of carcinoma in 2014, she has had Alzheimer’s disease for the last three years. Because of this second diagnosis, she became a member of EXIT A.D.M.D. in French-speaking Switzerland. In March 2018, Germaine decided to initiate the process of assisted suicide and contacted the association secretariat. She was asked to put together a file, including confirmation of her status as a member of the association; her handwritten, or otherwise notarized, request for assistance; documents attesting to her physical and medical condition; and, ideally at this stage, certification of her mental competence. The file was then sent to one of the association’s medical advisors, who assessed the request. In the case of a favorable assessment, the secretariat would contact a volunteer, who then received the file. This represented the first step in constructing the association’s resolve to plan for the assistance.
Next, Hélène agreed to meet with Germaine and called her to arrange an appointment. This is the first moment we would like to describe and discuss. This initial exchange was vitally important because it represented the only space for reaching an understanding between the volunteer and the patient. Thus, by the end of the exchange, the volunteer needed to decide whether or not she would accept to provide the requested support.

During this discussion that we attended, Hélène first made sure by referring to the medical file that Germaine understood the possibilities and legal limitations of assisted suicide. She checked that the patient was aware that, should her mental competence be compromised as a result of her Alzheimer’s disease, the assisted suicide could not then be carried out. After this reminder, Hélène invited Germaine to introduce herself by telling her life story. This allowed the volunteer to assess several criteria in turn, without ever having to mention them explicitly: a clear, informed consent; freedom from undue pressure in her decision; her ability, on the day, to ingest the lethal substance by herself; her attending physician’s stance on her request; and the persistence of her decision over time. This discussion revealed how regulation operated in the practice of support: violation of legal provisions could open up the risk of being prosecuted. In fact, any suicide in Switzerland is considered a ‘violent death,’ setting in motion an inquest by the public prosecutor.

This is largely why Hélène negotiated with, and obtained permission from, Germaine to contact her attending physician, if necessary, in order to renew her certificate of mental competence or to check whether he would prescribe the lethal substance when the time came. This last point takes on considerable importance because, unlike in Belgium, medical professionals in Switzerland are only partly responsible for overseeing/supervising assisted suicide. Hélène, who has no medical training and is not a healthcare professional, must therefore appreciate the position and influence of medical authority in the process, while not assuming it is necessarily homogeneous among practitioners.

This assessment process gives Hélène the chance to verify whether the assistance to be provided is in keeping with legal provisions, existing recommendations, and the criteria set forth by her association: a whole host of factors that very frequently escape those who request assistance in dying. At the same time, the volunteer seeks to position herself as a mediator in a process that involves actors with differing interests and feelings. She has to discuss the very practical aspects of carrying out assisted suicide. Other norms then come into play. The issue is no longer to be viewed primarily through a medico-legal lens; instead, actions are reconceptualized as a ‘pedagogical’ endeavor about death. Such a ‘pedagogy’ stems from the subjectivity of actors, their relationship to death and degree of acceptance of it, as demonstrated through broad, open discussions concerning an array of more or less socially accepted reasons and legitimate provisions that can contribute to understanding, or providing an even stronger basis for, a decision.

Discussions between Hélène and Germaine thus lend themselves to narrating the journey of one’s life, exploring those aspects justifying a particular decision, and gaining confidence. They shed light on the importance of being able to express and display one’s ‘resolve’ and of building a trusting relationship. In talking about her life journey, Germaine spontaneously brought up a number of reasons, which allowed Hélène to get a better idea of the person. Hélène sorted through and ranked these reasons, occasionally probing a few details while offering her opinion on certain statements. Hélène put Germaine’s words into perspective when Germaine defined herself as “no longer good for anything” or claimed to be “a burden to others.” By the same token, she considered that the fear expressed by Germaine to end her life in a care home was borne out of a negative representation based more on fantasy than reality. This fear would not constitute sufficient grounds for requesting an assisted suicide. Throughout the narration, the legitimacy of the will to resort to assisted suicide was constructed and, in turn, strengthened the volunteer’s own determination to perform aid in dying that few people, at bottom, would agree to carry out.

These various clarifications, which might have otherwise limited Hélène’s willingness to provide support, led her to recognize the validity of Germaine’s request. The volunteer thus confirmed her acceptance to provide support to the patient right to the very end. In Hélène’s eyes, the conditions had been fulfilled: there was the presence of a potentially fatal illness and intolerable suffering (that did not constitute a legal criterion per se); mental competence; sufficient motor coordination to perform the final gesture; and in more subjective terms, the feeling of having lived a full, even accomplished, life; acceptance of death and evidence that family members had been adequately informed of her intentions. Hélène also made sure that Germaine’s negative self-perceptions did not
contradict with her expressed feeling of having lived “a full life” or that these self-perceptions did not appear to be the only ‘good reasons’ to resort to assisted suicide. The negative aspects were thus taken into consideration but ‘neutralized’ in the exchanges between the women.18

This pedagogy seems to follow a double logic: the idea of befriending death and constructing meaning. Germaine stated that she was “not afraid of death.” She explained that she had already buried her mother, her father, her son, and two of her husbands. She was ready to accept death because she had the feeling of having lived a full life, with plenty of joy and suffering: “Oh, my life, from moments of rage to moments of happiness!” In describing her hard life and proclaiming her satisfaction from its richness, Germaine more strongly impressed upon Hélène her determination. Her daughter Marie, who also attended this first meeting, reaffirmed this impression by commenting on her mother’s character: “She’s a strong-willed woman [ … ]. She does what she wants.”

After agreeing to be involved in Germaine’s case, Hélène then brought up practical matters of planning the assisted suicide—the second moment that we wish to highlight. She now had to take into account another instance with its own normativity: the group of family members and its internal dynamics (Gamondi et al. 2018; Pott et al., 2014). To attest that ‘best practices’ were followed, volunteers avoided providing assistance on their own. They asked for a third party to be present—usually a family member, sometimes a friend or a neighbor—who could bear witness to the events taking place.19 This is why Hélène enquired about the presence and role of loved ones regarding Germaine’s wish to receive assistance. She therefore took care in updating the information Germaine’s family had and tried to learn how they viewed her plans in order to integrate them as best as possible into the preparations. She made sure to emphasize that the act required courage and explained that their presence then would be beneficial for their own grieving process. The existence of conflict or long-held discord among family members could also be reason enough not to assist or to interrupt the ongoing support process.

Germaine’s situation demonstrates that the volunteer did not impose a preexisting normative framework in the support process. Instead, Hélène drew on a disparate set of norms she had gradually made her own, based on medico-legal recommendations, procedures enacted by her membership association, and her cumulative experiences of suicide support. This combination of norms grounded her ‘pedagogy’ of support and enabled her to assess the acceptability of a request for assistance. Committing to provide such assistance meant assessing the varied normative instances, which must fit together as adequately as possible to prevent legal prosecutions and complications with family members from occurring following the death. The importance of this assessment could clearly be seen on the day the suicide was carried out, the third moment that we wish to highlight. The action of the different actors and professional bodies—the patient, the volunteer, family members, police officers, doctors, coroners, prosecutors, and funeral staff members—fit into a pattern and time-frame that arise from previous practice but are uniquely configured on every occasion.

Even though the choice of time, date, and location of the assisted suicide is left up to the key players, it also depends on a set of practical considerations as to how these key players will coordinate themselves. This synchronization, to a greater or lesser extent successful depending on the circumstances, occurs based on the needs and interests of the different professionals involved.20 In the end, it is the result of a unique combination of normative apparatuses organizationally (the availability of certain professionals), relationally (the presence of certain family members), and socially (significant for the individuals concerned through the expression of their subjectivity): for example, associating the date of one’s death with an important event in one’s life, such as an anniversary or, as in Germaine’s case, the end of the summer, her favorite season. Hélène’s support involved creating the conditions for a compromise among these different normative registers or, in other words, preventing conflict from occurring, which could disrupt how the assisted suicide progressed. Hélène attempted to adapt, as much as procedures would allow, to the wishes of Germaine and her loved ones.

This may be why the adjustments between different, or even opposing, normative constructions underlying the intervention and representations of the various actors mostly surface in public debates and the media, or within the structures, associations, and institutions responsible for defining the boundaries of, and procedures for, assisted suicide. These divisions, nonetheless, are mainly implicit in the realm of actual support, at least in the cases we had the opportunity to observe directly. In short, open conflicts and divided opinions over assistance in dying are mostly expressed in critiques “about” the apparatus, yet are somewhat rare “within” the apparatus.
The day of the suicide itself, the third moment we would like to examine, gives us an opportunity to draw attention to these aspects. While Hélène had emphasized to family members the benefits of being present at this final moment for the sake of their own grieving, some had questioned the soundness of this norm, with regard to Germaine’s brother, the last surviving sibling, who was very close to his sister. Here, the freedom to decide to end one’s life collided with the freedom for family members to decide whether or not they would attend the suicide, an issue that Hélène no longer questioned at this stage of the assistance.

Similarly, all those present during the final act may be summoned as witnesses and are strictly required to wait for the police to arrive before leaving the premises. After Germaine’s assisted suicide, one of her sons in attendance refused to stay, despite Hélène’s entreaties. He told her, “If they’re looking for me, well – I’ll be over at Bobby’s having a pint.” While Hélène did have to mention the son’s early departure to the police officer, he did not pursue the matter. He approached those family members still there and enquired about Germaine’s medical condition. Sarah, one of Germaine’s granddaughters, promptly replied, “But Grandma wasn’t really sick!” This comment met with the disapproval of her parents, who were aware not only of its inaccuracy but also of the undesirable consequences it could have for the assessment of medical reasons justifying assisted suicide. This discordant note, neutralized by the volunteer’s explanations of the medical reasons behind the assisted suicide, drew no reaction whatsoever from the police officer.

The arrival of the funeral director provides one last example of this search for compromise. In cases of assisted suicide, funeral arrangements are often made well in advance. In Germaine’s case, her final wish was to have her ashes scattered in the valley where she grew up; she did not want a tombstone, a ceremony, or an urn. This wish ran completely counter to her daughter’s, who, nonetheless, bided by her mother’s choice, almost down to the last detail.

This brief illustration, emphasizes the importance of a plurality of norms that underlie assisted suicide in practice when it is carried out by associations. These norms are not all formally instituted or codified in the Swiss state and biomedical apparatuses. Rather, they have been developed and are continually adapted in line with the experience of these associations and their interactions with other professional bodies and other actors involved in these situations. In this way, they set the parameters for the volunteers’ assessment when they receive a request for assisted suicide. They help define the arrangements for support based on an understanding of the family context and the person’s life history. Developed over the course of volunteers’ experiences, these norms fundamentally come to embody the legal apparatus. They are flexible enough to be appropriated and give rise—a priori—to a ‘pedagogy of support,’ but also rigid enough to require—a posteriori—a chain of actors to ensure that medico-legal criteria are met.

**Subjectivities and norms for aid in dying: a dialectic to be spelled out for every situation**

The cases of Annabell and Germaine have been reported in somewhat different styles, with varied emphasis on analytical elements drawn, respectively, from observation and research interviews. These differences are, in part, due to the specific features of each field and the ways of accessing it, and, in part, to the traditions and research ethos of the research teams involved. These unique qualities might present difficulties when doing a comparative analysis, but they do not prevent such an analysis. On the contrary, the diversity of approaches they reveal may pave the way for unexpected in-depth analyses, most of which have not been taken up here at all. This article is grounded in very limited empirical data, clearly meaningful to the different contexts in which it was collected but in no way ideal-typical of these contexts. The comparison we conducted, in our view, should primarily be seen as the opening chapter of a broader research project, to which other local experiences, both epistemological and empirical, might now contribute.

Whether we consider the apparatus of euthanasia in Belgium or that of assisted suicide in Switzerland, we can identify a series of similarities in the politico-legal framing of practices, which include the need to have unimpaired mental competence; to be diagnosed with an incurable disease, or to experience intolerable and unbearable suffering on a daily basis; to have tried unsuccessfully and used up all available therapeutic options; to not have been unduly influenced by third parties when making the decision, which must be consistent and hold over time. Far from being exhaustive, this list allows us to assess a certain normative coherence that we will need to examine more closely in this conclusion, while also accounting for the specific features of the contexts in which these practices take place.

Yet despite their many similarities, these apparatuses are clearly different from each other, firstly
concerning the moment in the process where the normative constraint acts most strongly: while in both cases the medico-legal criteria are examined before the suicide is carried out, the relatively blurred view on whether these criteria in Switzerland are, in fact, binding leads to the need for a medico-legal validation at the end of the process, justified on the grounds that an assisted suicide is considered a “violent death”; unlike in Belgium, this qualification requires anticipated normative processes regarding the support, and it involves the intervention of actors, who are not called upon in the case of Belgium (where controls are only made a posteriori by a committee of experts), such as police officers and coroners.

Next, these apparatuses differ from each other in the extent to which the medical professions are involved. In Belgium, the physician plays a crucial role in euthanasia, as evidenced by the central importance of the colloque singulier between the physician and patient, and how the physician is involved in carrying out the final death-inducing gesture. In Switzerland, physicians play a key role from the initial stages by certifying the patient’s mental competence and prescribing the lethal substance, but they are not directly involved in the fatal gesture. The doctor-patient relationship is replaced by one between a volunteer and a person wishing to end her life. The physician then intervenes in the latter stages, as part of the medico-legal investigative procedure.

These two relational configurations condition the arrangement of several registers of normativity. In Annabell’s case in Belgium, the central role played by the medical profession in carrying out her request for aid in dying likely explains that a confrontation between normative stances arises, much more clearly than in Germaine’s case in Switzerland. This confrontation is first observed between the physician, nurses, and psychologist, and then between the nurses and the person requesting euthanasia. The primacy of the relationship between Annabell and her doctor, and the relative exclusion of nurses who, in this particular situation, only take part at the very end of the process, point to a divergence in normative stances in how “care” is defined and what relational timeframe is involved. In keeping with their professional ethos, the nurses express the need to locate the suicidal gesture in the context of a relationship that develops over time. Put to the test in the organizational phase, these are therefore different and even oppositional norms when it comes to relational engagement: thus, the patient’s decision comes, variously, up against the physician’s particular ethics of engagement, the psychologist’s ethics of professional support, and the nurses’ ethics of relation.

This dimension is not at all apparent in the Swiss case, although it may surface in assisted suicides that take place in care homes or hospital settings. This is mainly due to the limited involvement of medical professionals. Indeed, in Switzerland, the relationship primarily unfolds between a volunteer from an association and the person wishing to commit suicide. This form of intersubjectivity leads to a process of adapting not only to other normativities, but also to other models of confrontation. As it happens, associations also bring to bear their own normativity: Hélène, the volunteer, assesses the experiences of the person she is supporting, especially “the feeling of having lived a full life” and “having discussed her plans with her loved ones.” Moreover, she dismisses any of Germaine’s statements about “having become useless” or “being a burden to others.” These discussions thus demonstrate a rapport that fosters trust and sharing, during which life experiences can be exchanged. In Belgium, by contrast, for a euthanasia request to be accepted, the patient, who is never sure to obtain satisfaction, must, first and foremost, convince the attending physician and frame the request in medical terms, bearing in mind the strict legal and ethical boundaries. In Switzerland, the support process is more clearly separate from the institutionalized power structure, which in no way precludes a “diffuse” form of normativity from filtering in (Memmi, 2003, p. 268), perhaps even more so than through institutional bodies, with no guarantee either that the suicide request will be granted.

In Belgium and Switzerland, we observe processes that may be different but still pertain to forms of ‘pacifying’ death. The dynamics of these apparatuses, as such, give rise to what might be called forms of conversion, both individual and collective, of tensions in the face of death. In Belgium, the medical establishment is omnipresent, wielding its authority and roster of specialists, while the law provides a constant backdrop. Management of the process is deeply affected by the institutional order and its many and varied actors. Here, pacifying entails a sequence of rather complex micro-level power plays—a “micro-physics” of relationships. The situation is different in Switzerland, though, where the relationship is legally framed from the beginning of the process but then “filtered out” of a context seen as overly institutional so that it can develop in a less hierarchical, less heterogeneous space. As a result, the family would remain the only source of normative discord.
We have attempted here to draw comparisons between micro-systems of normalization and to analyze what they reflexively elicit in order to understand their unique features better and to identify their broadly common traits. The sociology of aid in dying that we are proposing takes as its primary focus the processes of normalization that structure this kind of assistance. Normalization takes place through a set of apparatuses, which we can, at least in part, categorize as follows: State normativity (the legal framework); the normativity of various professional bodies; organizational normativity; discursive normativity—aid in dying having its own specific vocabulary and performativity, while being grounded in, yet revealing, its own anthropology; the normativity of the relationship to the body; technical normativity; relational normativity, which underlies the relationships that develop between those requesting aid in dying, healthcare staff, and volunteers, not to mention family members and friends. These normative sets fit together and adjust to each other. The resulting arrangements are specific to each national context and design a specific normativity of death, which could be defined as an apparatus of apparatuses. By analyzing these designs, the ultimate goal of this research program would be to define the new paradigmatic forms taken by aid in dying in the contemporary era.

Notes

1. To account for the specific features of each political/legal context, we adopt the terminology used in each country for our ethnographic descriptions (i.e., “assisted suicide” in Switzerland and “euthanasia” in Belgium). When we put national practices into perspective and/or do not differentiate between them, we use the preferred generic term, “aid in dying”.

2. For Switzerland, the research team included Marc-Antoine Berthod, Dolores Angela Castelli Dransart, Alexandre Pillonel, and Anthony Stavrianakis. It conducted the study, Appreciating Death: An ethnography of assisted suicide in Switzerland, funded by the Swiss National Research Foundation (Project no. 169367, September 2017–October 2020). For the Swiss case presented here, we had the opportunity to meet Germaine through the EXIT A.D.M.D. Association for French-Speaking Switzerland. In April 2018, we followed her volunteer, Hélène, and the researchers were able to attend Hélène’s first meeting with Germaine and her daughter, who were living together. We later negotiated the following arrangements with Germaine: first, to conduct several interviews and exchanges with her (twice), her daughter (twice), and other members of her family (once); and second, during these different meetings, with the consent of everyone involved, to be present at the actual assisted suicide (in August 2018). For Belgium, the team included Guy Lebeer, a sociologist specializing in the study of the political structure of medicine through new democratic practices and medical ethics, and Natasia Hamarat, working under Dr. Lebeer’s direction and conducting a socio-ethnographic inquiry into the construction of the practical legitimacy of requests for euthanasia in hospitals. Her doctoral research was funded by an aspiring-researcher contract from the Belgian Scientific Research Foundation (F.R.S.-FNRS, 2014–2018), Euthanasia “in action”: A sociological analysis of a practice under debate (Centre METICES, Université libre de Bruxelles). In the context of this 24-month inquiry, carried out in two Belgian continuing and palliative care hospital units, Hamarat interviewed and conversed with Annabell during her hospital stay. The researcher observed and documented discussions in the healthcare team about Annabell’s medical condition throughout her hospitalization up until the day she died.

3. Importantly, Swiss federal law “does not include the existence of ‘a right to’ assisted suicide” (Mauron, 2018), whereas in Belgium, euthanasia legislation stems from a process of putting the issue of patients’ rights on the political agenda. In fact, the Law of 28 May 2002 on euthanasia, the Law of 14 June 2002 on palliative care, and the Law of 22 August 2002 on patients’ rights must be analyzed together in how they were developed in a context of institutionalizing a more democratic management of bio-medicine, identifiable at all levels of the healthcare system (Genicot, 2010). In the end-of-life realm, social demands are mainly focused on rejecting therapeutic obstinacy and come from both the palliative care movement and the aid-in-dying movement (Bernheim et al., 2008). At that time, the issue of euthanasia was placed on the agenda by various organized medical, legal, association, and political actors, in particular, from 1982, the A.D.M.D. (Association for the Right to Die in Dignity) of Belgium and from 1983, its Flemish counterpart, Recht op Waardig Sterven (R.W.S.). Following the federal elections of 13 June 1999, the setback of the Social Christian parties, relegated to the opposition for the first time since 1958, presented a real opportunity to initiate the legislative process on this issue (Dobbeleare & Voyé, 2015; Hamarat & Lebeer, 2019).

4. Law of 28 May 2002 on euthanasia, Moniteur belge: https://www.ejustice.just.fgov.be/cgi_loi/change_lg_2.pl?language=fr&nm=2002009590&la=F (retrieved April 23, 2021).

5. Since 2014, the law has been extended to minors (without any age limit), only in situations of constant and unbearable physical pain; the youngsters must be “mentally competent,” as attested by a child psychiatrist or psychologist, and the legal guardians must have agreed for the act to be carried out (art. 3§7).

6. The attending physician must also assess whether or not the death will occur “in the short term/brève échéance” (art.3§3). While the law does not define “short term,” leaving it up to the medical practitioner
to decide, a short term is not the case if death is clearly not expected in the coming months. If death will not occur “in the short term,” a second independent physician, psychiatrist, or specialist of the pathology in question must be consulted (art.3§3.1) and a waiting period of at least one month must be observed between the time when the patient’s written request is made and the time when the euthanasia is carried out (art.3§3.2).

7. See especially Lossignol (2014) and Englert (2015).

8. Although euthanasia can be carried out on weekends, particularly in the patient’s home, by general practitioners who might prefer to be free of their regular professional duties, this is not the norm in hospital settings, where euthanasia is generally performed on weekdays.

9. While the term “string-puller” could refer to those personal qualities needed to carry out one’s plans for euthanasia abroad (strategies for getting around the legislative restrictions in one’s country of residence), here it is used to emphasize the fact that the patient adopts an instrumental attitude towards her relationship with the healthcare team when making her euthanasia request. In this case, it echoes the notion of “peculiar personality” and refers to manipulative actions, or even manipulate personalities, in contexts where the category has been objectified by psychologists and/or psychiatrists, or in situations where the healthcare team disagrees with this objectification.

10. Unlike suicide, this category does not jeopardize life insurance payments.

11. The CFCEE is comprised of 16 members (eight physicians, four of whom are university professors, four jurists, and four members “from settings dealing with issues of severely ill patients”). Linguistic parity and pluralistic representation must be ensured. Every two years, this Commission is supposed to provide the Belgian Parliament with a descriptive report and, if applicable, recommendations for practice. These reports are available at: https://organesdeconcertation.sante.belgium.be/fr/organe-d%27avis-et-de-concertation/commission-federale-de-controle-et-devaluation-de-leuthanasie (retrieved April 23, 2021). These associations are statutorily non-political and non-religious. In French-speaking Switzerland, the association with the largest number of members is EXIT A.D.M.D. Suisse romande.

12. Some French-speaking cantons, such as Vaud, Neuchâtel, and Geneva, nevertheless, have enacted legislation related to these matters, although not with a view to guaranteeing a right, but rather to defining conditions of access to assisted suicide for residents in publicly subsidized care homes.

13. The situation is more complex when professionals are involved, in particular if the suicide must take place in a care home (Castelli Dransart et al., 2015, 2017; Pillonel et al., 2019).

14. The lack of clear guidelines concerning the period of validity for assessments of mental competence (from six months to one year, depending on the information source) is a typical example of a norm coming to be constituted, a fluctuating definition constructed according to forms of logic and interests specific to each professional body involved in the apparatus of assisted suicide.

15. Assisted suicide is most often practiced by ingesting a lethal substance taken either orally or intravenously.

16. It should be noted that there is a range of stances within the assistance-in-dying associations themselves. Some volunteers do not consider either the medico-legal recommendations or the importance of forming a relationship with the person as necessary. Conversely, others emphasize the importance of either or both factors as absolutely essential for assistance to be provided.

17. While this was not a problem in Germaine’s case, it has arisen in other situations. Vinciane, an 88-year-old woman living in a care home in the canton of Vaud, had her request for assistance turned down following an initial interview because the volunteer assessed that the woman did not have an incurable disease and was not experiencing unbearable pain, therefore did not qualify for an assisted suicide. The association’s medical advisor, however, had given the green light for assisted suicide in this case.

18. In some cases, depending on the association, volunteers who find themselves alone are able to film the suicide to demonstrate to the judicial authorities that the assistance provided was in keeping with legal requirements.

19. A family member in the home, but standing in a room next to the one where the lethal substance was being ingested, would not be held to the obligation of taking part in a police interview.

20. This point must be observed when the person requesting assisted suicide is residing in an institution subject to cantonal legislation that stipulates it. However, when the person is living at home, the exploration of therapeutic options will depend on conversations held with the volunteers.

21. The medicalization also has an impact on where these practices take place. The Swiss model promotes assisted suicide in one’s home. By contrast, the Belgian model looks to the health care institution for carrying out euthanasia. The hospital thus becomes the very site of dominant normativity – even though more and more acts of euthanasia are taking place in patients’ homes.

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