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Imagining terminality: anticipations of suicide with assistance in Switzerland*

Imaginarse la terminalidad: anticipación de suicidio asistido en Suiza

ABSTRACT

This article explores how people who solicit assistance in dying imagine and anticipate their own terminality. Its objective consists in describing and interpreting the fact that these individuals go beyond their medical condition when commenting on such a request and on their engagement in this process. Based on an ongoing ethnographic inquiry funded by the Swiss Science Foundation and carried out in Switzerland, where assistance with suicide is permitted within a unique legal framework, the article shows the importance of taking into consideration the role that affective and imaginative internalized contents – imagination, broadly conceived – play in the realization of assisted suicide. These contents are key to appreciating a decision to request to die with assistance as well as its justifications.

Keywords: Death – Assisted suicide – Ethnography – Imagination – Switzerland

RESUMEN

Este artículo explora como personas que buscan asistencia para morir imaginan y anticipan su propia terminalidad. Su objetivo consiste en la descripción y la interpretación del hecho de que estas personas superan su condición medical cuando comentan tal busca y compromiso en este proceso. Basado en un estudio etnográfico financiado por el Fondo nacional suizo para la investigación científica y realizado en Suiza, donde el suicidio asistido está permitido gracias a un marco legal único, el artículo destaca la importancia de considerar el papel de contenidos afectivos y vinculados a la imaginación que se interiorizan durante el proceso de suicidio asistido. Estos contenidos son claves para apreciar la decisión de solicitar una muerte asistida y su justificación también.

Palabras Clave: Muerte – Suicidio asistido – Etnografía – Imaginación – Suiza

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n this article, we explore the imaginative contents conveyed in the narratives of persons who are involved in the completion of assisted dying, and of those who are in the process of requesting such assistance. We seek to track the ways that people forge their decision to end their life in this manner and the ways they imagine, accordingly, their own terminality. Our suggestion is the following: that the ways in which a person, who is about to end her life with the assistance of others, imagines the place and time of dying demands attention; it might even be key to appreciating such a decision to request to die with assistance and it may form part of its justification. With this suggestion, we intend to broaden the scope of works that attempt to grasp the rationale underlying this practice. To this end, we do not set the focus on the role of the biomedical condition in the dying experience (Bataille, 2003; Papadaniel, Brzak and Berthod, 2015) nor more specifically in the decision-making procedure (Gamondi et al., 2015); neither do we target the influence played by actors of the medical field (Kaufman, 2005) or the family members (Zala, 2005). In an original manner, we highlight instead the role that imaginative contents play surrounding such a decision.

We draw our material and reflections from an ongoing ethnographic inquiry funded by the Swiss Science Foundation and carried out in Switzerland, where assistance with suicide is permitted within a unique legal framework, which we will present. In this research, we try to describe as concretely as possible the realities of the practice of assisted suicide in this country. We conduct observations and interviews – formal and informal – in relation to a series of requests to die with assistance, up until the completion of the suicide and the recovery of the dead body. For each situation, we meet with the individuals – to the extent possible – who take part in the process: volunteers working for right-to-die associations, professionals and warrantors of the medico-legal framing, as well as relatives. We also meet - the number of encounters vary considerably according to each situation that last approximately from one week to several months - with the persons who are about to complete suicide with assistance as soon as they have formally asked for it and until the final gesture, if possible. Between September 2017 and the time of writing (June 2019), we have documented or are still documenting a dozen situations (among which six have been completed). We furthermore observed twenty on-the-scene corpse examinations and realized more than sixty interviews with right to die association's volunteers and employees; health professionals; policemen; pharmacists; prosecutors; family members and proxies.

To sustain our argument, the article is structured in three parts. First, we discuss the notion of imagination in regards to terminality. It is noteworthy that imagination is not conceived in our approach as a definite concept. It is rather associated with affective and imaginative internalized contents that have real effects, realized in the mise-en-scène of desire (conscious and unconscious). These imaginative elaborations might be then expressed through verbal images that possibly communicate a personal desire or choice (Barthes, 1975; Stavrianakis, 2017; 2018). Second, we mobilize our empirical data underscoring not only the importance of memories of past end of life experiences, but also of visualizations of landscapes, ambiances and places in our attempts to interpret a decision to request dying with assistance. In our third section, we conclude with a discussion of the interplay between these temporal and spatial



dimensions characterizing part of the imaginative contents that potentially underlie such a decision.

Envisioning terminality

What are the personal, biographical, historical, social, inter-subjective, conscious and unconscious vectors, to name but a few, that parameterize the experience of the here and now for the persons who ask for assisted suicide and are in the process of fulfilling such a request? To answer this question, we have endeavored to observe and describe, and then to try and analyze the 'imaginative horizons' – as the anthropologist Vincent Crapanzano puts it – that extend the experience of reality "into that optative space or time – the space-time – of the imaginary. It is this realm that gives us an edge, at times wrenching and painful, at times relieving and pleasurable, on the here and now in all its viscous immediacy" (2003, p. 14).

In this perspective, the imaginative horizons correspond to the constantly flowing boundaries and frontiers underlying and shaping one's sense of being present at a certain place, at a certain time, taking up that moment within a specific narrative mood; Crapanzano names the optative, but of course we must be open to the range of moods through which imaginaries are forged, the subjunctive and future perfect being two key registers (Rabinow and Stavrianakis, 2019). They refer to both movements of estrangement and of communion with what is experienced, perceived and thought. Briefly said, they open up people's subjectivity and sensibility to projections, dreams or utopias regardless of their stimulating, delusional or frustrating effects.

Crapanzano (2003) relates these imaginative horizons to the trope of the arrière-pays – the hinterland, the beyond, the elsewhere – developed by the French literary critic and poet Yves Bonnefoy (2005). In his writings, the latter introduces a pleasurable or creative, exciting or tense play with the uncertainty and the uncontainability of the ordinary course of existence.¹ Through references to pictures or narratives and words about homes and sceneries, Bonnefoy generates an intimate relation between an imagined place or a landscape and the actual presence in the here and now, especially at crossroads where choice arises.

"The beyond is like shadows – the ombres to which Bonnefoy frequently refers: it cannot be contained" notes Crapanzano (2003, p. 16). Interestingly, this very idea is nicely illustrated in the work of another writer and critic, André Aciman, especially in his short text Shadow Cities (1999). Here the author transposes landscapes of cities and places he used to love but had to flee over his life course into narratives of New York City where he lives now. These descriptive and imaginative overlaps of places and lieux are experienced in fleeting moments on street corners or squares. For instance, they give consistency and sense to the ordeal of exile. With these references, we would like to stress the fact that the trope of the arrière-pays gives priority to geographical features over the characteristics of another notion to which it is always closely linked, the notion of time.

¹ On this notion, central to Bonnefoy's work, see also Buchs (2003).



In relation to assisted suicide, we argue that these 'imaginative horizons' play an important role, even more so when a person comes to figure out, or try to grasp, her own terminality. As the anthropologist Abou Farman states convincingly, there is nowadays an injunction to identify what time is left when someone is dying. During the past few decades, this metric temporal dimension – a number of months, weeks or days that are left – became the necessary standard that any concerned person ought to take into account in order to confront death openly and explicitly with the medical staff: "Time has become the key subjective experience of terminal illness" (2017, p. 98); it follows that "the terminal body is a body that ticks with the sound of its own end" (2017, p. 99). Farman's arguments challenge this statement and undermine the normative assumption following which the amount of time left before dying should be specified and recognized as such. This assumption would leave the impression that "terminality requires a body whose time is limited to itself only; it requires not a body in (or even out of) time but a certain kind of time in the body" (Farman, 2017, p. 101).

It is after World War II – the anthropologist states – that studies really started to look at the "stamp of time on the organism. [...] A lifetime comes to mean something very contained, numerical, measurable, and, most important, tending to an inexorable, biologically fixed end, or what Pearl called irreversible time" (2017, p. 103-104). This principle became constitutive of the notion of finitude that prevails today in ordinary medicine; it precludes any idea of eternity or transcendence. For Farman, this measurable time at the end-of-life is "a precondition of terminality" (2017, p. 104). From a scientific perspective, biologically or medically speaking at least, the ideal of managing life and organisms corresponds to a forever ticking of time or, even better, to the mastering of the stop and go of an eternal ticking. The anthropologist continues:

the statistical, cellular, and genetic techniques make time manifest in the body as biological and biotechnological processes. Through prognosis the biological and the temporal have become thickly entangled such that biological crises get translated into temporal crises (Farman, 2017, p. 105).

Consequently, the biomedical conceptualization of time appears as a positioning factor for the sense each person makes out of an end of life situation and of its evolution. During the dying process, physicians, health professionals, patients and their proxies might be influenced by this linear, measured and ticking idea of time. But it doesn't mean that every individual conceives in a similar way how such situations will or should end, when it comes to taking a position, to justifying an action, or to arguing for a decision, in each moment of the dying process. Divergences on the optative unrolling of end-of-life scenarios might nurture the feeling that things are happening too fast, or too tardily; that a request for aid in dying should occur in a timely fashion, i.e. when all relevant dimensions and issues related to the concretization of the final gesture have been collectively pondered and discussed.

Biomedicine, in Farman's view, has shifted the way we are apprehending death from a social and moral perspective to a temporal one. Farman reaches the climax of his excessively totalizing diagnosis in the claim that quality of life is determined within a temporality that is



constantly estimated and (re)evaluated until death occurs so that "terminality is the underlying condition of the politics of life" (2017, p. 106). To sustain his argument, Farman's article mixes theoretical approaches towards end-of-life and a personal experience of accompanying his partner and late wife, the artist Leonor Caraballo, who suffered from breast cancer and passed away in 2015. It is on the latter register that, anthropologically, we are able to grasp the problematization of illness, proposed biomedical intervention, and time, without making an epochal diagnosis: "she didn't want to die, but she knew what she was doing. She didn't want to exchange her creativity for a couple of months more of dull-bare life" (2017, p. 110).

In fact, while considered in a 'terminal stage' from a biomedical point of view, since 2013, she went to Peru to shoot a movie against the recommendations of her doctors, an attitude about which Farman makes the following comment: "to forego treatment is to be viewed as suicidal or, worse, stupid. To break the mirrors, to be a pharmakonoclast, is to become morally suspect or, worse, a hippie." (Farman, 2017, p. 109). And he notes: "she was an anti-terminalist, discussing the edit decisions on her deathbed" (2017, p. 110-111).² She was essentially escaping – or more accurately – not following the biomedical efforts to fasten uncertainties of dying and its experience to strict temporal measurements and probabilities. Her attitude could be said to have instantiated what Stavrianakis (2016) has elsewhere characterized heuristically, in relation to Durkheim's classic model of types of social virtue connected to suicide as a social fact, as an obstinate mode of counter-social conduct.

In line with this perspective, we argue that assisted suicide at large denotes a similar detachment from the bio-political end-of-life script, a script in which authorized experts link the management of bodies and lives to knowledge of sick populations. This is revealed through many heated political debates on the subject that led a few countries in these past two decades to progressively recognize a (so-called) right to die and adapt their legislation accordingly.³ This detachment, however, is not so self-evident. Being able to choose the date of one's own death is frequently invoked as the inexorable justification for helping someone who wants to end his life. When considered as echoing genuine autonomy, the notion of choice remains consequently and intrinsically linked to a linear conception of time: suicide will put a full stop to the ticking of time imposed on terminal bodies. Deciding the very moment of his own death might appear then as the paradigmatic expression of the individualistic desire to control everything until the very end. Those who sustain this conception would then be prompted to interpret this desire to end one's life with assistance as a mirroring consequence of the biomedical normalization processes characterizing terminality. If so, choice becomes essentially a matter of time.

We need however to be cautious in thinking that there is above all a desire to take control over the dying process or, more passively, not to leave this control in the hands of biomedicine. To focus on the importance of time in requests of dying with assistance can be

³ Inbadas et al. (2017) mention The Netherlands (2001), Belgium (2002) and Luxembourg (2009) as having legalized euthanasia; Canada (2016) has a federal law allowing medical aid in dying; some States within the United States (the first one was Oregon in 1997) also have legalized physician assisted suicide; Switzerland who does not prosecute those who assist a suicide as presented in this article, and Colombia who has a similar arrangement. We can add Australia to this list, as the State of Victoria legalized assisted suicide, starting mid-2018, See Baidawi (2017).



² Icaros. A vision by Leonor Caraballo and Matteo Norzi. Available on: <u>www.icarosavision.com</u>. Consulted on: 05/27/2019.

misleading as it can mask the role that the notion of place – the arrière-pays mentioned earlier – plays in the decision-making process and in the conception of autonomy. Attention to the imaginary of assisted suicide allows other tempos, other temporalities, into the here and now of a request for help to leave life.

If we listen carefully to what individuals think and say about their own death and the perspective of putting an end to their life, we see that the determination of the date is only collateral to the perceived bio-medical conceptualization of time. Their discourses and narratives include imagery of lieux and not only time. We think it gives a better understanding of people's motivations and justifications when the request for assistance with suicide is produced with the aid of the trope of the arrière-pays, which leads us beyond the sole bio-medical rationale for assistance with suicide.

Imaginative horizons of assisted suicide

To illustrate and discuss this hypothesis, we will now draw empirical data from our ongoing research entitled Appreciating Death. Ethnography of Assisted suicide in Switzerland that started in September 2017 and runs for three years. To situate the narratives we are referring to, it is noteworthy to give first of all some information about the context that they stem from. Assisted suicide is a form of death that represents only a small percentage of the overall deaths in Switzerland. For the year 2016, the Federal statistical office registered 928 assisted suicides for a total of 64'694 deaths (1.43%).⁴ The way it is practiced in this country is unique in its form, as it is not a right and does not depend on the patient's condition being medically declared as terminal. Happening most of the time at home, this act is not punishable if and only if the person who ends her life makes the final gesture herself and if the accompanying individuals - generally organized by right to die associations⁵ - do not act on selfish motives (article 115) of the Swiss Criminal Code). Four cantons - Vaud (2013); Neuchatel (2014); Geneva (2018); Valais (2019) - established however their own legislation, mainly to force publicly subsidized facilities (hospital, nursing home) to consider and evaluate within their walls a request for assisted suicide as far as the above conditions are met. For the rest, various committees and professional corporations – mainly from the medical and ethical fields – and of course right to die associations edict their own recommendations and protocols to ensure that the act is performed according to the federal legal frame, one that gives ample room for interpretation.

In this context, the legal conformity of the procedure is always attested and evaluated, after the person has died, as it is not considered a natural death but a 'violent death'. This categorization is at times contested and doesn't really match the perceptions of 'right to die'

⁵ There are less than a dozen such associations in Switzerland; they are privately run, apolitical and secular. They do not perceive public funds for their activities. For our research, we mainly worked with the main association active in the French-speaking part of the country – EXIT Suisse romande – that helps persons who reside in Switzerland only, and with another one - lifecircle (Eternal SPIRIT Foundation) – established in the canton of Basel, that accept also foreigners.



⁴ This number also represents the 47% of all the suicides registered for the same year. Cf. Swiss Health Observatory. Available on: <<u>https://www.obsan.admin.ch/fr/indicateurs/suicide</u>>. Consulted on 05/27/2019.

actors and even those of the persons who request to die with assistance. It is worth noting here that the institutionalization of death and dying – at least when established through state regulations – does not concern the request nor what is happening before suicide. It is consequent to such a categorization that a criminal procedure is necessarily undertaken, to verify that any given assisted suicide was realized according to good practices and did not infringe the legal requirements.⁶ As a result, police officers are called right after the suicide to take a deposition and a medical examiner comes on site to check the body; to take pictures in case a prosecutor would later ask to further investigate the situation; as well as to establish the death certificate. These professionals, as well as right to die associations, see this procedure as the warrant of good practice; in this regard, some consider this control as effective in stopping abuses and a means to prevent a descent onto the commonplace of a slippery slope; some professionals and associations deem this postmortem procedure valuable as it protects a possible manner of dying that currently exists in a minimal legal framework – dying with assistance is not a criminal offence as far as the conditions are met – a framework the Swiss Confederation is in no rush to augment.

According to these specificities, it seems valuable to explore and discuss some of the imaginative contents conveyed in the narratives of persons who are about to end their life with assistance as well as those of accompaniers, professionals or family members involved in the process. We can first take up contents related to spatiality, through conceptions of mobility and immobility as part of the 'imaginative horizons' that play an important role in explaining or justifying a request to die with assistance. Manon for example, who has been volunteering for the 'right to die' association EXIT in the French speaking part of Switzerland for about two years, has accompanied various persons in their suicide once every two months on average. She states this point clearly when explaining the components at the root of her commitment. Two aspects stand out. The first one is associated with Manon's ordeal with cancer. Four years ago, she was diagnosed with an aggressive brain tumor and had to undergo a risky surgery. At that moment, she explains, "I became aware how important it was that someone, without judgment, could listen to me saying 'I want to die'. But nobody listened to me. Immense aloneness."⁷ Manon felt guilty nurturing such a wish that was in fact linked to what could occur during and after the surgery:

If I had known I had an association like EXIT behind me, I would not have had this feeling. For afterwards, basically, if the surgery had gone bad. At that time, I wished I could have heard: 'we understand your wish [to die]. If things go wrong, we [the right to die association] will be there for you'. This strengthens the wish to be alive!⁸

⁸ Interview conducted by Marc-Antoine Berthod with Manon, Geneva, September 14th 2018.



⁶ Article 253 from the Swiss Criminal Procedure Code, 'Unnatural deaths', first paragraph: "If there are indications that a death did not occur naturally, and in particular indications of an offence, or if the body is unidentified, the public prosecutor shall order an inspection of the body to be carried out by a specialist doctor in order to establish the cause of death or to identify the body" Available on:<<u>https://www.admin.ch/opc/en/classified-compilation/20052319/index.html</u>>. Consulted on 05/27/2019.

⁷ We translated all our informants' quotations from French into English.

Manon feared above all being in a vegetative state: "with my surgery, no problem if I had died. But there is the fear of being buried alive, i.e. being in a coma and feeling everything. This is what I feared. I don't understand that physicians minimize this aspect." In our view – even though in this specific case dying with assistance would not be possible, because in Switzerland the person needs her capacity for discernment until the final gesture – this visualization of being 'buried alive' – being without any agency – might nurture the idea and even the motivation to request such assistance; it justifies such a thought in Manon's narrative, as it appears as a way to prevent experiencing such immobility. Other people convey the same fear too. Lauren and Quentin for example, two staff members working for the association EXIT A.D.M.D Suisse romande, said respectively: "being trapped in his body and having his full mind, this must be terrible" and, "if I project myself, the worst is not being able to move". These evocations of indeterminate immobility push forward projections and anticipations, among which those of assisted suicide. Interestingly, they highlight spatial features – through the notion of immobility – embedded in temporal ones, the potential durability of this condition for example.

To a lesser degree, this fear pertains to the same register as the one expressed in narratives describing someone laid in a bed or in a chair within the walls of an institution. Not as radical as the vegetative state but more common and more diffuse, the fear of endless agony is solidly anchored in narratives of many people who recall past histories of a loved one's death.⁹ Manon – and this is the second salient aspect of her comments about her commitment – started our interview spontaneously with a reference to the death of her mother in law: "she died in palliative care; her agony was too long [...], very difficult. The proxies have their responsibility in the process: to resist, to resist as long as possible". These imaginative contents refer here to the idea of not letting die, associated with an institution where people at the end of their life are taken care of. This situation appears as 'worse than death' itself.

This expression echoes the one detailed by Jared Stark (2018). This literary critic endeavors to understand, in broad terms, the emergence of new forms of anticipations of death and the connection of such forms to processes of dying in contemporary societies. He reminds us that, not surprisingly, the timing of death has increasingly become a matter of choice. This is linked to the fact that – as Stark argues – imaginative contents of death and dying, especially those conveyed in literary works in his case, tend to make long lasting end of life situations appear as worse than the occurrence of death. To sustain his argument, he refers to the work of the camp survivor Jean Améry¹⁰ who makes parallels between hospitals, their couloirs and halls, and the standardization and industrialization of death is the fear of not being permitted to die – that is, of an ongoing exposure to the worse than worse" (2018, p. 138). If

¹¹ During one session receiving chemotherapy treatment, Emilie is listening to Mozart. The patient next to her ask her if she is listening to classical music. Answering positively, the other patient says: "You're right, Hitler was doing the same thing in the gas chamber". This association of two musical ambiance or environments, of the Nazis death camps and chemotherapy treatment in hospital arise as a negative imaginary that led in part Emilie to become one year after her treatment an accompanier for right to die association.



⁹ Within our research team, Stavrianakis (2018) pointed out the importance of these past experiences of death and dying within the narratives of persons who are requesting dying with assistance.

¹⁰ Jean Améry is a concentration camp survivor who published various books on the victim's condition and suicide, among other themes, and who ended his own life in 1976.

so, vivid impressions of staying and waiting for one's own death in these places operate in the background. They sustain the determinate refusal to experience living in such a condition in the future. Germaine shared her views with us, in line with this perception. We met her three times – two times in the presence of her daughter – a few months before she ended her life with assistance in August 2018, a moment we also were able to participate in. Germaine had cancer; three years ago, which also corresponds to the period when she became a member of the 'right to die' association EXIT, in her early seventies. She was also diagnosed with Alzheimer's disease. Helen, the accompanier from EXIT who was following her, told us that Germaine feared a degradation of her illness, which would potentially lead to the loss of her capacity for discernment and annihilate the possibility of requesting her help.

During our first meeting, Germaine described some of her life experiences, and family relationships; most of her close relatives are said to agree with her decision. And after Helen explained the procedure to be followed, especially on the chosen day, Germaine, in agreement with her daughter, highlighted how lucky people in Switzerland are to be able to request such of form of dying, by contrast with other experiences they have known with their own parents or heard about in various narratives: "it must be horrible to be stuck in an armchair for ten years!" She also says that she does not fear death: "it's not a big deal to drink something and pass away". Basically, she feels exhausted all the time and does not want to live anymore, especially as she can hardly walk now because of her hip pain, which limits her ability to visit family members. The prospect of being immobile for a long time is expressed here through an explicit image that nurtures, even partially, her desire – here and now – to end her life with assistance.

Let us take another situation. Aldo, who completed suicide with assistance in spring 2018 at the age of 79, was very clear about how he approached his own death. During our meetings two days before his death, and even half an hour before drinking the lethal substance – as we had the opportunity to be present when he completed his suicide with the help of EXIT – he emphasized the negative inklings experienced during the agony of his wife, who suffered from three different cancers and died in a nursing home. When asked about staying in a similar place rather than ending his life with assistance, he answered: "This is horrible, absolutely not. My wife stayed there for three years and four months". Describing himself as a "lone wolf" when justifying his constant refusal to receive help from medical and social services in his daily life, he added quite surprisingly about ending his life in an elderly care facility: "no, otherwise I would throw myself under the first train".

This association with violent suicide denotes a differentiation from what Aldo is about to undertake imminently with the help of EXIT. The refusal of enduring a prolonged institutional death, of any kind, is buttressed by the perspective of a peaceful and instantaneous death provided by the assistance in suicide, about which we will come back to in our last section, a death that expresses an individual response in reaction to the fear of dying 'there' (in an institution). The anticipation of living like his wife within an institution seems timeless. But the duration of the stay is not the only issue: the living condition that it indexes is also one. This principle appears similarly in his narrative when he commented on his feelings about having a fixed date to end his life: "I am very happy. Life is a marathon. I will finish it on Friday. To have



a fixed date is a relief. You know, I strike out every day on the calendar". Again, the imagery in Aldo's narrative is about a process with an explicit end. The notion of time is not associated with the performance of the marathon, and not with the quality of the final hundred meters. It is linked to the visualization of waiting at the finish line, creating thus an expectation that conditions the temporality of assisted suicide to a situational representation of death as an act, not dying as a process.

In the same line of thought, we can add that, on certain occasions, the ambiance at the deathbed can interfere with such a peaceful representation of death. Our meeting with Laura is exemplary in this regard. Laura is a 77 years old woman from the French upper class, who moved from Paris to Lausanne five years ago for one unique reason: to live in a country that allows her to end her life with assistance. Her cancer has spread for the last twelve years in different organs of her body, despite countless medical attempts to get rid of her sickness. But Laura's decision to realize an assisted suicide is not correlated to the first appearances of cancer. She points out the fact that she already had taken that decision long before, as a principle of autonomy as much as a solution for not suffering. Briefly said, to keep pain at a distance in her ordinary life.

Here again, the 'when' matters less than the anticipation of the mise en scène of the suicide. Laura considers the preparation of her own death as a very practical and everyday issue; as something we can laugh about even. But, as she indicates, this appears not to be the case for her children, who perceive her decision as an "horrible story". She consequently fears her children's presence when she will accomplish the final gesture, as their potential overwhelming reactions could jeopardize her project. This leads her to this thought: "They won't attend. I won't tell them when either. Because I believe they would spoil my own death, that's the thing. They will cry and I won't endure it. [...] We never know. You don't know how this will degenerate".¹² In this sense, as Aldo does and other persons we met, Laura – in accordance with the way she says she has lived her life – imagines her own death more in relation to an ambiance or a social environment, rather than focusing on controlling time.

The examples we put forward so far in the narratives of our informants indicate negative dimensions as they contrast with a conception of temporality supposedly oriented by biomedicine. There are, however, also positive contents in relation to death in their discourses and explanations. The latter often underscore the relevance of a 'proper death' and its mise en scène. Undertakers, coroners, policemen and also prosecutors evoke aspects of a 'comfortable death' in opposition to other situations they have to deal with: the relatives are prepared, sometimes even present; the clothes for the deceased are folded on a chair; all the documents are ready to hand out to the professionals. Dying with assistance is perceived as more peaceful and cleaner than dying by suicide through violent means.

These graphic arrangements are also very present in the justifications mentioned either by persons who consider requesting suicide with assistance or by acquaintances who report

¹² Interview conducted by Alexandre Pillonel with Laura, Lausanne, October 17th 2018.



stories they have heard on this subject.¹³ A prosecutor we met, Igor, reflecting on his personal opinion regarding assisted suicide, used an expression that conjured a situation of dying whose contours concerned not the timing that such an act enables, but concerned the setting in which it takes place: "A friend always mentioned how he wanted to die: in Greece, laying back in his Le Corbusier chair, in front of the ocean." Such spatial idealizations epitomize precise visions and desires concretely expressed by the persons who are about to absorb the lethal substance and try to die in a specific position, or ask to open a shutter to benefit from a better view.¹⁴

Appreciating death

Focusing our attention on the importance of an imaginary of space in the narratives of persons involved in the process of dying with assistance should not be seen as a way to occult the notion of time and its importance. Our intention consists in suggesting that the priority between time and space might be reversible in the ways 'imaginative horizons' are operating in sustaining and consolidating motivations, justifications or explanations towards assisted suicide: here space – lieux – predominates and parameterizes the manner in which time is taken up and reflected upon. It sets back the body in a certain conception of time, as Farman (2017) would say. To put it briefly, envisioned terminality in assisted suicide is very secondarily associated with a 'bonus' of time, or days to be gained. Aldo still enjoyed daily pleasures, like watching sports on television. But those pleasures meant nothing in regard to what Aldo wanted to achieve first and foremost: ending his life with assistance.

To postulate this reversibility, nevertheless leaves a question open: is it specific to assisted suicide? Our last section will try to open some paths for inquiry. Within our research team, Anthony Stavrianakis has begun to explore the notion of desire instead of choice – the latter being more easily linked to the control of temporality as we have shown – in the process of dying with assistance. Through his participant-observation based inquiry, he gradually came to see that the desire to end life in this way constituted a specific element of the assemblage of people and things that constitute a request for, and realization of, an assisted suicide, an element that is non-isomorphic with judgments of need, or practices of negotiation (Stavrianakis, 2018). Images of a desire, the assemblage of signs that underlies an actual desire to die with assistance, are constituted in the desire to know desire, borne by all who participate,

¹⁴ For further developments on postures and gestures, see Stavrianakis (2017); for a broader perspective on images, dying and death, see Thomas (2016).



¹³ On Friday August 17th 2018, the newspaper *Le Temps* published the story of Jacqueline Jencquel who comments her decision to die with assistance on January 2020. One of her sons is said to make a documentary on her last year of life until her suicide. Entitled 'Mourir encore belle, I'an prochain', the article mentions the difficult agony of her grandmother, who died at 38 from cancer, as related by her mother; then it quotes Jacqueline's words regarding the institutionalization of death: «I devoured life, I don't want to be spoon fed» [our translation from French]. About the scene of her death, it is described like this: «The day of her departure, in January 2020, she wishes to bring her husband and three sons together in Saanen, invite them at a nice dinner table, eat, drink, talk.» (Lecomte, 2018). If very telling, such a story introduces also a *mise en scène*'s dimension that should not be generalized; it mainly sheds light on social class issues, as persons from the upper class and *haute bourgeoisie* are more eager to control the image of their ageing body and to frame a probable request to die in a client relationship (Pillonel, 2018).

the researcher included. To be clear, we do not insinuate with this terminology the presence of a 'wish to die' – which is almost never apparent as such in the discourses of our informants – but a desire to die in this specific way, a desire that the inquirer is drawn to grasping.

As stated earlier, such desire is fueled by experiences of former deaths: frequently the experience of prior deaths functions as a negative parameter, not wanting to die in a certain way, not wanting to die "like that", where the "that" indexes, frequently, a negative experience with the medical milieu. Such negative experiences are cited as a key reason why people join "right to die" associations: a bad experience shows individuals how they do not want to die. Positive experience can lead to the opposite outcome, like in the case of Karl, a 78 years old man with a diagnosis of an amyotrophic lateral sclerosis, who realized his assisted suicide inspired by the death of his father who died at home after receiving from his medical doctor a last shot of morphine. However, in addition to negative examples, there is also the active imagery that parameterizes an anticipation of death. This imagery nurtures a desire to end one's life in a certain manner and function in our view as 'imaginative horizons' in a decision and a request to die; they mainly serve experiencing the here and now as Stavrianakis suggests:

It seemed to me, as I began to constitute in my imagination a series of cases, and a series of repetitions, that what was being repeated was precisely not memories of past deaths, but rather a form given to images of dying that bear – in one way or another – on a present desire towards the process of dying (Stavrianakis, 2018).

We can now push forward this argument to sort out a component of a request for aid in dying. Besides situations where acting alone is impossible for practical reasons and limitations of bodily capacities, we think there is a point worth mentioning in this request for assistance: to solicit others' help in the dying process implies a recognition of a demand, epitomized by the concrete, social and relational, engagement not only from the accompanier from EXIT but also – though variable in its intensity – from the close relatives or even the family doctor who establishes the medical certificate, or the report regarding capacity for discernment. This necessary participation might induce a certain sense of waiting for the person who wants to die. In this perspective, images related to lieux, as we have highlighted before, can serve to express one's desire in this regard, but also to suggest anticipations other persons are forging about such a request and the conception of their own engagement in the procedure.

We suggest this component is particularly relevant in Switzerland according to its relatively loose legal frame,¹⁵ as the participation of third persons in suicide is not an entitled right, but a voluntary answer to a demand. This plays a role in imagining terminality, as impulsivity or premeditation in the act take another shape when assistance is expected. Here the notion of time is structured by this conception of waiting, performed through the assistance provided by others. If this point needs to be further documented, we can mention as a possible indicator

¹⁵ As Stark notes: "the right to die "bears with it the possibly irreducible risk of appearing as a duty, one must also keep in mind that the movement from right to duty can translate also into un untenable obligation to live" (2018, p. 27).



the discourse held by the five persons working for EXIT association and the volunteers we met – and who set the tempo – regarding the patience, courtesy and gratitude of the persons who are about to die this way, during the procedure.

This is why imagined places, the arrière-pays, nurture a desire – in a more complex way than merely choice. But this desire has to be combined with a certain sense of waiting that is present in the requests to die with assistance. This notion of waiting gives consistency to the notion of time, which has not necessarily to be perceived anymore as imposed on a suffering body, on a person at the end of her life; it could rather be linked to the conditions underlying the acceptance from a third party to assist the person. This might be a specificity of this contemporary form of dying. To illustrate this point, we can go back to Aldo. When asked about the title of our research – Appreciating death: ethnography of assisted suicide in Switzerland – written on a document handed out to him, he smiled and answered spontaneously: "this was written for me". Aldo wanted to concretize his suicide without necessarily desiring death, but in a manner that would include a social or a relational dimension.

Our analysis is guided by the fact that Aldo immediately emphasized the component of gratitude in the title of our research program; not the other facet it might also convey, regarding the capacity to measure or seize an event, or by extension to control it. Aldo visualized a certain form of death; he desired a specific form. But this desire – we argue – was not immune to a passive dimension: to let oneself be driven through assistance of another person, even if the final gesture has to be executed alone. This final gesture certainly emphasizes the sense of agency but without being exclusively an indicator of a fundamental desire. This is at least our interpretation of how Aldo 'appreciated' death, and not dying.

To conclude, we might say that people who are about to die by suicide with assistance are also moved by imaginative contents related to places, environments, positions and gestures. Going back to Bonnefoy's metaphor, the arrière-pays helps them to be partially freed from the ticking of time during the end of life. It enables to deploy more widely the 'imaginative horizons' and to be – as Leonor Caraballo – an anti-terminalist of a certain kind. Setting a precise time of death might be then considered as a way to refuse the inscription of a metric – but uncertain by definition – conception of time in the dying body and the dying experience at large; to repeal it even. It can be perceived as an attempt to re-inscribe the body in time in order to liberate a subjective play with a horizon of terminality that is not determined in a probabilistic manner. Consequently, it gives room to the elaboration of imaginative contents – undetermined or precise – underlying the decision to voluntarily end one's life with assistance.

Bibliographic references

ACIMAN, André. Shadow Cities. In: ACIMAN, André (Ed.). *Letters of Transit:* Reflections on Exile, Identity, Language, and Loss. New York: The New Press, p. 19-34, 1999.

BAIDAWI, Adam. Euthanasia law passes in Australia for first time. *The New York Times*. New York, Nov. 29th 2017. Available on: <<u>https://www.nytimes.com/2017/11/29/world/australia/australia-euthanasia-victoria-assisted-dying.html</u>>. Consulted on: 05/27/2019.



BARTHES, Roland. Roland Barthes. Paris: Seuil, 1975. 191 p.

BATAILLE, Philippe. *Un cancer et la vie:* les malades face à la maladie. Paris: Balland, 2003. 256 p.

BONNEFOY, Yves. L'Arrière-pays. Paris: Gallimard, 2005 [1972]. 175 p.

BUCHS, Arnaud. Aux sources de l'arrière-pays. Yves Bonnefoy à l'horizon du surrealism. *Poétique*. Paris, v. 136, n. 4, p. 419-431, 2003. Available on: <<u>https://www.cairn.info/revue-poetique-2003-4-page-419.htm</u>>. Consulted on: 20/12/2018.

CRAPANZANO, Vincent. *Imaginative Horizons:* An Essay in Literary-Philosophical Anthropology. Chicago: The University of Chicago Press, 2003. 260 p.

FARMAN, Abou. Terminality. Social Text. Durham, NC, v. 35, n. 2 (131), p. 93-118, 2017.

GAMONDI, Claudia et al. Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study. *BMJ Supportive & Palliative Care*. On-line, v. 5, n. 2, p. 146-152, jun./2015.

INABAS, Hamilton, et al. Declarations on euthanasia and assisted dying. *Death Studies*. Online, v. 41, n. 9, p. 574-584, 2017. Available on: <<u>https://www.ncbi.nlm.nih.gov/pmc/articles/</u> <u>PMC5951142/</u>>. Consulted on: 20/12/2018.

KAUFMAN, Sharon. *And a Time to Die. How American Hospitals shape the End of Life*. Chicago: The University of Chicago Press, 2005. 412 p.

LECOMTE, Christian. Mourir encore belle, l'an prochain. *Le Temps*. On-line, 10/17/2018. Available on: <<u>https://www.letemps.ch/societe/mourir-belle-lan-prochain>.</u> Consulted on: 05/27/2019.

PAPADANIEL, Yannis, BRZAK, Nicole and BERTHOD, Marc-Antoine. Individuals and humanity: sharing the experience of serious illness. *Zeitschrift für Ethnologie*. Berlin, v. 140, n. 1, p. 131-147, 2015.

PILLONEL, Alexandre. Le corps autonome des classes supérieures: expression d'un 'pouvoir d'agir'? *Gérontologie et Société*. Paris, v. 40, n. 15, p. 97-110, 2018.

RABINOW, Paul and STAVRIANAKIS, Anthony. *Inquiry After Modernism*. ARC: Wilsted & Taylor, 2019. 222 p.

STARK, Jared. A Death of One's Own: Literature, Law, and the Right to Die. Evanston: Northwestern University Press, 2018. 180 p.

STAVRIANAKIS, Anthony. Obstinacy and Suicide: Rethinking Durkheim's Vices. *HAU: Journal of Ethnographic Theory*. Chicago, v. 6, n. 1, p. 163–88, 2016.

STAVRIANAKIS, Anthony. Thinking the Obvious. Determination and Indetermination in a Voluntary Death. *Terrain. Anthropologie et Sciences humaines*. On-line, 01/20/2017. Available on: <<u>http://journals.openedition.org/terrain/16103</u>>. Consulted on: 20/12/2018.

STAVRIANAKIS, Anthony. Survivances des images de la mort. L'agencement du désir dans une mort volontaire assistée. *Raisons Pratiques*. Paris, n. 28, p. 109-137, 2018.



THOMAS, Helen (Ed.). *Malady and Mortality*: Illness, Disease and Death in Literary and Visual Culture. Newcastle upon Tyne: Cambridge Scholars Publishing, 2016. 351 p.

ZALA, Marlis. *Chronique d'une mort volontaire annoncée:* L'expérience des proches dans le cadre de l'assistance au suicide. Fribourg: Academic Press Fribourg, 2005. 96 p.

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