Aion Journal of Philosophy and Science 2, 2025

Imagining the Future of Death

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Abstract

Death is a core aspect of the sustainability of our societies. With our ageing populations and increasingly chronic pathologies, end-of-life is a major issue for contemporary and future societies, in terms of care, medical and economic costs and meaning. Public policy and healthcare systems have yet to succeed in restoring value and meaning to death and end-of-life, which are seen as failures or obstacles dealt with reluctantly. Faced with the powerlessness of scenarios based on the cost/benefit balance, imagination offers an alternative method for, on the one hand, envisaging the evolution of contemporary death systems if nothing changes, and, on the other, considering possible alternatives that could restore meaning and value to death and end-of-life by transforming systems from within. Three applications of an imagination heuristic are developed herein: the first uses the scenario model, no longer to estimate costs and benefits, but rather to project extrapolations that provide a better understanding of current issues; the second analyses the art of conversation as an imaginary exploration of suffering and its ability to restore meaning to the final period of life; the third studies non-medicinal interventions in art as a concrete form of imagination. These three experiments with imagination identify ways in which subjectivities and organisations can be transformed to establish a caring culture as opposed to a culture of risk.

Keywords*: Death, Ageing populations, end-of-life meaning, healthcare systems, imagination experiments, art, caring culture*

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Résumé
La mort constitue la condition de soutenabilité de nos sociétés. Dans un contexte de vieillissement des populations et de chronicisation des pathologies, la fin de vie détermine un enjeu majeur des sociétés contemporaines et futures, à la fois en termes de prise en charge, de coûts médico-économiques et de sens. Or ni les politiques publiques ni les systèmes de soins ne parviennent à redonner leur valeur et leur sens à la mort et à la fin de vie, qui apparaissent comme des échecs ou des obstacles à repousser. Face à l'impuissance des scénarios fondés sur la balance coût/bénéfices, l'imagination offre une méthode alternative pour, d'une part, envisager l'évolution des systèmes de mort contemporains si rien ne change, et, d'autre part, envisager des alternatives possibles susceptibles de redonner sens et valeur à la mort et à la fin de vie en transformant les systèmes de l'intérieur. Trois applications d'une heuristique par l'imaginaire sont ici développées : la première reprend le modèle des scénarios non plus pour estimer des coûts et bénéfices, mais pour projeter des extrapolations qui permettent de mieux comprendre les enjeux actuels ; la seconde analyse l'art de la conversation comme exploration imaginaire de la souffrance et capacité à redonner du sens à l'ultime période de l'existence ; la troisième étudie des interventions non médicamenteuses en art comme forme de l'imaginaire. Ces trois expérimentations de l'imagination identifient des lignes de transformations des subjectivités et des organisations pour établir une culture du soin à la place de la culture du risque.

***Mots clés** : Mort, vieillissement de la population, sens de la fin de vie, systèmes de santé, expériences imaginaires, art, culture du soin*

When considering the major challenges societies will face in tomorrow's world, international, European and French organisations all identify the end-of-life issue as an essential element, highlighting our ageing populations, the shortage of palliative care facilities, the anthropological importance of this moment in life, and the suffering that can sometimes be unbearable and overwhelm the person concerned[1]. All reports also point to major inequalities in access to palliative care: in some countries,

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[1] "Strengthening palliative care as a component of comprehensive care throughout the life course". WHO 67.19. 24th May 2014. Sharkey L, Loring B, Cowan M, et al., "National palliative care capacities around the world: Results from the World Health Organization Noncommunicable Disease Country Capacity Survey." *Palliat Med* 2018;32:106-113. 10. Halpern SD. "Toward Evidence-Based End-of-Life Care." *N Engl J Med* 2015;373:2001-3. https://doi.org/10.1056/NEJMp1509664. Pennec S, Lépori M, Pontone S, Guion V, Evin A. "End-of-life medical decisions in French overseas departments: results of a retrospective survey." *BMC Palliat Care* 2024;23:224. https://doi.org/10.1186/s12904-024-01552-x.

this concerns access to morphine and opioids; in developed societies, the over-treatment of pathologies can paradoxically contribute to increasing suffering at the end of a person's life. To respond to this challenge, the two standard proposals made today draw on epidemiological and public health arguments to justify increasing the supply of palliative care and, in a growing number of countries, offering medical assistance in dying (MAID), in the form of assisted suicide or euthanasia.

Based on the same observation, this paper proposes an alternative methodology for apprehending the future of death using imagination and, in particular, aesthetic resources as an imagination laboratory. This research aims to show that the future of end-of-life considerations cannot be reduced to either a matter of resources concerning the number of palliative care units or mobile teams, nor to the decriminalisation of medical aid in dying, but instead requires a systemic transformation rooted in our relationship with nature and life[2]. In 2019-2021, the planetary experience of the Covid-19 pandemic shed light on the tragic end-of-life experiences of so many people deprived of support, and their loved ones deprived of mourning during that period. This health crisis gave rise to a collective awareness of the situations faced by people at the end of their lives more generally, and the decriminalisation of medical assistance in dying was accelerated around the world. In 2022, the Lancet Commission on the Value of Death drew a direct link between the ecological crisis and the end-of-life crisis: in both cases, we seek to master nature and life, refusing to recognise ourselves as an integral part of nature and life. The end-of-life crisis we are currently experiencing is part of a system: Kastenbaum identifies "the societal system of death" as the set of parameters which determines both the practical conditions (actors, institutions, places, moments, objects) and the embedded representations that today structure end-of-life support (symbols, images, texts, words, imagination)[3]. Yet the main aim of the system is to eradicate death: the entire healthcare system is today defined as a fight against death and ageing; education and the economy focus on performance and autonomy; insurance companies present death as a risk; the organisation of the stages of life and the institutionalised nature of end-of-life care conceal the importance and meaning of this final period of existence.

To address this systemic problem, "medical solutions" are not sufficient. A purely rational analysis in terms of risks, costs and benefits cannot address the radicality of our scepticism about the meaning of death and end-of-life. We need to re-imagine end-of-life and death by going back to the root of our distress, which is a crisis of meaning[4]. Imagination offers a method not only for understanding, but also as a source of creation[5] for inspiring change, both collectively and on an individual level.

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[2] White, L., "The historical roots of our ecologic crisis", *Science*, 1967, 15, 3767.

[3] Kastenbaum R., *Death, society, and human experience*. St Louis, MO: CV Mosby, 1977.

[4] Abel, J. Kellehear, A., "Dying and death reimagined," *Palliative Care & Social Practice*, 2022, Vol. 16: 1-14. G. Steiner, *Le Sens du sens*. Paris, Vrin, 1988, p. 53.

[5] Hocini, F. Dallaporta, B., "L'imagination aux sources de la création, dans le soin comme ailleurs". *Soins*, 886, 2024, p. 60-63.

Since the works of Wittgenstein, Ricoeur and Cavell, philosophy and social sciences have emphasised the importance of imagination in identifying contemporary and future issues, but also in providing realistic avenues for initiating change. There are three levels on which to implement this method of imagination.

Firstly, the imagination allows us to construct a realistic utopia based on trends in the contemporary system of death. Like fiction - science fiction, for example - it identifies probable developments based on our present situation: this makes it possible to become aware of the tragedy of our contemporary rationales, as we are incapable of grasping the major problems generated by our scientific and technological systems, such as the ecological or end-of-life crises[6]. This level enables us to focus on systemic issues. A second level captures the forms of (end of) life experienced by individuals today, confronting them with imaginary forms of (end of) life that may justify the desire to change: as such, it contributes to a self-education that enables us to initiate personal and social transformation. The third level focuses on art as "imagination at work", through masterpieces, performances and experiences that combine both personal subjectivity and collective resonance. Rather than seeking evidence, arguments or facts, art explores possible avenues and proposes subjective experiences that mobilise emotions and elicit collective responsiveness in the sense of a sociology of relations[7]: more precisely, it constitutes a sphere of responsiveness. In these three levels, or dimensions, philosophy not only provides a different way of accessing knowledge, but above all enables us to *recognise* the importance of what is at stake, to become aware of our collective responsibility and to make us want to change. In this way, it deploys an imagination laboratory and a sphere of resonance to help invent the future system of death.

1. Imagining end-of-life in the future: a realistic utopia to transform a complex system

Over the course of the twentieth century, death was transformed into a risk integrated into an epidemiological paradigm[8]. After the Second World War, risk analysis became a decision-making tool based on scientific expertise, and, according to Ulrich Beck, the vector of a reflexive modernity capable of internalising an assessment of the risks arising from our sciences and technologies[9]. At the same time, North American bioethics adopted the risk paradigm to establish the principles of decision-making in medicine, abandoning the idea of establishing a framework of shared values

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[6] Sallnow L. et al., Report of the Lancet Commission on the Value of Death. *"Bringing death back into life", Lancet 2022; 399: 837-84, p.* 838.

[7] Rosa, H. *Résonance: une sociologie de la relation au monde*, Paris, La découverte, 2018.

[8] Gaudillière, J.P., "Statisticiens et santé publique: l'invention des facteurs de risques", in *Inventer la Biomédecine*, Paris, La découverte, 2002, p. 218-245.

[9] Beck, U., *Risikogesellschaft: Auf dem Weg in eine andere Moderne*, Frankfurt: Surhkamp, 1986, translated: Risk society.

concerning fundamental human issues: in the context of pluralist democracies, the only potential consensus is aimed at minimising risks[10]. This new conceptualisation of ethics relegates substantial values to the private sphere. So, through epidemiology, biomedical research and bioethics, medicine integrates the risk paradigm into a logic of rational analysis of the cost/benefit balance[11]. This general framework has led to the promotion of a healthcare system that aims first and foremost to preserve life, slow down ageing (anti-ageing) and eradicate death. Today, through its success, this system generates also long and complex end-of-life situations, where patients - and sometimes caregivers - experience the approach of death as a failure, or even as abandonment.

Yet we must recognise that, biologically speaking, death is part of a physiological process and is not pathological. We must also recognise that human - and perhaps animal[12] - death cannot be reduced to a biological or medical matter, but calls each of us, individually and collectively, to question the meaning of existence including death. In this more global perspective, the end of our life is not a risk to be eliminated or avoided, but an experience to be given new meaning and importance. Indeed, the risk paradigm does not answer the question of meaning.

The Lancet report entitled “Bringing dying home” (2022) seeks to address, on the one hand, people’s wish to die at home, when the vast majority die in institutions, and on the other, the fact that death no longer has a ‘home’, because it seems to constitute a scandal or an anomaly that contravenes the logic of autonomy and mastery. How can we transform society so that it recognises the importance and meaning of death[13]? How can we move away from reducing death to a medical problem and restore its full anthropological, social and existential value? Through panel discussions and literature review, the Lancet commission first describes the international contemporary conditions of dying, and then constructs a realistic utopia, drawing on Rawls’ method[14] in the end-of-life field, to propose an imagination experience through five forms of life which each condition a distinct value of death. This projection of imagination promotes a holistic approach to the end-of-life issue which, within the parameters of reflection, internalises the relationships, the representations and the uncertain, ambiguous and paradoxical emotions we may experience at the end of our lives. Therefore, it integrates the social determinants of death, dying and bereavement and conceives of death primarily as a relational and spiritual process,

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[10] ". . . attempts to bring the common morality into greater coherence through specification risk decreasing rather than increasing moral agreement in society" Beauchamp T., Childress J., *Principles of biomedical ethics* 1979, 2001, p. 407.

[11] Carvallo, S., "Le tournant postgénomique: du risque à la vulnérabilité.", in: *Les vulnérabilités liées à la génomique*, Carvallo, Faivre, L., Paris, Erès, 2025, p. 17-53.

[12] Monso, S., *Playing Possum: How animals understand death*, Princeton University Press, 2024.

[13] Kellehear, A., The social nature of dying and the social model of health. In: *Oxford Textbook of Public Health Palliative Care*. Kellehear, A., Oxford: Oxford University Press, 2022, p. 22-29.

[14] Rawls J., *Law of the peoples.* Cambridge: Harvard University Press, 1993.

rather than as a physiological event[15]. It thus produces five extrapolations from the present situation.

The first scenario ("death overwhelms health systems") imagines a spike in deaths, following a pandemic, a climate event or a nuclear war, for example. We now know that these phenomena can happen, and that our health systems cannot meet the global demands resulting from catastrophes of this scale. The second scenario ("immortality and inequality") continues the current trend towards two-tier medicine, which not only develops cutting-edge methods to improve treatment and extend life expectancy, but also allows private companies to flourish, promising immortality or sophisticated treatments reserved for a select few, thereby reinforcing health inequalities. We also know that care at the end of life is one of the areas of healthcare where inequalities are greatest. The third scenario ("climate response-greater equality") radically transforms our healthcare systems, internalising climate change and aiming first and foremost to attain health equality. In this scenario, death appears as a condition for the sustainability of civilisation: everyone sees it as a moment in the life cycle. The fourth scenario is a rebalancing-focus on health-care system reform and the goals of medicine: priority is not given to scientific and technical successes, but rather to assisting and accompanying suffering throughout the lifecycle. The aim is no longer to prolong life or delay ageing, but to give meaning to life right up to death. Support is not just the responsibility of care professionals, but also of volunteers and, more broadly, of citizens and small local communities. The fifth scenario ("assisted dying spreads") generalises assisted dying not only for people with a life-threatening prognosis, but more broadly for people expressing unbearable suffering or a psychiatric condition, people with dementia or those who are tired of life[16]. It corresponds to the current situation in Belgium, the Netherlands and Canada, where the criterion of a life-threatening prognosis is no longer required to benefit from medical aid in dying[17].

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[15] "Radically reimagining a better system for death and dying, the Lancet Commission on the Value of Death has set out the five principles of a realistic utopia: a new vision of how death and dying could be. The five principles are: the social determinants of death, dying, and grieving are tackled; dying is understood to be a relational and spiritual process rather than simply a physiological event; networks of care lead support for people dying, caring, and grieving; conversations and stories about everyday death, dying, and grief become common; and death is recognised as having value." Sallnow, "Report of the Lancet Commission on the Value of Death: bringing death back into life", *Lancet*, Vol 399 February 26, 2022, p. 837.

[16] Sallnow, "Report of the Lancet Commission on the Value of Death: bringing death back into life", *Lancet* Vol 399 February 26, 2022, p. 869.

[17] Boer, T. A., "Dialectics of lead: fifty years of Dutch euthanasia and its lessons", *International Journal of Environmental Studies*, 2018, 75:2, 239-250, DOI: 10.1080/00207233.2017.1415834; Theo Boer, Dutch Professor of Medical Ethics: "I believed that a rigorous framework could prevent the derives of euthanasia: I'm not so sure anymore". Le Monde April 7, 2025. Government of Quebec, Commission on End-of-Life Care. "Rapport sur la situation des soins de fin de vie au Québec du 1er avril au 31 mars 2023", Bibliothèque et Archives Nationales du Québec, 2025 https://organesdeconcertation.sante.belgique.be/fr/documents/euthanasie-publication-des-chiffres-pour-2024-de-leuthanasie-en-belgique. Dierickx et al. "Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported

This heuristic methodology follows the format of the scenarios used by the International Panel of Climate Experts but does not aim to assess risks. It considers the life forms and death values within each system. It takes into consideration the emotions, relationships and interpretations that individuals and communities attribute to death. Indeed, the question of meaning is not a purely analytical or logical one; it is not reduced to knowledge and evidence; it also embraces the emotions and relationships that contribute to recognising what does and does not matter, and resonates with the whirlwind of life that envelops us. It invites us to anticipate the interrelated tendencies which structure the contemporary system of death, and to shape the future according to our priorities.

2. Imagination, meaning and conversation

Today, in resonance with the ecological crisis, there is a social quest to invent new forms of life involving transformations in the organisation of work, housing, food, transport, leisure… and also the end of life. Numerous post-Covid studies show, for example, how people today are staging new "greener" representations and practices of mourning[18], or how people are designing end-of-life trajectories in original ways[19]; cemeteries are becoming gardens in which ecosystem services are assessed and the carbon footprint of different funeral rites are compared[20]. These developments are not primarily based on scientific knowledge and evidence but express a quest for meaning that no longer finds an obvious answer in traditional forms. Rather, they reflect the importance of responding to the scepticism that threatens our standard social behaviour with absurdity, and the desire to become better[21], particularly by taking environmental impacts into account and producing a new aesthetic

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cases", BMC Psychiatry 2017, 17:203.

[18] Cherblanc, J., Zech, E., Gauthier, G., Verdon, C., Simard, C., Bergeron-Leclerc, C., Grenier, J., Maltais, D., Cadell, S., Sani, L., Bacqué, M.-F. "Sociography of funeral rituals in times of pandemic: from prevented rites to appropriate rites." *Canadian Review of Sociology/Revue canadienne de sociologie*, 2022, 59:348-368. Wang, S.S.Y., Teo, W.Z.Y., Yee, C.W. & Chai, Y.W., "Pursuing a good death in the time of COVID-19", *Journal of Palliative Medicine*, 2020, 23(6), 754-755. Pearce, C., Honey, J.R., Lovick, R., Creamer, N.Z., Henry, C., Langford, A., Stobert, M. & Barclay, S., "'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic". *BMJ Open*, 2021, 11(3), E046872.

[19] Mondal, A. P., Bhowmik, P., "Physician Assisted Suicide Tourism - A Future Global Business Phenomenon", *The Business and Management Review*, Volume 10, Number 1, 2018, pp. 35-43.

[20] Quinton, J. M. et al., "Beyond burial: researching and managing cemeteries as urban green spaces, with examples from Canada, *Environmental Reviews*, Vol. 27, No. 2 (2019), pp. 252-262. Decker Jr., C., Muniz, E., and Cruz, N.-J., "Environment systems: a new concept on cremation", *Journal of Sustainable Development of Energy Water & Environment Systems*, 2018, Vol. 6, No. 2, pp. 363-380. Keijzer, E. The environmental impact of activities after life: life cycle assessment of funerals, *International Journal of Life Cycle Assessment*, 2017, Vol. 22, No. 5, pp. 715-730. Lee, K.-H., Huang, C.-C., Chaung, S., Huang, C.-T., Tsai, W.-H., and Hsieh, C.-L. "Energy saving and carbon neutrality in the funeral industry", *Energies*, Vol. 15, No. 4, 2022, Article 1457,

[21] Cavell, S., *Cities of Words: Pedagogical letters on a register of the moral life,* Harvard University Press, 2004.

able to restore meaning: individuals choreograph trajectories towards death through journeys, rites and ceremonies, a whole aesthetic that gives direction and meaning to this final period[22].

While the individuals experience the search for a new form of end-of-life, death and mourning on their own singular scale, this quest also takes on a social and international dimension. It furthermore involves care professionals, funeral directors, urban planners, political decision-makers and associations. This interweaving of scales underlines the fact that individuals alone cannot decide on meaning, which is never reduced to a private affair, but depend on social structures and resonate with social valence[23]. By confronting the criteria of my culture "with my words and my life as I pursue them and as I may imagine them, and at the same time confronting my words and life as I pursue them with the life my culture's words imagine for me[24]", I try to recognise the meaning of what I do and want to say. I recognise that what I express about myself - about my suffering, for example - is rooted in a time, a culture, a community, a language and institutions, which give it the value of a punishment, a redemption, a pathology, a symptom, a failure, a passage, a celebration, etc. Because I am never alone in choosing what to say. I am never alone in choosing the meaning of my death, which aggregates the words and values of the tribe according to their responsiveness[25].

Distinct from pain, suffering lies precisely at the heart of an interpretation, in that it often indicates the impossibility of giving a shared meaning to those moments marked by the end of life, which seem to constitute nothing more than a long wait for a countdown. On the brink of death, the lived experience loses its obvious meaning and may even appear as nonsense. In France, the Comité Consultatif National d'Éthique (CCNE) notes that "the end of life is no longer perceived as an essential time in the human experience[26]." In the 1960s, Cicely Saunders, a pioneer of palliative care in London, emphasised the particularity of this existential moment: suffering can give rise to a desire to get rid of life in order to escape this ordeal. "Such pain is a situation rather than an event and the hardest aspect of this situation for the patient is that it seems to be meaningless as well as endless[27]."

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[22] Buchbinder, M., "Choreographing death: A social phenomenology of medical aid-in-dying in the United States". *Medical Anthropology Quarterly*, 32(4), 2018, 481-497. Stavrianakis, A., "Thinking the Obvious. Determination and Indetermination in a Voluntary Death." *Terrains* 2018. https://doi.org/10.4000/terrain.1610

[23] Rosa, H., Resonance. A sociology of our relationship to the world. London, Polity Press, 2019.

[24] Cavell, S., *The claim of reason, Wittgenstein, Skepticism, Morality and Tragedy,* New York, Oxford University Press, 1979, p. 125.

[25] Erard, M., "Concevoir une linguistique de la mort". *Anthropologie et Sociétés,* 45, 1-2, 2021, p. 95-108.

[26] Avis 139 - CCNE. "Ethical issues relating to end-of-life situations: autonomy and solidarity" 2023. Ccne-ethique.fr, p. 9.

[27] Saunders, C., *The Management of Terminal Illness.* Hospital Medicine Publications, London, 1967, p. 14.

Suffering is thus intrinsically linked to the difficulty of finding meaning at the end of life. In 1982, E.J. Cassel, a physician, emphasised the intertwining of suffering and meaning: “Personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking it into account[28].” Yet, according to Cassel, medicine does not sufficiently address the dimension of suffering: it reduces the scope of its intervention to the somatic and naturalises the experience of misfortune that the patient experiences as a whole. To fail to take care of suffering is to doom medical intervention to failure, not necessarily in therapeutic, physiological or biological terms, but in terms of care. It may even intensify the suffering of the person concerned, as he or she observes the non-recognition of his or her suffering.

> Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself[29].

Moreover, while pain is often treated by sedation, suffering cannot be treated in this way: many stories tell of the suffering of anaesthetised people who felt no pain and could not communicate their anguish[30]. More fundamentally, suffering expresses a global existential situation experienced by one individual: it is a call, like a distress signal[31]. It refers to experiential knowledge, which needs to be recognised as such[32]. Since its inception, palliative care has stressed the importance of taking into account the suffering of people at the end of life, notably through conversation, which involves listening and dialoguing together, maintaining interest in ourselves and in one another.

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[28] Cassell, EJ., “The nature of suffering and the goals of medicine”. *N Engl J Med 1982*;306:639-45, p. 134.

[29] Cassel, EJ. *N Engl J Med*. 1982; 306:639-45.

[30] Birch, J., *The Edge of Sentience: Risk and Precaution in Humans, Other Animals, and AI*. Jonathan Birch, Oxford University Press, 2024.

[31] Guérin, B., Carvallo, S., Aubry, R., *La Détresse existentielle*, Besançon, PUFC, 2025.

[32] I am fortunate too, above all, in being a doctor who isn't in a hurry, so that I have time to know and to enjoy my patients, and I very often take a portable tape-recorder round with me, which, of course, they all know about. It is a very great help, both to get permanent records of them talking about their pain and its relief, but also about their attitudes towards their illness; what they know about it, and what they find particularly hard, and it is very revealing, both for them, and about myself too when I play it back. Typescript of a talk, “I was sick and you visited me", given at St. Mary's Hospital, London, 30 May, 1961; Cicely Saunders' archive, St. Christopher's Hospice, Sydenham.

Considering the suffering of the other implies situating oneself at the level of a subjective experience expressed through a voice that addresses their distress to a community of language. Contemporary philosophy and medicine both focus rather on the content of the statement. Thus, they consider the argumentation involved in the discourse, for example when they enjoin the construction of a rational, free and informed decision under the model of consent, which often consists of "ticking boxes". Conversely, the professional's statement does not represent personal subjectivity, but is configured by the obligation to deliver clear, impartial information with tact and moderation, to help the patient make an informed decision. On the contrary, the voice indicates the intrinsic presence of one subject addressing another, but also its ability - or inability - to find, in the words of the tribe, a way of saying - or not saying - what they want to say, and to be listened to, understood, recognised in their subjectivity. Under the pretext of rationality or procedure, there is a tragic risk of only being able to express oneself through forms or ready-made formulas that prevent them from finding their voice - that is, their way of saying - a form of life appropriate to who they are. By contrast, conversation offers the necessary space-time to adjust their voice to the ear of another: it aims neither at mastery nor at a decision, but discusses experiences in all their nuances and complexity, sharing interpretations that are always uncertain, sometimes ambivalent. It expresses emotions, powerlessness and desires. It opens up an imaginary exercise: if I die tomorrow.... If I live another eight months... Would you leave? What would you do? What about our house? Do you remember?

When doctors broach the subject of death with patients, they often describe the discussion as difficult, because they feel they are stepping outside of their legitimate perimeter and broaching intimate issues which generate affects, emotions, relationships, history and even spirituality. Many patients say they have not had the opportunity to share their deep emotions about death with their oncologist[33]. They remain mute, speechless concerning their intimate lives. When they do take place, these conversations often happen at the time of a crisis, too late, for example during an emergency hospitalisation. Moreover, it is not clear who should initiate the discussion: should it be the specialists confined to their field of expertise, the nurse, the psychologist, or each individual on a visit-by-visit basis? We are currently witnessing a reinforcement of the tendency to compartmentalise roles between doctors and paramedical professionals (psychologists, sophrologists, art therapists, etc.): young doctors report feeling helpless when faced with symptoms that fall outside the strictly medical field and will tend to delegate more quickly[34]. They de-medicalise some support requests by referring them to paramedical or supportive care professionals,

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[33] L. Sallnow et al. "Report of the Lancet Commission on the Value of Death: Bringing death back into life", *Lancet* 2022; 399: 837-84, p. 864.

[34] Sarradon-Eck, A. M. Dias, R. Pouchain, "Ces patients "particuliers". Comment les jeunes médecins démédicalisent les symptômes inexpliqués?" *Sciences sociales et santé*, 2020/1, 38, p. 5-30.

rather than assuming them as part of their support mission. At the same time, they categorise a group of patients as “heartsink patients”, in that they go beyond the ordinary scope of care and do not really fit in with standards.

Why is it so difficult to ask the patients about their understanding of the situation, their fears, their dreams and concerns for the future, their priorities, their conceptions of values, to try and get a feel for their end-of-life experience and, possibly, to imagine what comes next? We know how essential this conversation is for making sense of the situation. Indeed, nurses report the importance of these free moments, which often take place at 2 a.m. when the hustle and bustle of the ward calms down. The nurse and patient meet simply as individuals, who recognise the importance of the radical experience of being human when approaching death[35]. They resonate with each other. Am I already dying? What does my presence mean, when I can do nothing else but be here?

As opposed to the contractual model of consent, which aims to co-construct a shared decision, conversation enables an encounter and a resonance where each person can recognise her or his own humanity through that of others. It allows emotions, silences and imagination to resonate, to evoke what is important to the individual. Stanley Cavell shows how conversation blurs the roles of expert and layman: two people talk and know that

> No man is in any better position for knowing it than any other man - unless *wanting* to know is a particular position. *And this discovery about himself is the same as the discovery of philosophy*, *when it is the effort to find answers, and permit the questions*, which nobody knows the way to nor the answer to any better than anybody else. As such, what makes it relevant to know, worth knowing? But relevance and worth may not be the issue. The effort is irrelevant and worthless until it becomes necessary to know such things[36].

Through the singularity of a conversation, everyone can reinvent themself: by finding an interlocutor capable of recognising the importance of what they are trying to say, they overcome the scepticism of having nothing to say or finding themself in a meaningless situation. Together, both experience a kind of resonance to discriminate between what is significant and what is trivial. Thus, what is important is neither

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[35] Human-to-human moment between nurse, patient and their families.... These moments are epitomized in the 2 a.m. moment, when the bustle of the hospital or the home has settled, and it is just nurse and patient in solidarity. And there we are: human-to-human amid both suffering and hope with the full range of emotions possible. It is these moments when the patient might ask: Am I dying? (...) How the nurse remains present, listens, internalizes, responds, uses the silences and continues to bear witness can profoundly shape the next moments of living and dying. (...) In recognizing the profound experience of the patient facing death, the nurse also holds a mirror of reflection. (...) What am I learning in this moment, from this patient? Rosa, W. Ferrell. B., “The 2 a.m. Moment and the Art of Our Science”. *Journal of Hospice & Palliative Nursing*, vol. 25, nº 3, June 2023, pp. 115-115.

[36] Cavell, S., *Must we mean what we say?* [1969], Cambridge, Cambridge University Press, 2002, p. XLII.

content nor argument, but to reach a harmony - in the musical sense of the word - which, on the horizon, symbolises the possibility of a universal agreement on what is essential when one is facing death. On the threshold of death, conversation opens the way to a shared imagination in the form of memories, desires, fears and projections. It thus constitutes a matrix for access not to knowledge, but to mutual recognition: recognising what is important, recognising a voice. Because at this very moment we are all “self-made”.

3. Giving shape to the imaginary: Non-medicinal interventions in art

In addition to conversation, art offers another modality for imagining end-of-life. Indeed, palliative care units are increasingly offering art interventions to break away from a purely analytical or rational relationship and open up an imaginary matrix elaborated by patients with artists on board[37]. This is because art is a way of breaking away from rationality, letting go and experimenting with other dimensions of relationships.

Cicely Saunders was one of the first to stress the importance of symbols as a way of expressing suffering and finding meaning by opening up and exploring avenues through the imagination. As a result, the hospital in which she practiced, Saint Christopher Hospice, created a Creative Living Center to integrate art into care for patients and their loved ones, caregivers, training and research. In France, the Maison de Gardanne, dedicated to palliative care, has premises hosting artists in residence: distinct from art therapy, it welcomes artists who, through their performances and creations, enable patients to reconnect with themselves and with each other. Through art, as through conversation, the patient plays an active role, is no longer bored and even finds a sense of pleasure. This aesthetic experience improves self-esteem, restores relational availability and enriches the sense of existence[38]. According to patients’ self-assessments, their overall feeling of distress diminishes: anxiety, fatigue, sadness, unease or depression after the procedure are reportedly lower than before[39]. In addition to the patient’s own experience, the works of art produced can be shared throughout a community and last beyond their death. Finally, this creative process also gives another dimension to the experiences of family members and professionals. An ambitious project in the United States was launched in 1993 to transform the culture of death through art[40]. In this project, artistic intervention is not limited to

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[37] Pasquet, St., Giffard, M., Chassagne, A. “Les approches non médicamenteuses en soins palliatifs: enquête sur les pratiques en France”, *Médecine Palliative*, 2025, doi: 10.1016/j.medpal.2025.02.002.

[38] Taal, J. (2004), "Assumer le cancer par l'expression créative et imagination", *Revue Francophone de Psycho-Oncologie,* 1, p. 25-32.

[39] Lefevre, C., Ledoux, M. Filbert, M. Art therapy among palliative cancer patients. Aesthetic dimensions and impacts on symptoms. Palliative and supportive care. 2015, 1-5.

[40] Project on Death in America. Transforming the culture of dying: the project on death in America 1994-2003. New York: Open Society, 2004.

Clark D. The project on death in America: twenty years on. 2014; published online Sept 11.

people at the end of their lives, but concerns all citizens, to “bring death home”, not just in palliative care services, but in our ordinary homes, not as a morbid obsession, but to tame it. Historically, many artists have taken up the question of death. Among others, Jenny Holzer took up the form of ‘Lament’ in an art exhibition combining columns and words in 1989[41]. In 2024, she invested the Guggenheim Museum with a *Light Line* multimedia exhibition on the figures of contemporary death[42]. The architecture of this New York museum draws us into a spiral comparable to Dante’s descent into the circles of hell. In cinema, the multitude of films about the end of life reveals a renewed recognition of its importance.

Cavell particularly analysed the case of cinema as a medium that elicits a subjective and collective experience to explore meaning in its obscure aspect when the evidence disappears. This experience does not take the form of rationality or argumentation, but of *significance*, relevance, importance or *mattering*. Cinema makes us aware of complex emotions, relationships and situations that resonate with the viewer’s own life[43]. Sometimes, a film can transform one’s existence, just as an encounter can, because by dramatizing a story, cinema makes intensely real what might ordinarily seem worthless. The sharp increase in the number of films about the end of life is a sign of the renewed interest directors and viewers are taking in this stage of life: prior to the 2000s, the theme of the end of life hardly ever appeared on screen, apart from in Bergman’s masterpiece *Cries and Whispers* (1972). Since the 2000s, at least one film on this theme has been released every year[44]: while we usually do everything to avoid thinking about it, cinema makes the experience interesting and important. These films do not attempt to be masterpieces, but they all explore the feelings, emotions and relationships that play out under the shadow of death, and recognise its significance. They all help to shed light on the end of life as an internal priority of our culture.

All these aesthetic initiatives (art interventions in palliative care services, artistic creations about death, films about the end of life) agree on the limits of a purely rational approach to the end of life, on the importance of imagination in developing

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http://endoflifestudies.academicblogs. co.uk/theprojectondeathinamericatwentyyearson/

[41] https://www.clevelandart.org/art/2019.19. Accessed on 16.04.2025

[42] https://www.guggenheim.org/exhibition/jenny-holzer; https://www.frieze.com/article/jenny-holzer-light-line-2024-review. Accessed on 16.04.2025

[43] Cavell, S., *Pursuits of Happiness: The Hollywood Comedy of remarriage*, Harvard University Press, 1984.

[44] C'est la vie (2001), Facing Death (Elisabeth Kübler-Ross, 2003), Mar adentro (2004), Million Dollar Baby (2004), Le Scaphandre et le papillon (2007), La Vérité sur Jack (You Don't Know Jack, 2010), Les Yeux ouverts (2010), The Descendants (2011), Terry Pratchett: Choosing to Die (2011), Quelques heures de printemps (2012), La Belle endormie (2013), Miele (2013), Still the Water (2014), Before We Go (2014), La Vanité (2015), La Dernière leçon (2015), Vivre sa mort (2016), Black Bird (2019), Cherry Blossoms and Demons (2019), Tout s'est bien passé (2020), Supernova (2020), Le cahier de Tomy (2020), Les Equilibristes (2020), De Son Vivant (2021), Plan 75 (2022), The room next door (Almodovar, 2024), Le Dernier souffle (Costa Gavras, 2025).

ways of expressing, and on restoring a shared meaning of death and end-of-life. They recognise the relevance of art, precisely because it achieves a personal interpretation and can arouse shared emotions and values. Sharing meaning does not mean reaching a consensus on divisive issues such as medical assistance in dying: the pluralism of contemporary societies makes reaching any agreement on the ethical value of assisted dying or assisted suicide impossible. Nevertheless, art makes it possible to reach agreement in terms of resonance, so that together we can recognise the importance and value of this final period of life.

As an extension of these artistic productions, research based on art does not aim to discover new objects, but rather to better understand dimensions of subjectivity that are ordinarily poorly identified, but which matter intensely when you are dying[45]. It can take at least three forms: treating an artistic work as research material, considering an artistic practice as an experiment, or proposing an art intervention.

When based on works of art, art-based research is not confused with art history or art criticism, insofar as it does not claim to know more about the work, the author or the technique, but rather to capture knowledge about the world evoked through the works. In this way, the diversity of films on end-of-life issues enables us to better understand the different trajectories explored by individuals, the dilemmas experienced by loved ones and caregivers, and the emotions and suffering involved. Fiction thus plays a role analogous to that of the human and social sciences, in that it enables us to understand social and human facts[46]. The work can direct attention to elements or dimensions that are usually omitted; it can narrate and represent social facts. In the words of Howard Becker, it acts as a "vehicle of social analysis[47]", in that it can make us see, understand and feel important issues for social theory or philosophy. Indeed, art - like humanities and social sciences - considers fiction to be an intrinsic dimension of the human sphere. As such, the work embodies a fiction in action, an imagination made present and concrete through an artistic medium. It opens the way to interpretations, to apprehend the complexity and uncertainty of interpretations.

In the film *Cries and Whispers*, we perceive the exacerbated tensions of ancient relationships, which are redistributed around Agnès' end of life between her sisters, the maid, the doctor and the pastor. We also perceive how the end of her life mobilises the memories, emotions, dreams and regrets that populate the solitude of the dying person. The film stimulates our conceptual and emotional imagination to better analyse this life event[48]. Emily Dickinson's poems give words to the suffering that, for many of us, constantly threatens to destroy language: "There is a pain - so utter - /

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[45] Leavy, P., *Method meets arts. Arts-based research practice*, NY-London: Guilford, 3rd ed., 2020.

[46] Beer, D. "Fiction and social theory: E-special introduction", *Theory, Culture and Society*, vol. 33, n° 7-8, 2016.

[47] Becker, H. *Telling About Society.* University of Chicago Press, 2007.

[48] Cavell, S., *Pursuits of Happiness: The Hollywood Comedy of remarriage*, Harvard University Press, 1984.

It swallows substance[49].” Nancy Huston’s novel *Dolce Agonia* (2001) features Sean Farrel in the advanced stages of cancer, who brings together a dozen friends and lovers in the evening of their lives to explore the uncertain feelings that intertwine before death. It gives the reader the impression that he is the uneasy witness of this ultimate whirl of life. Mark Rothko’s *Black on Grey* (1970) invites us to contemplate the fragile frontier between death and old age. All these contemporary works populate our “imaginary museum”, proposed by Malraux in a bid to take us out of art history, so that we could inhabit our culture through a personal shared relationship. They build a museum without walls, where, through digital reproductions, paintings, films, books, poems, sculptures, architecture, dance, music and collages find “the greatest significance of artistic style that they can adopt” and now offer “moments of art[50].”

The second modality of art-based research mobilises artistic performance to create an aesthetic form that can give us access to new ways of feeling, seeing or hearing. In particular, it enables us to take account of the affective, sensory and experiential dimensions of end-of-life, to access the truth of what a subject experiences without being that person. In this way, suffering, dereliction and fatigue can be understood through theatre, music, dance and poetry. In such cases, artists are needed to put into words, sounds, images or movements a representation which achieves a real presence. Indeed, George Steiner has explained how performance means first an experience that “*incarnates* (the notion is grounded in the sacramental) *a real presence of significant being. (...)* It is a singularity in which concept and form constitute a tautology, coincide point to point, energy to energy, in that excess of significance over all discrete elements and codes of meaning...[51]” R. Campo, a physician, underlines the extent to which the healthcare system today is unequipped to offer spaces of meaning, both for caregivers and for patients and their families. In addition to his medical duties, he is developing initiatives to recreate artistic moments, for example as editor of the “Poetry and Medicine” section of JAMA (*Journal of the American Medical Association*) or in the Arts and Humanity initiative at Harvard Medical School. Poetry can explore the importance of the end-of-life experience, precisely because it breaks with the informative and rational function of language[52].

The third modality of research based on arts conceives art as an intervention to import another way of existing into care organisations[53]. In this case, the artist

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[49] Dickinson, E., Fr515, in: R.W. Franklin, *The poems of Emily Dickinson: Reading edition*. Cambridge: MA, The Belknap Press, 1999. This poem was published in 1929, then in its original version in 1955.

[50] Malraux, A., *Le Musée imaginaire. Psychologie de l'art.* Labyrinthe, 22, Geneva, 1946, p. 2.

[51] Steiner, G. *Le Sens du sens. Présences réelles*, Paris, Vrin, 1988, p. 86-87 for the english version, p. 63 for the french text.

[52] Campo, R., “Poetry and the meaning of care”, JAMA, 2024, 331/22, 1969. “Illness, and Poetry, can transform us”, JAMA, 2025. 333/4: 352.

[53] Wang Q., Coemans S., Siegismund R., and Hannes K., "Arts-based methods in socially engaged research practice: a classification framework", *Art/research International: A transdisciplinary Journal*,

intervenes as a layman in the health facility to engender a displacement, or a shift. This is the case, for example, with tango dancers, who intervene in palliative care services: this intervention may come as a surprise insofar as patients cannot dance the tango themselves, but the strength and sensuality of the dance, which intimately combine the bodies of a man and a woman, enables memories and desires to emerge. They encourage introspection but also renewed interaction. In her movie *De Son Vivant* (2021), Emmanuelle Bercot films a palliative care unit. Although she assumes a melodramatic composition, Bercot depicts the concrete elements of the care organisation set up by the department head Gabriel Sara, who regularly invites musicians and tango dancers to the Mount Sinai Roosevelt Hospital in New York[54]. Their dance portrays what ordinarily seems unspeakable and invisible, restoring the importance of feelings, regrets and desires, and rekindling the flame of life and love. It also broadens the definition of care, being not a question of acting on bodies, but of providing an opportunity to experience oneself, one's past, one's desires, one's suffering, one's dereliction. In this respect, art contributes to a reform of care[55] seeking to recognise the subjectivity of the person at the end of their life. Dance responds to a demand, rather than a need, as argued by F. Worms, following Winnicott, distinguishing between what is organic and objective, and what concerns subjectivity[56]. Levinas takes up this distinction to analyse this fundamental call for recognition and consolation, opening us up to the question of meaning. As he defends the aspect of subjectivity, he also assumes that suffering is always useless. It cannot be justified: its incommensurability with ordinary experiences must be recognised[57].

Indeed, art does not claim to heal or erase pain or death, but it does recognise the value of subjective experience - even anguished experience - the importance of suffering and the value of death, which can also become a source of creation. "A writer's work, like the water in an ever-moving well, reaches a height which is in proportion to the depth to which suffering has penetrated his soul[58]." Marcel Proust said it best. Since Dr. Rita Charon's impetus in the 2000s, narrative medicine and hospital biographies have proven, in their own way, the virtue of storytelling in giving meaning to pathological experience, and not abandoning it to scientific and technical factuality alone[59].

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vol. 2, n° 2, 2017.

[54] Bercot. E., Dossier de présentation du film *De Son Vivant*, Personal communication, October 17, 2024.

[55] Sallnow, L., *op. cit. Lancet* 2022, p. 872

[56] Worms, F., *Le moment du soin: à quoi tenons-nous?* Paris, PUF, 2010.

[57] Levinas, E., *Useless suffering, Entre nous: Thinking-of-the-other*, M. Smith, B. Harshav trans. New York: Columbia University Press, 1998, p. 94.

[58] "*Les œuvres, comme dans les puits artésiens, montent d'autant plus haut que la souffrance a plus profondément creusé le cœur*." Proust, M., "Le temps retrouvé", *À la recherche du temps perdu,* Gallimard, La pléiade, 1989, t.4, p. 487.

[59] Charon, R., *Narrative medicine. Honoring the stories of illness*, New York, Oxford University Press, 2006.

Through these three heuristic dimensions (work, performance, intervention), art shows that we must go beyond the simple level of knowledge to recognise the importance of experience. It also reaffirms the intrinsic nature of subjective experience, thus offering opportunities for connection, resonance and empathy with the person concerned. In Cavell's words, art

> [...] magnifies the feeling and the meaning of a moment, its equal part of it to counter this tendency, and instead to acknowledge the fateful fact of a human life that the significance of its moments is ordinarily not given with the moments as they are lived so that to determine the significant crossroads of a life may be the work of a lifetime[60].

But art also opens up avenues of transformation. Aesthetic experience can leave its mark on the individual and induce a new beginning. In 2024-2025, we carried out an art intervention with doctors in the field of palliative care, medical students and artists in dance, poetry and music in partnership with the Museum of Fine Arts of Lyon. The students' verbatims provide insight into what young future doctors understand through artistic creation. First of all, they experience the expressive power of art:

> A1. What I discovered through the work of these artists, dancers, musicians, video artists or poets, was the power of art to enable expression. The work is not there to explain, but to make us feel and express. It offers an opportunity to highlight the patient's subjectivity, imagination, emotions and desires. 02.04.2025

They also observed how art enables us to be present in a way that matches the intensity of the patient's experience:

> A2. ... an intensely alive form of presence. More than gestures or words, it was looks, silences and emotions that reminded me of what the word "together" means: creating a common space where everyone has their place, and where vulnerability creates links rather than solitude. 02.04.2025

Finally, they felt transformed by the art:

> A3. ... shifted my approach to care, restoring the place of subjectivity and the human element beyond technical care. In the course of my work, I've learned that far from being a luxury, art can become a real lever for transforming the relationship between caregiver and patient. 02.04.2025

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[60] Cavell, S., "The thought of movies", *Themes out of school: effects and causes.* San Francisco, CA, North Point Press, 1984, 3-26, p. 11.

Under the shadow of death, the aesthetic relationship takes precedence over the clinical result in that it gives meaning to these borderline situations. It also enables us to give form to the unspeakable and the invisible, and to create a link, even when ordinary speech is no longer adequate. For example, one student emphasised that he had understood the experience of fatigue that a person at the end of life can feel through a theatrical scene, by drawing on his own experience of fatigue exacerbated by the sensitivity of words. As a result of this aesthetic experience, several students decided to change their practice, becoming less focused on the result and more attuned to listening and wanting to enter into a relationship with the person. Another student drew on the etymology of palliative - *pallium* - blanket or cloak, and spoke of art "as a cloak (that takes care of someone)" for both patient and caregiver. Through art and imagination, they initiated self-education.

Imagination is at the heart of a fundamental quest for meaning about end-of-life and death, as part of a reverie - in Rousseau's sense of the term - it is radically transformative, or "transmutative" following Starobinski's words: the self is transmuted, and the pain is converted in the feeling of a presence[61]. Only death interrupts the *Rêveries du promeneur solitaire*[62] in the spring of 1778: at the end of an existence marked by persecution and misfortune, imagination opens up an experience of significance and a source of creation. Today, this imaginary world takes on other public forms through healthcare institutions and research: artistic media, conversation, interventions of artists driven by convictions shared with doctors, the commitment of associations offering time and space in art venues to share such aesthetic explorations[63]. In this respect, all these initiatives are a reminder that the meaning one can give to his or her experience is never purely private but is woven through lines of connection between the subject and culture, as imagination confronts his or her culture's representations and meanings with his or her own words and life[64]. These initiatives inaugurate a culture capable of accompanying suffering, end-of-life and mourning, able to give meaning to the tragic experience of death: a caring culture[65]. Rosa distinguished between the mute relationships of use and logical analysis on the model of efficiency and the benefit-risk balance, where things tell us nothing, and the horizontal, diagonal or vertical relationships of resonance that come to make sense[66] by weaving non-utilitarian links with loved ones, places, nature, with care professionals and with artists and art open up a sphere of resonance.

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[61] Starobinski, J., "Rêverie et transmutation", *Jean-Jacques Rousseau et la transparence et l'obstacle, suivi de sept essais sur Rousseau*, Paris, Gallimard, 1971, pp. 415-429, p. 420, 427.

[62] Rousseau, J.-J., *Les rêveries du promeneur solitaire, Œuvres complètes*, Paris, Gallimard, La Pléiade, t.1.

[63] https://passeur-de-mots.fr/

[64] Cavell, S., *The Claim of reason, Wittgenstein, Skepticism, Morality and Tragedy*, New York, Oxford University Press, 1979, p. 125.

[65] Tronto, J. *Le Risque ou le care ?* Paris, PUF, 2012.

[66] Rosa, *Resonance, ibid.,* p. 195-306.

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