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L'Esprit Créateur, Volume 61, Number 1, Spring 2021, pp. 81-94 (Article)

Published by Johns Hopkins University Press

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Frédéric Badré's *La grande santé*: Palliation as a Literary Practice?

Anna Magdalena Elsner

IN 2015, SHORTLY BEFORE HIS DEATH and three years after receiving the diagnosis of Amyotrophic Lateral Sclerosis (ALS), the French writer and painter Frédéric Badré published a book entitled *La grande santé*.¹ This was followed by the publication of “L’intervalle,” an essay that appeared posthumously in the *Nouvelle Revue Française*.² These two texts, which document Badré’s dying, are the only explicitly autobiographical and certainly the most intimate ones within his œuvre.³ They distinguish themselves from other contemporary French end-of-life writing in that they interweave a personal account of dying with discussions of numerous works of literature and the visual arts.⁴ Through this sophisticated web of references, Badré questions how dying reshapes his concept of health and what role both real and imaginary interlocutors play in accompanying him. The text entails another characteristic feature, namely Badré’s use of ekphrasis,⁵ which becomes a way to test the limits of literary representation. These three distinct topical and formal features—Badré’s refashioning of “health” as a concept able to contain his new self, the role of literary texts in establishing a community of suffering, and his pronounced verbal engagement with visual art as a form of spiritual accompaniment—are held together by a compelling refusal of binaries distinct to his engagement with dying. In this article, I propose that Badré’s multimodal poetics captures an experience that is complex and resistant to the simplifications of binary thought and thereby creatively responds to some of the key values associated with the paradigmatic end-of-life care modality in the West, palliative care, and its adjacent philosophy.⁶

Etymologically speaking, “palliative” derives from the latin “palliare,” a word that encompasses a range of interconnected meanings such as “to cloak,” “to hide,” “to shield,” “to disguise,” and which is mostly understood as meaning “to alleviate” pain. Though the term is not originally connected to death and dying specifically, the root “pall” refers to the “cloak or vestment but also a cloth to cover a coffin.”⁷ In its current use, the term is primarily associated with the specific approach to end-of-life care developed at the end of the twentieth century.⁸ “Palliative care” was first officially defined by the World Health Organization (WHO) in 1990.⁹ It is rooted in the pioneering work of Cicely Saunders, who combined scientific research into pain relief for the dying with attending to their narratives.¹⁰ Among the different features of

her holistic approach to end-of-life care, three aspects, reflected in the WHO's current definition of palliative care, have a particular affinity with Badré's work. These are its ambition "to accept dying as a normal process," its aspiration to include families actively in the care provided to the terminally ill, and its acknowledgement of the need for spiritual accompaniment at the end of life.¹¹

Given the central role that narrative methodologies played in shaping palliative care, several intersections between literature and palliative care have been acknowledged—from within the field of palliative care itself, but also from literature and film scholars. It has for example been highlighted that the "skills of narrative medicine are integral to palliative care," and that the tools of narrative analysis on which narrative medicine relies are ultimately also palliative tools, namely the close-reading of and attention to stories of both patients and caregivers.¹² Looking at the Romantic era, Brittany Pladek has claimed that there is a literary tradition of palliation, a search for holism and unity between literature and medicine. Pladek regards this tradition as having ultimately led to the contemporary "therapeutic holism in the health humanities." She argues that writers such as Woodsworth, Shelley, and Keats developed what she calls a "palliative poetics," namely a diverse set of "models of literary therapy that did not assume literature could cure—that is, could make a person whole again—and so located its therapeutic value elsewhere."¹³ With regard to contemporary visual art, Emma Wilson has observed that, "looking at the etymology of 'palliation' and 'palliate,' some of the meanings of these words seem more apt in an artistic than a medical context."¹⁴ Wilson has pointed out that moving image media engage with the secondary meaning of "disguise" and its evocation of fantasy, play, and distraction as a form of assuagement specifically. She has coined the term "palliative art," which is meant to capture that for some contemporary filmmakers, art-making turns into "a form of pain management, offering the living a mode of absorption and distraction" (Wilson 3).

This article builds on these connections between literature, art, and figurative forms of palliation. Yet it aims to set up a closer link between Badré's work and the specific meanings and philosophical values that palliative care has taken on in the healthcare context. To be clear, Badré, who is in a long-term palliative situation given that his disease is incurable, never explicitly refers to palliative care. And even medicine generally is assigned a marginal role in his exploration of the shifting relationship between writing, the self, and dying. Nevertheless, Badré reflects on topics such as the meaning of health in illness, the place of others in dying, and the rivalry between science and spirituality.

These larger ethical and social reflections about dying and the opposition to binaries frequently relied on for thinking about it, as well as Badré's appropriation of ekphrasis as a literary form of particular relevance for end-of-life writing, thereby realign some of the key tenets of palliative care.

Health and dying: anti-palliation

Badré's aim in *La grande santé* is to portray his experience of ALS and to explore what it says about terminal illness and dying in our time more widely (*La grande santé*, cover). As such, the closing sentence of *La grande santé* is a powerful tribute to palliative care's ambitious aim to "accept dying as a normal process" (*WHO* "Palliative Care"). Badré writes, "Je reste là, immobile, et j'attends d'être guéri pour que ma vie reprenne son cours normal" (*La grande santé* 194). Nothing about his terminally ill state is experienced as ordinary. He refuses to accept that dying ends in death and even irrationally expects to be cured and to return to the life he knew prior to his diagnosis. This resistance to binaries, a general tendency of Badré's work which is epitomized at a representational level in the turn to ekphrasis, is therefore already inscribed in Badré's book's title. *La grande santé* places the subversion of the "dual citizenship," as Susan Sontag has described the drastic difference between health and illness, boldly at its very beginning.¹⁵ The prominent positioning of "health" in the title of a book about terminal illness gestures to the fact that for Badré health co-exists with illness and dying. Indeed, there is a very deliberate 'mixed economy' at play on many levels of his text, the paradoxical nature of which he summarizes in the following terms: "Je me sens en grande santé. Pourtant, quand le diagnostic de la SLA est posé, toute ma vie est modifiée" (Badré, *La grande santé*, back cover).

The reference to Friedrich Nietzsche's concept of "die grosse Gesundheit," "great health," in Badré's book's title elucidates the connection between health and dying, even if Badré does not discuss Nietzsche's view on health specifically. In *The Gay Science*, Nietzsche defines "great health" as "the ideal of a human, superhuman wellbeing."¹⁶ For Nietzsche, as a commentator has put it, "health is not of a pain free state—on the contrary, he sees pain as a necessary constituent of great health"; "health is demonstrated in the way one deals with one's own sickness, and not in the absence of sickness."¹⁷ It is against the background of this inclusive definition of health—one that refuses the anesthetizing of pain and suffering—that Badré positions dying as integral to health in *La grande santé*.

In this view, writing the decay of a dying body and the alienating effects of disease turns into a vital testimony of health. Sharing his experience of

ALS is a conscious effort not to soothe, alleviate or distract, but on the contrary, to uncover, reveal, and acknowledge suffering. The following passage from *La grande santé* brings to the fore how the portrayal of physical and psychological suffering, as well their social impact, can be integral to health:

L'autre soir, autour d'une conversation avec des amis, j'ai soudain voulu intervenir. D'ordinaire je préfère me taire. Là, je parle sous le regard concentré de l'assemblée qui veut éviter de me faire répéter mes gargouillis. Soudain, un petit chien se plante en face de moi et se met à aboyer en me regardant. Je n'ai pas su s'il avait peur ou s'il se sentait complice. Je me suis tourné vers Séverine: "Quand je parle, je donne l'impression d'aboyer, n'est-ce pas?" Elle m'a répondu: "Non, on dirait plutôt un hululement." Une part de moi devient animale. (*La grande santé* 101)

The topos of a diseased and dying body taking on animal features or turning into an animal altogether is widely explored in twentieth-century French literature and philosophy, and the focus on the transformation of Badré's language chimes in with these motifs.¹⁸ Badré exposes the "creatureliness" of dying,¹⁹ which he presents as a fleeting "impression," thereby hinting at the ekphrastic quality of his writing. His bodily transformations are so dramatic that they effectively erase his human features, including voice and words, blurring the boundaries between his animal and human self. The shifts in vocabulary—the progression from "gargouillis" to "aboyer" and "hululement"—highlight the exceptional cruelty of the situation. Importantly, however, these shifts are embedded in a seemingly casual interchange between Badré and his wife. This framing brings to the fore the tragic nature of his situation, but also highlights a 'healthy' reaction to it—documenting it allows Badré to claim a position as an outside commentator, while at the same time integrating this exceptional experience as part of the texture of what constitutes his new reality of everyday life.

Certainly, commenting on a dying body from the vantage point of a lucid mind speaks to the specific experience of ALS. Badré writes, "mon corps et moi nous ne nous entendons plus. [...] Mes mains ne sont plus des mains, mes bras ne sont plus des bras, et ma langue n'est plus ma langue ("L'intervalle" 59).²⁰ He pushes the image even further when he states, "Mon corps se suicide. J'ai beau me trouver en complet désaccord avec lui, je vois bien qu'il ne se range pas à mes raisons. Alors, j'affermis mon esprit pour combattre du mieux possible cette volonté de mourir" (*La grande santé* 101–2). And yet, the suicidal process of his body strengthens Badré's will to live. It is for that reason that his work cannot be described as autothanatographical, if we understand the term in its strict sense, namely as referring to the writing of one's

“death.” Rather, Badré writes about his dying, which even if it is geared toward the endpoint of death, is understood as another form of living.

In this context, it is telling that a concept of health is absent from the WHO definition of palliative care. This absence gestures to the fact that aspiring to health is considered as outside the reach of those facing life-threatening illness. But if Badré calls for the coexistence of dying and health, this is also because his definition of health is more modest in scope; it is, as Badré writes, “un ajustement entre le corps et l’esprit” (“L’intervalle” 64). He thereby substitutes perfection with the ability to adapt. This emphasis on “ajustement” evokes the thought of the French philosopher and physician Georges Canguilhem who criticized normative understandings of health and illness used in medical and scientific thought and instead called for “adaptability” as the defining feature of health.²¹ By giving health a central place in a narrative about dying, Badré, just as Canguilhem, criticizes the language of norms and refuses to accept the ‘normalcy’ of dying. His aim instead is to adjust to the new reality of his life, and part of that healthy process includes naming—and not hiding—the hardship he is facing. The rich modes of representation he uses—which involve his turning to literary and visual interlocutors both at a topical and formal level—allow him to engage in precisely such a vital process of adjustment.

Proximity and distance: auto-palliation

Literature is assigned a privileged role in Badré’s understanding of health. He remarks, “Je tire de ma bibliothèque la force de vivre” (*La grande santé* 155). His illness may be “une expérience douloureuse de la séparation,” but “l’antidote au cauchemar, le moyen de rester éveillé, la grande santé a pour nom littérature” (*La grande santé* 106). The invasion of medicine is viewed as endangering the access to health that literature provides: “L’hôpital s’invite chez moi. Il veut sa place. Il veut que j’enlève une partie de ma bibliothèque pour s’installer. C’est une horreur!” (*La grande santé* 102). On the one hand, Badré presents health as a state disconnected from the medical health-illness dichotomy. On the other hand, literature is linked to health because it constitutes a potent response to physical discomfort.

How this process works becomes clear in the book’s many abrupt moments of transition, when Badré moves from his experience of disease to theoretical explorations of literature. One such example that rapidly shifts between the experiential and the aesthetic—one of the defining features of Badré’s writing—appears when he switches mid-sentence from the growing weakness of his arms to the nineteenth-century Russian poet Ossip Mandel-

stam: “Le matin, dans ma douche, quand je peste contre la faiblesse de mes bras, grelottant sous le mince courant d’air qui s’invite dans la salle de bains, je pense à Mandelstam” (*La grande santé* 50). The poetry of Mandelstam seemingly appears as a non sequitur to Badré’s physical distress, a sudden and absurd transition from the body to the mind. Yet that shift exemplifies the palliative—in the non-metaphorical sense of pain-alleviating—effect someone like Mandelstam encapsulates. Mandelstam is a remedy that can counteract Badré’s physical discomfort. He is not a mere ‘distraction,’ but via a chain of intertwined personal and literary associations, functions like “une efficace madeleine de Proust” (*La grande santé* 48). As the tasting of the Proustian madeleine triggers involuntary memory, Mandelstam stands for a complex process that intertwines mental and physical experience, and, in turn, just as the madeleine does, it produces mental and physical effects. Mandelstam intersecting a sentence that lays out the details of Badré’s physical suffering thereby illustrates that turning *to* Mandelstam entails more than turning *away* from his own suffering: it signifies an active and potent response to suffering.

Engaging with Mandelstam also means leaving behind the isolation of Badré’s condition. Mandelstam himself was cruelly exiled by Lenin; he was “réduit à la misère” as Badré puts it. Mandelstam’s many years of imprisonment, persecution, and desperation, and the constant question of whether to endure the hardship or commit suicide that characterizes his poetry, feels familiar to Badré. His engagement with authors, thinkers, and artists whom he defines as able truly to share his experience, allows him to establish a community of suffering. For Badré, as for other contemporary end-of-life writers,²² Franz Kafka’s *The Metamorphosis* becomes an important point of reference in this regard. One of the aspects of *The Metamorphosis* that resonates with Badré is the question of isolation: “Je plains le malade solitaire. Je suis heureusement très entouré. Comme Gregor dans *La métamorphose*, je deviens un fardeau pour mes proches” (*La grande santé* 140). He asks, “Comment un malade solitaire peut-il affronter l’administration kafkaïenne des aides?” (*La grande santé* 141). He answers his question with an enumeration of an endless list of the administrative tasks, phone calls, letters, and applications that await someone diagnosed with a terminal illness. He highlights the extent to which he depends on being helped by family and friends, and he is indubitably grateful to have others to depend upon. Yet he is all too aware that he is a burden for them (*La grande santé* 143, “L’intervalle” 62), and he resents how some of those on whom he depends relate to him since his diagnosis—“j’en ai horreur des tons apitoyés ou, pire, qu’on me parle comme un enfant ou à un vieillard sénile” (*La grande santé* 143).

It is through Kafka, who “met en scène la violence des rapports familiaux” (*La grande santé* 106), that Badré can relate to his continuously meandering relationship between proximity and distance with those who care for him. He presents a more doubtful view of the belief that family and friends constitute a support system for the terminally ill. Importantly, Badré repeatedly alludes to the fact that he is sparing the reader the details of the more hurtful scenes, thereby covering and hiding—to go back to the etymological roots of ‘palliative’—the many ways in which interactions with others have become painful: “Je passe sur les innombrables sources de tensions que cette situation provoque inévitablement” (*La grande santé* 140). In “L’intervalle,” he remarks, “Cette situation est source de violence. Nous devons apprendre à maîtriser cette violence” (“L’intervalle” 62). Badré thereby questions whether the ones closest to terminal patients may be those farthest from them.

Badré also reflects on the explicitly palliative characteristics of his engagement with Kafka’s story. He recognizes that he is drawn to *The Metamorphosis*—because his and Samsa’s stories are alike—and yet, he remarks that reading about Samsa’s experience is fascinating, which is irreconcilable with the actual hardship of his condition: “Au fond, j’envie un peu le destin de Gregor. Voilà un bel exemple du pouvoir de la littérature [...]. L’impitoyable réalité de la SLA, sous mes yeux, m’effare. Pour moi, le cauchemar, c’est ça. La métamorphose de Gregor relève aussi du cauchemar. Je lui trouve pourtant quelque beauté. Pouvoir du langage!” (*La grande santé* 114). Badré describes the proximity and community that writers and artists afford him. Yet he soberly recognizes that they are unable to transform his own reality into something beautiful and meaningful that it is not. He is not buying into an idealization of the healing powers of the arts: *The Metamorphosis* may tell a story similar to his own, but his experience cannot be embellished by a comparison with Kafka. The “pouvoir du langage” cannot change the experiential dimension, but what it offers, as Badré remarks, is a springboard for thinking about how his experience of dying affects his own aesthetic expression of it. Engaging with Kafka therefore ultimately means engaging in a meta-representational form of thinking.

The palliation of ekphrasis

Badré is both a writer and a painter. Accordingly, painting—while he is still able to do so—as well as engaging theoretically with the visual arts and the last works of painters in particular, pervades his writing about his terminal illness. Literary scholars have commented on the dominance of the visual in contemporary literature and culture generally. This heightened presence of the

visual, as some have proposed, has led to new forms of intermediality as well as a revival of ekphrastic writing. In contemporary literature, ekphrasis, the classical genre of rhetoric narrowly described as the literary description of visual art, has been reinterpreted as an emotional and embodied response to visual images. It is often understood as a commentary on modes of representation themselves.²³ This understanding applies to Badré in particular, as *La grande santé* and “L’intervalle” overflow with ekphrastic writing, in addition to which his painterly vision triggers visual metaphors unrelated to actual artworks. By granting the meta-representational mode of ekphrasis such a central role in an autobiographical text about dying, Badré turns the ekphrastic into a vector for exploring the reliability of the verbal, as well as staging the collision of the scientific and spiritual at the end of life.

The way Badré unfolds his terminal diagnosis—what has come to be described as the “primal scene” in illness and end-of-life narratives²⁴—illustrates the importance of the ekphrastic in his work. The actual moment of diagnosis is ironically subverted. Badré stuns his physician by acting relieved not to have cancer or a virus. His doctor seems disappointed to get only “un léger sourire, l’air probable du Lazare qui ressuscite” (*La grande santé* 18) in return for a diagnosis as detrimental as ALS. This transgression has to be juxtaposed to Badré’s description of a demolition site, which precedes and follows the breaking of the bad news by his physician. Badré contemplates the demolition site while waiting for his diagnosis in the courtyard of the Hôpital Saint-Joseph:

Me fascinaient les deux pelleteuses en train de démolir le vieil hôpital sous les fenêtres de ma chambre. J’étais frappé par l’habileté de ces grosses machines qui détruisaient et triaient les déblais, avec la délicatesse d’une main et la brutalité d’un bœuf. Dans un nuage de poussière, je voyais disparaître méthodiquement les allées de consultation, les blocs opératoires, les toilettes, les sous-sols. Images de catastrophe, cette mise en ruine. J’ai contemplé la démolition plus longtemps que tout le reste, comme englobé dans le processus. Une sorte de théâtre vivant, au décor titanique ou une installation géante d’art contemporain qui abolirait les frontières entre le monde artificiel sortie de l’imagination d’un créateur et la réalité tangible. Ce champ de ruines, c’était le lit défait de mon existence. (*La grande santé* 15)

Badré’s state of absorption encapsulates his take on writing about his terminal condition: as he enumerates the hospital’s distinct functional elements, his witnessing of their piecemeal destruction turns the site into a “théâtre vivant.” The gradual disappearance of borders that plays out before his eyes enables his creativity, as the image he transcribes in words makes the workings of his imagination tangible for the reader.

The uncanny relevance of this “vision d’apocalypse” (*La grande santé* 18) dawns on him once he receives the medical diagnosis. The description of the

destruction of a hospital seemingly clashes with the fact that the diagnosis he is about to receive casts his life in the throes of medicine. But the terminal nature of the diagnosis moves beyond the sphere where medicine has a claim to power: dying cannot be contained within the narrow confines of the hospital. It is therefore not the doctor's naming of the disease, but Badré's afterthought—"la vision des deux pelleteuses tourbillonne curieusement devant mes yeux. En un éclair, je comprends le sens de cette vision" (*La grande santé* 18)—which allows him to understand the gravity of his situation. The image conjured by his imagination thereby liberates his life—and his dying—from the destructive effects of a diagnosis conveyed bluntly in words.

Experiencing the limitations of language as a means to capture the experience of dying gives rise to the ekphrastic in Badré. This literary device is particularly pronounced in his response to religious works of visual art. Affording Badré communion, consolation, and hope, ekphrasis turns into a form of spiritual accompaniment. At the same time, the ekphrastic processes of transformation Badré undertakes are accompanied by an underlying fear and estrangement emanating from the fundamental resistance between word and image.²⁵ These tensions recall the concepts of "ekphrastic hope" and "ekphrastic fear," which the art historian and literary scholar W. J. T. Mitchell has introduced to explore the emotional stages of ekphrasis.²⁶ Mitchell thereby emphasizes the shifting confidence in the potential of representation and processes of transformation more widely, highlighting that the linguistic expression of the visual both engenders new relationships and meets fundamental resistances and boundaries when words appear inadequate to express an image. In Badré, this meandering emotional process is mapped closely onto religious motifs and thereby allows him to shift registers frequently between consolation and lamentation.

Badré's engagement with Titian's last painting *Pietà* in *La grande santé* highlights this dual emotional mode. It culminates in Badré's considerations about the intermedial potential of visual art as a means for self-care in times of debilitating illness:

Je l'ai regardée [la *Pietà*], méditée et même, plusieurs fois, dessinée. Des croquis sur le vif, pour mieux saisir un détail. Mes dessins écrivent ma vie par d'autres moyens. Dessiner (*designare*) est l'autre verbe pour méditer. La terrible maladie qu'est la SLA me prive de forces pour continuer à tenir un crayon. Alors je dessine encore, dans ma tête. (*La grande santé* 194–95)

Badré crowns his ekphrastic rendition of the *Pietà* with remarks concerning the possibility of representation itself: his response to a visual image in writ-

ing simultaneously enhances (“mieux”) and destabilizes the process of literary creation, surmising that a strict distinction between the categories of the verbal and the visual breaks down as part of the process of transformation. Interweaving his own multimedial take on life-writing with an ekphrastic rendition of the *Pietà*, Badré creatively blurs the boundaries of form and function of the language characterizing one art form with that of another. On the one hand, Titian’s *Pietà* allows Badré to engage with the ways in which an inter-artistic encounter—his response to the painting in *La grande santé* (*La grande santé* 194)—makes him see his own situation more clearly. On the other hand, his remark also signals a suspicion about the limitation of the verbal mode at the end of life. While Mitchell’s claims about metaphoricity make room for the emotional encounter on a theoretical level, Badré claims the relevance of ekphrasis as an emotional catalyst in the intimacy of autobiographical end-of-life writing. In Badré, ekphrastic hope and fear are rooted in his ability to connect the verbal and the visual, but the community or estrangement this connection affords him also takes on a spiritual dimension.

This dimension becomes particularly pronounced in the way Badré foregrounds the different responses to Christ’s death between Mary, the mother of Jesus, and Mary Magdalene in Titian’s painting. Mary Magdalene is furious and unaccepting; she confronts death with reason and, according to Badré, thereby encapsulates science’s aim to eradicate death altogether. Mary’s calm acceptance, on the contrary, is grounded in mysticism’s response to death. It is her “confidence intrigante” (*La grande santé* 194) to which Badré feels increasingly drawn. And yet, as Badré concludes, Titian’s painting leaves the conflict unresolved: “la lumière de la science brille du même éclat que celle de la résurrection. L’une écho l’autre” (*La grande santé* 194). In a similar vein, Badré’s work is imbued with the irrational hope for a scientific cure while he simultaneously intimates that he identifies with Mary: “je me suis tout de suite senti le contemporain de cette *Pietà*” (*La grande santé* 194).

“L’intervalle” further explores the potential of the ekphrastic as a means to outline the role played by a spiritual perspective in a narrative about dying. Badré opens the text with a discussion of the Spanish contemporary artist Jaume Plensa’s installation entitled “Together,” which he visited as part of one of his last trips to Venice after his diagnosis. Plensa’s work was commissioned for the 56th Biennale and consisted of two larger-than-life sculptures installed in the Basilica San Giorgio Maggiore—a gigantic hand suspended from the cupola over its altarpiece and a giant head situated in the nave. Both sculptures are made from wire mesh, allowing the church light to shimmer through their structure, thereby turning their larger-than-life presence into ephemeral,

FIGURE 1. Jaume Plensa, “Together,” Abbazia di San Giorgio Maggiore, Venice. Photo: Grald Cordonier.²⁷

apparition-like objects. Badr focuses on Plensa’s head sculpture specifically (Figure 1). He thereby connects “L’intervalle” to the scene of diagnosis in *La grande sant*, where Badr’s vision of the demolition site allowed him to anticipate a future self that resonates with Plensa’s head sculpture. In *La grande sant* Badr predicted, “dans un temps venir, il ne me restera plus de proprement humain que la tte, tandis que mon corps devra tre suppl par un engin mcanique, une sorte de pelleteuse mon chelle, pour fonctionner” (*La grande sant* 18). Plensa’s installation turns into the incarnation of Badr’s apocalyptic vision, while it is itself transformed into an ekphrastic presence in “L’intervalle.”

These mutual interactions trigger a process of transformation that extends beyond the stylistic. In describing the installation, Badr wonders whether he should understand Plensa’s sculpture—and by extension his own impending death—either as a decapitation or a divine benediction. Meandering, again, between Mitchell’s hope and fear, he remarks that in this current moment of suspense, Plensa’s work speaks to him precisely because he does not have to

decide which one it is to be: “L’artiste ne nous enferme pas dans un système dogmatique. Au contraire, il ouvre l’espace. Nous sommes là, minuscules, devant ces géants. Notre espace et le leur s’entremêlent. [...] La création de Plensa ni ne console ni n’insiste sur l’absurde, ou l’horreur. Elle ouvre nos yeux sur l’invisible” (“L’intervalle” 60). Plensa cannot resolve Badré’s present situation. But just as Titian’s painting, Plensa becomes the basis for an ethical encounter that blends into spiritual accompaniment as part of the momentary ‘togetherness’ created in the Basilica. Badré deepens the meaning of Plensa’s sculptures in his own words. Simultaneously, he experiences the limitations of these words as Plensa resists his appropriation. Plensa’s work thereby signals an important resistance to dogmatism, a refusal to let any one approach and any one mode of representation to express it—be it scientific or spiritual—dictate the appropriate response to Badré’s experience of dying. And yet, Plensa’s head is installed in a Basilica, unable to close itself to the church light that shimmers through its wire mesh. Badré’s rendition of Plensa’s head inscribes it within that church, whereby the text itself gestures to the fact that it will remain enclosed in an endless cycle of reproducing this spiritual space.

“Je raconte mes antidotes” is how Badré defines his writing on dying (*La grande santé*, cover). His take on autothanatography is thereby intimately linked to palliation—engaging with literature and the arts in particular is presented as a kind of Derridean *pharmakon*, a potent response or remedy to his dying. As such, Badré’s work, just as that of the Romantic poets, bears testimony to Pladek’s “palliative poetics.” Badré finds a safe haven from the reality of a worsening condition in writing. At the same time, documenting his dying constitutes a means to acknowledge the dreadful reality of a debilitating illness. His marked engagement with other writers and artists also triggers what Wilson calls the “mode of absorption and distraction” that takes Badré away from his present situation (Wilson 12). As part of this process, Badré carves out a space for thinking about dying that is connected to but also transcends the personal experience. He sketches out that a flexible concept of health becomes an important reference point for the dying, he offers a nuanced perspective on the role of family support in terminal illness, and he engages with the unresolvable rivalry between spirituality and science at the end of life. He thereby provides thought-provoking impulses for thinking about the conceptual basis of some of palliative care’s key principles. The aim of this article has not been to diminish the relevance and practical significance of these principles. Rather, I have proposed that Badré’s account of dying

questions the binaries that define some of palliative care's indubitably important tenets—such as the affirmation of the normalcy of dying, the role of others in end-of-life care, and the need for spiritual accompaniment. Through Badré's innovative use of ekphrasis his work resists turning into a critique of palliative care, but rather presents itself as an alternative version of palliation. In his ekphrastic response, Badré highlights that words or pictures on their own are insufficient to illustrate the processes of transformation and non-binary thought that are key to his experience of dying and its representation. He thereby opens up new avenues of thought for the role of palliation in end-of-life writing.

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Notes

1. Frédéric Badré, *La grande santé* (Paris: Seuil, 2015).
2. Frédéric Badré, "L'intervalle," *Nouvelle Revue Française*, 617 (2016): 59–65.
3. Prior to that, Badré had published a biography of Jean Paulhan, *Paulhan le juste* (Paris: Grasset, 1996), a book of literary criticism, *L'avenir de la littérature* (Paris: Gallimard, 2003), several newspaper articles, and founded, together with Yannick Haenel and François Meyronnis, the magazine *Ligne de risque* (1997).
4. An exception is Ruwen Ogien's *Mes mille et une nuits: La maladie comme drame et comme comédie* (Paris: Albin Michel, 2017), which interweaves references to literary and philosophical works into an autobiographical essay about terminal illness.
5. This article uses the terms "end-of-life writing" and "autothanatography" interchangeably in order to refer to autobiographical writing about dying. However, Frédéric Weinmann highlights that from a theoretical point of view an autothanatography should be understood as "un écrit ayant pour objet l'histoire d'une mort particulière, racontée par le mort lui-même" (Frédéric Weinmann, "*Je suis mort*": *Essai sur la narration autothanatographique* [Paris: Seuil, 2018], 12). Badré refers to his impending death; however, he does not assume a post mortem authorial position.
6. In *The Philosophy of Palliative Care: Critique and Reconstruction* (Oxford: Oxford U P, 2006) Fiona Randall and R. S. Downie make the case that the World Health Organization's definition of palliative care is in fact a condensation of a "philosophy," since it reflects the values held by healthcare professionals specializing in palliative care (11).
7. David Clark and Jane Seymour, *Reflections on Palliative Care* (Buckingham: Open U P, 1999), 80.
8. The term has been used in the more general sense of "pain alleviating" in medical writing since the Middle Ages. See Michael Stollberg, *A History of Palliative Care, 1500–1970: Concepts, Practices, and Ethical Challenges* (Cham: Springer, 2017).
9. David Clark, *To Comfort Always: A History of Palliative Care Since the Nineteenth Century* (Oxford: Oxford U P, 2016), 160.
10. Saunders recorded over 1,000 patient stories. See Yasmin Gunaratnam and David Olivere, *Narratives and Stories in Health Care: Illness, Dying, and Bereavement* (Oxford: Oxford U P, 2009), 33–38.
11. For the full WHO Definition of palliative care, see <https://www.who.int/cancer/palliative/definition/en/>.
12. Patricia Stanley and Marsha Hurst, "Narrative Palliative Care: A Method for Building Empathy," *Journal of Social Work in End-of-Life & Palliative Care*, 7:1 (2011): 40.
13. Brittany Pladek, *The Poetics of Palliation* (Liverpool: Liverpool U P, 2019), 20.

14. Emma Wilson, *Love, Mortality and The Moving Image* (Basingstoke: Palgrave MacMillan, 2012), 12.
15. Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), 3.
16. Friedrich Nietzsche, *The Gay Science*, Bernard Williams, ed., Josefine Nauckhoff, trans. (Cambridge: Cambridge U P, 2001), 247.
17. Giles Fraser, *Redeeming Nietzsche: On the Piety of Unbelief* (London: Routledge, 2002), 90–91.
18. See Anna M. Elsner, “‘Penser commence peut-être là’: Proust and Derrida on Animals, Ethics and Mortality,” *Modern Languages Review*, 111 (2016): 375–91.
19. The term is borrowed from Seamus O'Mahoney's *The Way We Die Now* (London: Head of Zeus, 2016), 254.
20. The described estrangement between body and mind recalls another French autopathography concerned with a similar phenomenon, Jean-Dominique Bauby's *Le scaphandre et le papillon* (Paris: Robert Laffont, 1997), as well the corporeal confinement of Alexandre Dumas's fictional character Noirtier in *Le Comte de Monte Cristo* (1844) (Paris: Gallimard, 1998), an important point of reference for Bauby.
21. Georges Canguilhem, *Le normal et le pathologique* (1966) (Paris: PUF, 1998), 128.
22. Tony Judt, who also documented his dying from ALS, refers to Kafka throughout his collection of essays entitled *Memory Chalet* (London: Penguin, 2011), and particularly in the essay “Night.”
23. Renate Brosch, “Verbalizing the Visual: Ekphrasis as a Commentary on Modes of Representation,” in *Mediale Performanzen: Historische Konzepte und Perspektiven*, Jutta Eming, Annette J. Lehmann, and Irmgard Maassen, eds. (Freiburg im Breisgau: Rombach, 2002), 103.
24. Anne Whitehead and Angela Woods, “Introduction,” in *The Edinburgh Companion to the Critical Medical Humanities*, Anne Whitehead and Angela Woods, eds. (Edinburgh: Edinburgh U P, 2016), 2.
25. Even if Badré describes only works of art of Christian origin, he makes no distinction between different religions, which is why I am adopting the more general term ‘spirituality’ instead of religion.
26. William John Thomas Mitchell, *Picture Theory: Essays on Verbal and Visual Representations* (Chicago: U of Chicago P, 1994), 152–54.
27. The photograph accompanies Gérard Cordonier's article “Un dernier tour à la Biennale pour se délecter de Venise,” *24 heures*, 3 October 2015, <https://z.umn.edu/6llh>.