Living with Dying in France: Contemporary French Writing about End-of-Life Care

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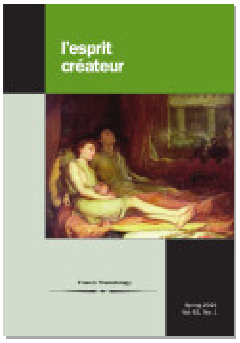

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THE FRENCH NATIONAL HEALTHCARE system enjoys a reputation for excellence, both in terms of outcomes for patients and the accessibility of care. However, the 2016 overview of French health policy put out by the Organisation for Economic Co-operation and Development raises concerns about the appropriateness of some care in the French healthcare system, calling for better engagement of patients in the decision-making process about treatment options.[1] This article examines the representation of terminally ill patients' experience of the French healthcare system in two recently published autopathographical narratives.[2] In *Réparer le monde*, Alexandre Gefen defends the idea that twenty-first-century French literary culture "a vu l'émergence d'une conception que je qualifierai de 'thérapeutique' de l'écriture et de la lecture, celle d'une littérature qui guérit, qui soigne, qui aide, ou, du moins, qui 'fait du bien.'"[3] Gefen's point is valid for the two authors whose work will be explored here, and can also be applied fruitfully to French society more broadly and its medical system as it accompanies its citizens at the end of life. "Je suis vouée simplement à imaginer une écoute *post mortem* et me satisfaire d'avoir été un peu utile," says Marie Deroubaix, pressing for legal reform to euthanasia laws in France through her book *6 mois à vivre: J'ai choisi de mourir dignement* (2012).[4]

In *Le tout dernier été* (2017) Anne Bert writes to free herself from the norms of her culture as regards dying: "j'ai décidé d'écrire sur ma fin de vie afin de me réapproprier ce fantasme si intime du mourir, en m'affranchissant de celui que notre culture et la loi française nous imposent."[5] These authors' writing about end-of-life care and their wish to be euthanized challenges normative attitudes to medical care and demands reflection on best practices. This article outlines the strengths and weaknesses of the French healthcare system from the point of view of those who use it at the end of their lives, the better to reflect critically on its current state and inform its future development. The aim here is to elucidate distinctly French attitudes to the contemporary experience of final illness, dying, and death in that country.

Many parental stories about a terminally-ill child present a positive image of the French system available to support the patient and their family in managing end-of-life care.[6] Such is not the case with Bert and Deroubaix's accounts of dealing with terminal illness. At fifty-six, Deroubaix was diagnosed with lung cancer, which quickly spread to her brain and became inoperable. Her posthumously published text includes a preface, occasional comments, and a final chapter by her husband Bertrand, and was the bestseller on Amazon in France the week after it was published.[7] Bert was fifty-seven when diagnosed with amyotrophic lateral sclerosis, a type of motor neurone disease that rapidly brings on paralysis; she completed her text and it was published two days after she died.

While different in style, both authors' works criticize similar aspects of the French healthcare system: doctors' reluctance to speak plainly about their illnesses; the power imbalance in the relationship between patient and doctor; and the lack of choice in the management of their death on French soil. Deroubaix must also deal with doctors' preference to pursue treatment despite her terminal diagnosis. Deroubaix and Bert recount their experiences of being diagnosed during what Whitehead and Woods call the "primal scene" of the doctor-patient encounter, their treatments and decisions about end-of-life care.[8] Experiencing what Foucault calls the "medical gaze," which separates their sense of self from their ill bodies, is a traumatic experience that their texts try to mitigate.[9]

The experience of one's own terminal illness requires entry into new spaces (such as clinics, hospitals, doctors' surgeries), the development of new relationships with healthcare providers, and a new phase in relationships with community, friends, and loved ones and with the unexpectedly very finite self. Susan Sontag tells us that:

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.[10]

Deroubaix and Bert bear witness to the disorienting experience of becoming citizens of this other French state of illness and medical care, a France of which neither of these authors was aware before the encounters related in their books. Their status as middle-class, professionally successful, financially secure women is germane to their experiences and decisions, a point to which I will return. Before her cancer moves to her brain and becomes terminal, Deroubaix is traumatized by a lung operation and the surgeon's severity with her afterwards. She resolves to avoid returning to such a disempowered, vulnerable position (Deroubaix 74–76, 115). Following her diagnosis and until her death, Anne Bert campaigned publicly on television, radio, her personal blog, and in the print media for legal reform of French euthanasia law.[11] Her death was reported across the French media, and her daughter Roxane Guichard continues to campaign publicly for changes to French law on euthanasia.[12] In her book, Bert states that "de ce récit, de ce combat [pour l'euthanasie en France], je ne fais pas thérapie—d'ailleurs se soigne-t-on de mourir? Je n'en fais pas non plus un texte militant. Non, il s'agit plutôt d'une incursion littéraire sur le rebord de soi" (Bert 17). Bert's decision deliberately to relegate the medical world mostly to the background of her text contrasts with her militant public persona; it also differs from Deroubaix's meticulous detailing of her encounters with it throughout her book.

The authors contend with the power structures of the medical world while simultaneously seeking human contact and a continuation of their sense of self in changed physical conditions. The unequal, even paternalistic power dynamics in their encounters with doctors preoccupy them both, because their doctors either refuse to be forthright about the prognosis (for Deroubaix) or resist discussion of it (for Bert) (Deroubaix 4, Bert 28–31).[13] Both resent the fact that their doctors withhold information from them: Foucault's concept of "le pouvoir/savoir" is apt here to define the way the French doctors the authors meet resist acknowledging terminal illness.[14] Through their writing, Deroubaix and Bert provide insightful testimony of the values and motivations of the French medical system, as they perceive them in their relationships with their doctors, and reject the alien, passive subjectivity they feel is thrust upon them within the medical system. They also honor their own lives and intimate relationships. Rita Charon affirms that:

> The powerful narratives of illness that have recently been published by patients reveal how illness comes to one's body, one's loved ones, and one's self. These narratives […] demonstrate how critical is the telling of pain and suffering, enabling patients to give voice to what they endure and to frame the illness so as to escape dominion by it.[15]

Charon focuses on patients and the positive effects of narrating illness for them as individuals; however, it is useful also to dwell on the ways in which such narratives depict the healthcare system that patients encounter—and may at times have to endure, and escape—the better to underline its strong and weak points as it responds to the ill person's condition and their priorities. For Deroubaix and Bert, the French healthcare system is uncomfortable. The crux of the matter is Deroubaix and Bert's attitude to the inevitable outcome of their incurable medical conditions. Both see possible prolonged suffering in their final days as futile, since there is no hope of recovery. Both reject the prospect of causing pain to their family, a point that will be explored further. Despite very limited time remaining at their disposal, both choose to invest some of it in writing a book that records their final months of life and their revolt against the norms of end-of-life care that would await and confine them, due to existing legislation. Reflecting on her decision to write, Bert notes, "Ce sont la médecine, incapable de m'apporter des soins curatifs, et la France, de m'accorder aide et assistance pour mourir, qui m'obligent à me prêter au collectif, dans l'espoir que cette exposition secoue les consciences et aide chaque Français à obtenir sa liberté de choix" (Bert 14). Bert calls explicitly here on her compatriots to bring about reform for greater individual freedom of choice. Deroubaix asks:

> Au-delà de ma propre histoire, n'est-il pas essentiel pour nous Français de convaincre le gouvernement de cette nécessité de pouvoir choisir en toute liberté la fin de sa vie? […] Donc, je me jette à corps perdu dans l'écriture […] avec l'espoir de suggérer une loi simplifiée sur l'euthanasie, imitant celle de la Belgique ou des Pays-Bas. (Deroubaix 132–33)

The authors appeal to the fundamental French concept of "liberté" in their calls for freedom of choice for all French people in shaping their end-of-life care, and the need for collective action to safeguard individual choice. Anne Hunsaker Hawkins states that "today, with the possibility that one's life might be prolonged indefinitely, […] what many now fear is a 'medical death'—the technological prolongation of life at the expense of any real sense of the quality of life."[16] Deroubaix and Bert are concerned with the quality of the end of their lives (and their afterlives—each takes care to organize her own funeral and final resting place). This is a concern not shared by their doctors in France, where triumph over illness seems to them to be valued above all else, due to "the pervasive ethos of denial" of death in our modern technological culture (Hawkins 94). The authors' wishes are at odds with the ethics of the healthcare system—newly qualified doctors in France must sign the "code de déontologie," also known as the "Serment d'Hippocrate," which is part of the "Code de la santé publique." The text explicitly states, "Je ferai tout pour soulager les souffrances. Je ne prolongerai pas abusivement les agonies. Je ne provoquerai jamais la mort délibérément."[17] Speaking from his professional perspective as a doctor, Bert's friend Hubert remarks, "Tu nous mets en limite de compétences" ("J'ai décidé de mourir" 43 mins, 44–46 sec). Euthanasia and assisted dying are illegal in France, where the revised 2016 Loi Léonetti (the 2005 version of which was in force at the time Deroubaix was writing) decrees that palliative care must be given to terminally ill patients who write advance directives and/or refuse continued treatment and request heavy and continuous sedation until death.[18]

Deroubaix and Bert are determined to control the end of their own lives and decide for themselves when they have reached the point where they wish to die (Deroubaix 28–32, Bert 36–38).[19] Fear of a lengthy, painful death robs Deroubaix of pleasure in daily life after her final diagnosis: "craignant la mort, on déteste la vie" (Deroubaix 19); she is dissatisfied with palliative care as practiced under the Loi Léonetti because she feels the law is either not respected or only belatedly in clinical settings, "ces mouroirs où l'on cuit à petit feu" (Deroubaix 26–27). Bert is offended by her lack of autonomy within the French medical and judicial systems, affirming that "notre liberté ne s'arrête pas à la porte de l'hôpital. Au terme d'une maladie incurable, le droit, seul, peut nous rendre égaux, nous qui sommes tous des cas particuliers, en nous permettant de choisir de ne pas subir ce que l'on juge, en notre âme et conscience, inacceptable" (Bert 16). Both reject the invasive treatment options and heavy morphine use offered by conventional French medicine in managing end-of-life pain. Instead, they wish to end their lives once they can no longer enjoy a certain degree of autonomy. Being euthanized is thus a politicized act these women undertake in the knowledge of how little time they have, and one they must orchestrate in cooperation with doctors within a demanding, carefully-regulated Belgian medical system that does not wish to become a euthanasia destination for foreigners.[20]

In bringing an independent attitude into their encounters with doctors, Deroubaix and Bert clash with a French medical culture that is reluctant to engage with patients' requests for empowerment at the end of their lives.[21] Deroubaix recounts antagonistic conversations with numerous doctors (Deroubaix 41, 70, 75–76) and sees that her desire to deliberate over her treatment and control her death disconcerts them: "pour les médecins, je suis un cas d'école, une patiente pas comme les autres, une 'impatiente'" (Deroubaix 11). Her husband observes that Marie's "esprit critique face aux 'spécialistes' passe pour une sorte de fanatisme. Elle réfléchissait, elle comparait. Cette attitude mettait certains médecins hors d'eux" (Deroubaix 75). Her doctors' zeal for treatment, even once her brain tumors are inoperable, also frustrates Deroubaix (Deroubaix 41). As a journalist familiar with writing about medicine, she feels able to reflect on medical research for herself. She explores medical literature on cancer treatment and its success, and wonders whether financial imperatives may lie behind the treatments her doctors encourage her to pursue in France (Deroubaix 44–48).[22] Her doctors' refusal to acknowledge that her cancer is incurable causes great distress: "mon combat est aussi contre ce silence. Ce silence médical qui hurle à mes oreilles et me réveille en pleine nuit" (Deroubaix 22). Felicity Goodyear-Smith and Stephen Buetow note that when paternalistic doctors withhold information from patients, “the implicit assumption is that patients cannot cope with or understand certain information” (Goodyear-Smith and Buetow 456). Deroubaix and Bert detect this attitude during their diagnosis, and it causes a breakdown of trust between them and their doctors. Deroubaix sees herself and other severely ill people as “des proies faciles” (Deroubaix 44) for the medical establishment. There is an urgent quality to Deroubaix’s writing, and her liberal use of exclamation marks shows awareness of her lack of time and conveys her sense of injustice. Of the several doctors she names by an initial letter, only one is portrayed positively, le docteur G. who, though supportive and sympathetic, is nonetheless resigned to the limitations of the system within which he works (Deroubaix 34, 56). When a Belgian doctor, le docteur T., accepts Marie’s request to euthanize her, both Marie and Bertrand separately comment on his phrase, “on ne vous laissera pas tomber […] je ne vous laisserai pas tomber” (Deroubaix 111), which gives Marie immense relief, and which for Bertrand shows the doctor’s commitment to “un combat pour les droits de l’homme” (Deroubaix 111). Similarly, after meeting her Belgian doctors, Bert notes, “Je ne suis plus seule” (Bert 113). The authors’ sense of solitude in the French healthcare system contrasts with their feeling of safety and companionship in the Belgian one.

Like Deroubaix, Bert is determined to manage her death as she sees fit: “la mort n’est que fiction. Et dans celle que je m’invente, il n’y a pas de place pour les regrets vains. C’est contre les autres fables que l’on veut m’imposer que je me bats. Et cette lutte, parce qu’elle m’expose, est une difficile épreuve” (Bert 13). Before her diagnosis, Bert was a successful writer of what she calls “littérature de l’intime,” so the subject matter of her final book aligns with her previous professional role. Bert is uncomfortable with the public attention generated by her campaign for law reform on euthanasia; in resisting the status quo, she feels compelled to step outside her life as a private citizen and bear witness to her end-of-life situation, which she stresses is not an unusual case (*France Télévisions*, April 12, 2017). Her solution in her book is to retreat into the private realm and revel in the natural beauty of her surroundings at home, in her happy relationships with her family, friends, and community, and carefully to contemplate the process of detaching, both emotionally and practically, from her life and environment, as her death approaches (Bert 106–7).

Deroubaix’s and Bert’s texts are *cris du cœur* that underline why and how these writers refuse to acquiesce to the passive role demanded of an ill person in Western medical culture and society. Because their diseases are terminal, they do not fit the dominant triumph narratives of illness and disability that Kathlyn Conway identifies, according to which “a person battles a disease, overcomes numerous obstacles, and, in the end, returns to life having learned some important lessons."[23] Conway states that these narratives tend to include or be based on at least one of the following four elements: (1) the Christian story of Jesus Christ's death and resurrection, which gives meaning to suffering and offers the promise of redemption; (2) the myth of capitalism, based on the notion that effort and determination will spell success; (3) the New Age myth that one's attitude and behavior are what matter most, the outcome of which is to ascribe blame to the sick person for their failure to adhere to a positive mindset; (4) the beautiful sufferer myth, based on antipathy to bodily imperfection, which has been popular since the Romantic poets and in nineteenth-century fictional accounts of consumption, and which underlines the importance of not appearing to be sick (Conway 20–24). Conway points out that the triumph narrative is one that most people in Western countries have internalized, and it leads to the expectation that people remain optimistic and transcend illness or accident. This ideal is an impossible one that many will struggle to live up to.

Conway's analysis provides useful tropes to look for in analyzing these texts. Deroubaix and Bert give no credence to Christian ideals of redemptive suffering,[24] and after initial hopes of battling their conditions (shown through their use of stereotypical language of war and fighting [Deroubaix 23, Bert 29]) they quickly accept that recovery is not possible.[25] Neither accepts the first diagnosis of her condition or submits unquestioningly to the treatment and regimes devised for them. Their rejection of physical decline and requisite intimate care may align with the beautiful sufferer myth: Deroubaix fears any loss of femininity, vigor, and intellectual ability and wants to retain them until the end of her life (Deroubaix 20, 39, 72, 79); Bert is indifferent to changes in her appearance but upset by the loss of her easy, joyful, dynamic relationship with her body (Bert 49–51). It is possible to see their wish to avail themselves of euthanasia as a triumph over death rather than incurable illness, because they can control and choose freely the moment when it happens.

In taking charge of their deaths, Deroubaix and Bert resist what is described as the paternalistic French medical culture that they encounter through their doctors. They also reject the stage of dying required of them, in favor of leaving behind unsullied memories of them as active, happy women (Deroubiax 111, Bert 122). Anita Harris states that "the ideal late modern subject is one who is flexible, individualized, resilient, self-driven, and self-made and who easily follows nonlinear trajectories to fulfilment and success."[26] Harris articulates the prevalence of the figure of the 'can-do' girl in contemporary society; although her research concerns young women specifically, her point is relevant to Bert and Deroubaix's situations. Their lives have been shaped by the changes wrought in French society by the MLF from the 1960s onwards, the decline in Christian observance, and women's increased participation in professional life since the 1970s, which Elisabeth Badinter observes is characterized by a new sense of personal fulfilment and social and economic success for middle-class women.[27] Both are professionally active, successful women who have enjoyed rude health, beauty, relationship success, and motherhood before their diagnoses. They are accustomed to managing all aspects of their lives successfully, and each refuses the prospect of a long-drawn-out death and the pain it would inflict on her family, especially her daughter (Deroubaix 14, 111; Bert 34–35). Their refusal to be cared for in their final decline suggests that the inherent vulnerability of all human beings is incompatible with their values as lived out day-to-day—values that align closely with those of men also, about whom I have written elsewhere.[28] Having nurtured their daughters, they refuse to be nurtured in turn, which causes tension between Deroubaix and her daughter Alexandra (Deroubaix 14, 120, 139). Angela McRobbie describes the notion of 'the perfect' as a horizon of expectation through which women are encouraged to define themselves in neoliberal patriarchal societies (McRobbie 2015).[29] She argues that feminism has been coopted by neoliberal societies to be compatible with an individualizing project. Deroubaix and Bert stress the importance of individual choice and freedom in the management of their end-of-life care and their deaths and reject the prospect of being dependent. Deroubaix is already "obligée de vivre l'assistanat au quotidien. Moi qui ai toujours accompagné ou dirigé les autres, je suis aujourd'hui à leur merci" (Deroubaix 19). Bert too is "à la merci des autres" (Bert 64) and mourns her need for assistance (Bert 23, 63–64), stressing the dislocation of mind and body as her illness progresses, robbing her of her body (Bert 52–54, 136–37). In order to prepare for her final journey to Belgium and her euthanasia, she feels the need to learn zen-like detachment from others, from desires or any future plans (Bert 106–7). Bert's conscious detachment and Deroubaix's resistance to her daughter's bewilderment demonstrate the force of their desire to retain what control they can when facing death.

In Anne Bert's poetic text, structured as seventeen short chapters preceded by an introduction, there are few details of her encounters with medical professionals, apart from a chilling description in the second chapter of the French neurologist announcing her diagnosis and their uncomfortable conversation, and by contrast, her comforting meetings with the Belgian doctors who are willing to support her wish to be euthanized, in chapters twelve and sixteen. The neurologist's coldness and obfuscation in chapter two cast a shadow over all that follows. Her voice is initially described as "douce, liquoreuse, presque flasque" (Bert 27), before she calmly describes Bert's condition, without naming it precisely. Bert is acutely aware of how the neurologist is managing their meeting:

> L'air de rien, elle commente la dégénérescence neurologique, mais sans bienveillance excessive ni compassion. Sûrement pour ne pas m'affoler, comme il sied de le faire pour ménager le patient en cas d'annonce cruelle. Pourtant, mon cœur tambourine. […] Je suis écartelée entre ce que je sais avoir compris et ce que je consens à ne pas entendre. Et je lui en veux de ne pas y aller franchement. Son attitude me cloue dans un état léthargique. Je ne dis rien, comme une idiote. Cela ne me ressemble pas. (Bert 28)

Bert both fears and hopes for greater frankness, which is not forthcoming, leaving her "frustrée, en disette de vérité. Je suis dans le brouillard, insensibilisée" (Bert 29). She repeatedly notes the soporific effect of the neurologist's unruffled manner and voice: "Rien en elle ne trahit toujours l'horreur de la maladie, sa gravité à peine. Je lutte pour ne pas céder à l'anesthésie" (Bert 29). Bert evokes Lewis Carroll's *Alice in Wonderland* to convey the effect of this one-sided conversation and the power imbalance it imposes on her: "Je retombe en enfance, une petite fille dans son fauteuil trop grand. Je suis Alice aspirée dans le terrier du lapin, projetée dans un monde absurde et déréglé" (Bert 29). This absurd, malfunctioning world is the French medical establishment as embodied by this evasive neurologist. Even when Bert, suspecting the truth, deliberately mentions motor neurone disease, the neurologist "ne cille pas" (Bert 31), refusing to name the condition. "L'impuissance des médecins me touche. Si désolée pour eux," notes Bert wryly at the end of her consultation. Shaking hands, she observes that the consultant's hand is "aussi relâchée que sa voix—peut-être l'abdication face à l'inguérissable" (Bert 32). Bert's illness defeats a doctor who lacks skill (and perhaps training) in dealing with or discussing incurable conditions with candor or compassion.

Bert's choices with regards to the form and content of her text consistently underline her autonomy and agency, however small, as her mobility diminishes. The medical world is relegated firmly to the background. No doctor is named, either in France or Belgium. However, the discomfort Bert experiences with her neurologist portends the quality of care that Bert believes awaits her if she remains in France at the end of her life. For Deroubaix and Bert, refusing to acquiesce to the requirements of French medical culture when it comes to invasive treatment of advanced illness and to end-of-life care leads to a stark choice. They must "fuir la France" (Bert 147) in order to retain bodily autonomy and the liberty that France ostensibly holds dear, but only for those who enjoy good health or accept unquestioningly the authority of the doctors who treat them (Bert 96). After her lung cancer operation, Marie Deroubaix fears "le système médical [qui] vous enferme" (Deroubaix 105) and wants to evade the "acharnement thérapeutique, l'enfer du système et l'inhumanité de certains" (Deroubaix 76) that she sees in French healthcare, and in the experiences of her compliant friends Natacha and Jacques. She marvels at a remark her Belgian cancer specialist makes at the end of one of their first consultations: "'Mais, madame, vous pouvez toujours réfléchir et refuser les traitements.' Ce discours était vraiment unique! En France, il aurait été inenvisageable" (Deroubaix 92).

Bert notes that "cette maladie de Charcot, en France, j'aurais eu l'obligation de la subir jusqu'au bout. Des mots, des textes de lois posés sur des patients qui n'ont plus leur mot à dire dès que le médecin les juge excessifs. Des voiles jetés sur la réalité des horreurs de fin de vie" (Bert 112). Deroubaux uses the same phrase: "En France, il faut souffrir jusqu'au bout" (Deroubaix 25). Kathlyn Conway states:

> When we cannot find it in ourselves to battle, to look healthy, to remain optimistic, we feel we are failing. [The triumph narrative] is also a narrative whose denial of limitation and death has a destructive impact on large groups of people. Those who cannot triumph are looked down upon; the needs of the disabled are not adequately addressed; and the dying are often not allowed to die before being subjected to high-tech interventions. (Conway 38)

Both authors decide to go to Belgium to end their lives under medical supervision. Both stress the immense comfort and relief from solitude that they feel once welcomed by the Belgian system where there is, Bert observes, "une autre médecine qui, quand elle ne peut plus soigner le corps, se décide à soigner l'âme" (Bert 112). Bert refers to the Belgian doctors who care for her as her "passeurs" (Bert 112), a classical reference to the ferryman Charon who bears dead souls across the River Styx, accompanying them on their final journey. These Belgian doctors give Bert back some calm and a renewed ability to think and say goodbye.

Deroubaix and Bert are angered by the need to leave home, family, and community in order to die without fear and what they regard as intolerable, indefinitely prolonged pain and helplessness (Deroubaix 104, 110; Bert 112). Despite their feelings, they must take care not to discuss in the French media details of how their euthanasia is organized, as to do so could jeopardize their acceptance for euthanasia by their Belgian doctors (Deroubaix 132; Bert *France Télévisions*, April 12, 2017). Both note the effort and expense involved in travelling repeatedly to and from Belgium for medical consultations and renting property in Belgium (one must be officially resident in Belgium to benefit from Belgian euthanasia laws), which means that their choice is not available to French people of lesser means, as Deroubaix acknowledges when describing the beautiful Art Nouveau apartment she rents in Brussels: "Évidemment, il n'était pas donné. J'avais de la chance de pouvoir me le permettre. Il faut se rendre à l'évidence, une euthanasie à l'étranger, cela coûte cher. Qui parle d'égalité devant la mort?" (Deroubaix 116). Deroubaix wishes that all her fellow French citizens had the same options open to them when it comes to end-of-life care and choosing when to die, regardless of their financial means (Deroubaix 117).

Her Belgian doctors are sympathetic and supportive, but nonetheless there are many bureaucratic procedures to follow in her weakening physical state, as she is obliged to put on a dumbshow of considering potential treatment options offered within the Belgian medical system before rejecting them, in order to establish her medical records in that country (Deroubaix 105–6). She must rent a home in Brussels and find two willing doctors, a GP and a coroner, outside the hospital setting who will perform her euthanasia at home. Overall, Deroubaix's text details a grueling administrative process, at a time when she is suffering more severe symptoms from her brain tumors.[30] The work involved in arranging her euthanasia consumes a great deal of the dwindling time that remains to her, which, together with her writing, means that she and her husband can savor only fleeting moments of peace.[31] For each woman, her determination to ensure that she can be euthanized underlines the unbroken continuity of her sense of herself as autonomous, self-actualizing and powerful, even unto death.

Conclusion

The image of the French healthcare system that emerges from these texts is one of excellence where recovery is possible, but severe limitations where it is not. The triumph narrative appears to shape the medical establishment's attitudes as much as it does those of the French public. The lack of compassion and openness shown by their doctors to Bert and Deroubaix suggests that French medical culture produces doctors with little or no training in how to deal with terminal illness or patients who do not desire aggressive treatment.[32] Writing as a doctor, Tyler Tate stresses the importance of individual relationships between doctors and their patients, and the need for doctors to be careful in how they speak to patients about their condition:

> the onus is placed on individual clinicians to actually listen to and understand their patients' stories. Since, ultimately, all language can both harm people and confuse, deceive, and conceal the truth, it becomes the responsibility of clinicians to practice and grow in the wisdom and discernment that is required to intuit the right words for the right times. (Tate 26)

The silence and domination that characterize Deroubaix and Bert's interactions with most doctors in the French medical establishment show that there is much work to be done to ensure that patient stories are heard and their wishes acknowledged, even if current legislation prevents them being fulfilled. The fact that these texts exist demonstrates the strength of the injustice both authors feel as they respond to their diagnoses and try to decide how best to act in the short time that remains to them. "Je suis la vivante qui crée son personnage de morte," says Bert (Bert 122). If their books are a kind of triumph narrative, it is in their determination to defy the obfuscation imposed by normative ideas of terminal illness and death in France.

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Notes

1. OECD Health Policy Overview, January 2016, https://z.umn.edu/6j68.
2. See *French Autopathography*, Steven Wilson, ed., *L'Esprit Créateur*, 56:2 (2016). Wilson affirms that the term 'autopathography' serves "to emphasize that subjective patient experience is a legitimate source of self-knowledge and of epistemological knowledge about the experience of illness and disability" (Wilson 3).
3. Alexandre Gefen, *Réparer le monde: La littérature française face au XXIe siècle* (Paris: Éditions Corti, 2017), 9.
4. Marie Deroubaix, *6 mois à vivre: J'ai choisi de mourir dignement* (Paris: le cherche midi, 2012), 52.
5. Anne Bert, *Le tout dernier été* (Paris: Fayard, 2017), 15–16.
6. Such narratives include Anne-Dauphine Julliand, *Deux petits pas sur le sable mouillé* (Paris: Éditions des Arènes, 2011) and Philippe Lefrançois, *J'irai voir les étoiles* (Paris: Éditions Anne Carrière, 2015). This is not always the case: Pierre Jourde criticizes the medical establishment in *Winter is Coming* (Paris: Gallimard, 2017), which documents his young son's death from cancer.
7. https://z.umn.edu/6j6a.
8. Anne Whitehead and Angela Woods, "Introduction," in *The Edinburgh Companion to the Critical Medical Humanities* (Edinburgh: Edinburgh U P, 2016), 1–2.
9. Michel Foucault, *Naissance de la clinique* (Paris: Presses Universitaires de France, 1994), 88.
10. Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), 3.
11. https://z.umn.edu/6j6b. This link contains Anne Bert's full open letter to the candidates for the French presidency in 2017. She received responses from most of the presidential candidates' teams; Macron's responded that revisiting the current legislation is not a priority. She discusses these exchanges in Antoine Laura's 2018 documentary "J'ai décidé de mourir," to which a link is provided below. See Anne Bert's France Inter interview with Léa Salamé, 6 September 2017, https://www.youtube.com/watch?v=SNxaoLD5B7A; Anne Bert's France Télévisions "C à vous" interview, 12 April 2017, https://www.youtube.com/watch?v=VHCxsukGI7w; Antoine Laura's documentary "J'ai décidé de mourir," created in collaboration with Anne Bert and released on Public Sénat, 13 October 2018, https://www.dailymotion.com/video/x7dio89; Anne Bert's final letter in *Le Journal du Dimanche*, published on the day of her death, 2 October 2017, https://z.umn.edu/6j6c; Anne Bert's RTL interview with Marc-Olivier Fogiel, 6 September 2017, https://z.umn.edu/6j6d; and Nathalie Rouiller, "Anne Bert: celle qui veut mourir vous salue," *Libération*, 11 April 2017, https://z.umn.edu/6j6f.

12. "Euthanasie: Anne Bert 'est partie comme elle le souhaitait' confie sa fille," RTL interview with Marc-Olivier Fogiel, 18 October 2017: https://z.umn.edu/6j6l. "Roxane Guichard: non le cas de ma mère 'n'est pas un cas isolé,'" Public Sénat (11 October 2018), https://z.umn.edu/6j6m. Among other media sources, Anne Bert's death was reported and discussed on the day of her death, 2 October 2017, on France Télévisions France 3 Grand soir 3, France Inter extrait 7/9, and RTL's Journal de 18h.
13. Sylvie Fainzang, "Lying, Secrecy and Power within the Doctor-Patient Relationship," *Anthropology & Medicine*, 9:2 (2002): 117–33.
14. Michel Foucault, *L'archéologie du savoir* (Paris: Gallimard, 1969).
15. Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford U P, 2006), 65–66.
16. Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*, 2nd ed. (West Lafayette, IN: Purdue U P, 1999), 91.
17. https://z.umn.edu/6j6n.
18. https://z.umn.edu/6j6o.
19. Marit Karlsson et al. show that perceptions of euthanasia vary significantly among terminally ill people. Marit Karlsson et al., "Dying Cancer Patients' Own Opinions on Euthanasia: An Expression of Autonomy? A Qualitative Study," *Palliative Medicine*, 26:1 (2011): 34–42.
20. The *Association pour le droit de mourir dans la dignité* website is clear about the difficulties of being euthanized in Belgium if one is not a resident, http://www.admd.be/non-residents/.
21. Their experience is not unique. See Felicity Goodyear-Smith and Stephen Buetow, "Power Issues in the Doctor-Patient Relationship," *Health Care Analysis*, 9 (2001): 449–62.
22. Financial motivations for the misuse of power in the doctor-patient relationship are discussed in Goodyear-Smith and Buetow.
23. Kathlyn Conway, *Beyond Words: Illness and the Limits of Expression* (Albuquerque: U of New Mexico P, 2013), 17.
24. Deroubaix does envisage an afterlife but without any Christian characteristics (Deroubaix 126); she also imagines reincarnation in the natural world (Deroubaix 134–35).
25. Scholarly research on doctors' engagement with patients and their use of language has reflected critically on violence metaphors. See Tyler Tate, "Your Father's a Fighter; Your Daughter's a Vegetable: A Critical Analysis of the Use of Metaphor in Clinical Practice," *The Hastings Center Report*, 50:5 (2020): 20–26.
26. Anita Harris, *Future Girl: Young Women in the Twenty-First Century* (London: Routledge, 2003), 16.
27. Elisabeth Badinter, *L'Un est l'autre: Des relations entre hommes et femmes* (Paris: Éditions Odile Jacob, 1986), 217–25.
28. See Áine Larkin, "Dependence and Masculinity in Contemporary French Writing about Disability," *L'Esprit Créateur*, 56:2 (2016): 121–34.
29. Angela McRobbie, "Notes on the Perfect," *Australian Feminist Studies*, 30 (2015): 3–20.
30. The work involved in being ill, even terminally, has been researched by Catherine Tourette-Turgis and Joris Thievenaz, "La reconnaissance du 'travail' des malades: Un enjeu pour le champ de l'éducation et de la formation," *Les sciences de l'éducation: Pour l'ère nouvelle*, 46:4 (2013): 69–87.
31. Bertrand Deroubaix includes a poignant note to this effect in his introduction and concludes that "Nous aurions pu parler, pendant qu'elle écrivait. Quelque part, ce récit que vous allez lire nous a enlevé des heures si rares, si comptées" (Deroubaix 8).
32. Frattini and Mino note that the very concept of palliative care is relatively new is France, where it dates from the mid-1980s, and provoked feelings of "malaise, méfiance, voire un rejet de la part du milieu médical" (Frattini and Mino 139) and where access to it remains patchy. Jean-Christophe Mino and Marie-Odile Frattini, "Les soins palliatifs en France: 'mettre en pratiques' une politique de santé," *Revue française des affaires sociales*, 2 (2007): 137–56.