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Author(s): Nicola Gavioli

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Bioethical Issues in Contemporary Brazilian Culture

Euthanasia and Literature

Nicola Gavioli

Este ensaio propõe uma reflexão sobre a contribuição da literatura brasileira contemporânea ao debate internacional sobre temas da bioética, com ênfase na representação da prática da eutanásia e do suicídio assistido. Ao analisar um romance de Carlos Heitor Cony (A morte e a vida, 2007) e de Eliane Brum (Uma duas, 2011), e textos breves de Moacyr Scliar e Dráuzio Varella, estabelecendo um diálogo com pensadores da vertente crítica dos “Disability Studies,” mostro como algumas obras literárias hoje estão ilustrando os aspectos mais problemáticos deste debate, apresentando pontos de vista incomuns (A morte e a vida) e evitando visões binárias e banais em favor ou contra a prática da eutanásia (Uma duas).

This article focuses on the way in which contemporary Brazilian literature participates in the international debate regarding bioethical issues, with a particular focus on the representation and discussion of euthanasia and assisted suicide. Analyzing novels by Carlos Heitor Cony (A morte e a vida, 2007) and Eliane Brum (Uma duas, 2011), short texts by Moacyr Scliar and Dráuzio Varella in dialogue with scholars in Critical Disability Studies, I demonstrate how Brazilian literature today is engaged in such problematic discussions as:

Nicola Gavioli is a Visiting Assistant Professor of Portuguese at the Florida International University in Miami, Florida. He holds a Ph.D. in Hispanic Languages and Literatures (with emphasis in Portuguese and Brazilian Studies) from the University of California Santa Barbara (2011). He co-edited with Vinicius Mariano de Carvalho the volume *Literature and Ethics in Contemporary Brazil* (2017) and has published essays in academic journals in the United States and Brazil. Among his research interests are the Brazilian and Portuguese novel, human rights and literature, and the works of Antônio Lobo Antunes. He is currently working on a volume on human rights and mental health in Brazil.

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patients' rights, disability, and "good death," presenting unusual points of view (A morte e a vida) and offering nuanced approaches that do not necessarily fit into binary simplifications for or against euthanasia (Uma duas).

Foreword

In his *Manifesto em defesa de uma morte livre* (2015), Portuguese philosopher Miguel Real argues that "a morte deixou de ser . . . um tema interdito" (85, 90). Indeed, today people are constantly exposed to references to death. Ubiquitous, but trivialized, representations of death are transmitted across popular media (Real 85, 90). Despite this visibility, trivializing death seems another way to exorcize it. Moreover, a serious discussion on the right to voluntary euthanasia and physician-assisted suicide is still largely absent. In many countries, voluntary euthanasia is controversial and divisive: few legislatures want to take up the matter. For the mindset of most politicians, economists, and technocrats, who conceive of human life as a subset of entertainment, productivity, consumerism, and perpetual good health, end-of-life issues can wait. For others, these issues pose existential dilemmas that only some unfortunate few—the severely sick—must address. On an individual level, many prefer to avoid personal meditations on death altogether, as if unconcern or procrastination might superstitiously spare the occurrence of disease and end of life decision-making. Unexpected events, illness, and trauma can strike anyone, and when they occur close to home, individuals are forced to consider the contours of euthanasia more carefully.¹

What happens to the psyche of a person when continuous pain cripples his or her body and when life seemingly has no value? Is strenuous resistance against disease always worth it? Should an individual be responsible for deciding how and when to die? Ignoring these questions legislatively creates psychological violence on those who must decide how to cope with a life of extreme physical and mental suffering.

Works of literature, reports, and *crônicas* that interrogate, provoke, and challenge the political and public silence on euthanasia, assisted suicide, and living wills, are per se examples of activist writing, no matter the position defended by their authors. In Brazil, these works are few and far between. In *Grande sertão: veredas* (1956), João Guimarães Rosa infuses a bioethical preoccupation into Riobaldo's monologue, as also noted by critic Valéria M. Souza.² Is medical forced-feeding right? He considers the question in this brief sketch that mixes superstition, popular belief, and medical intervention (and repression):

Como deu uma moça, no Barreiro-Novo, essa desistiu um dia de comer e só bebendo por dia três gotas de água de pia benta, em redor dela começaram milagres. Mas o delegado-regional chegou, trouxe os praças, determinou o desbando do povo, baldearam a moça para o hospício de doidos, na capital, diz-se que lá ela foi cativa de comer, por armagem de sonda. Tinham o direito? Estava certo? Meio modo, acho foi bom. (Rosa 59)

Evidently, this episode is not about “therapeutic obstinacy” toward patients in a coma, nor is euthanasia the issue. Nevertheless, this anecdote dominated by antagonisms (countryside versus city, popular religiosity versus scientific thought, peasantry versus military power), shows a bioethical sensitivity in the clash between personal agency and medical authority. The antagonism between personal choice and forced medicalization is the crux of the matter that I will explore in this essay, analyzing works by Moacyr Scliar, Dráuzio Varella, Eliane Brum and Carlos Heitor Cony.³ This selection of prose writing (*crônicas*, reports, and two novels) and poetry (in Cony’s novel *A morte e a vida*) testify in multiple ways to the relevance of the controversial end-of-life debate in Brazil, as well as in other countries across the globe.

An International Issue

Within the maelstrom of global news and cultural production on which we float, there are frequent references to the complicated debate around a “good death” in award-winning films,⁴ plays,⁵ newspaper features, magazine covers, and on the internet.⁶ The international relevance of the discussion has recently been highlighted by Rachel Aviv’s essay “The Death Treatment,” by an event that took place in Argentina, where, for the first time, the Supreme Court ruled in favor of suspending the artificial nutrition of Marcelo Diez, who had been in a coma since 1994⁷; by a controversial case in Belgium, where, after obtaining the right to assisted suicide after a lifelong struggle with depression, a 24-year old woman decided to opt for life at the last minute⁸; and the recent Italian case of quadriplegic DJ Fabo, who chose to die by his own agency in a Swiss clinic.⁹

Often, journalists tend to present a clear-cut position on the right to end a life of suffering, according to the political climate of the day and the ideological affiliation of their venue. Similarly, *crônicas* and columns often reveal personal agendas and beliefs. Literature gives shape to a more nuanced approach. The confrontation of the texts I chose will illuminate how binary thinking of acceptance or refusal of euthanasia is only one aspect of this fiction and becomes complicated by the singularity of each situation, the indefiniteness of human feelings (in Brum’s *Uma duas*) and by unusual perspectives, such as that of a seemingly unconscious patient (in Cony’s *A morte e a vida*). In the analysis of these works, I will end my essay with contributions by Disability

Studies scholar Harold Braswell and activists Alison Davis and Linda Andre. Disability Studies, still an incipient field within Latin American literary criticism,¹⁰ has reflected on, emphasized, and given theoretical organization to the huge level of anxiety and preoccupation around the issue circulating in today's social media and public forums worldwide. From the point of view of several Disability Studies scholars

the suffering of individuals eligible for euthanasia is due not to a person's biological condition but to social discrimination against the incurably sick and disabled. Desire to die among these populations occurs when patients internalize this discrimination. Rather than seeing euthanasia as the product of free choice, in other words, scholars argue that such a choice is the result of disability oppression (Braswell 2015, 80).

If, as I will show, Scliar reflects on his suspicions on the (possible) "oppression" exercised by the charisma of certain medical authorities (namely, Jack Kevoorkian) on their patients, and Varella expresses doubts on the factual occurrence of direct requests made by patients to be euthanized voluntarily, Brum and Cony are able to capture and dramatically represent the contradictions, fears, and uncertainty circulating in contemporary society around this theme.

The Brazilian Context

In 2005, UNESCO published the Universal Declaration on Bioethics and Human Rights, a roadmap for member states to legislate on relevant issues such as respect for human dignity in matters of medicine and science, limitations and finalities of medical experiments, and ethical uses of biotechnologies. Article 3 states that "The interests and welfare of the individual should have priority over the sole interest of science or society." "Dignity"—although a concept difficult to define—is not only a recurrent word, it is the backbone of the entire declaration. If doctors' paternalism prevails over the patients' informed autonomy of choice, the dignity of the ill is likely compromised. Whenever "one person overrides the autonomous choices and actions of another in the other person's best interests" we may incur cases of paternalism (King 166).

Establishing a "best interests" doctrine in one set of guidelines is complicated. For non-religious patients, biological life might not have a value per se to be continued at all costs. When a severely sick patient is forcibly kept alive by machines or drugs, treatment may seem like an authoritarian act. Some people might want to end their lives before they are incapable of making personal decisions. In this case, "best interests" would coincide with respect for patients' "biographical life," (Tarabbia 88), for the "*judgment* patients have

the right to express on their own life, *here and now*" (89, my translation) regardless of what doctors and relatives might wish for them. In nearly every country, voluntary active and passive euthanasia, as well as assisted suicide are considered crimes,¹¹ while orthothanasia¹² for terminally-ill patients and the gradual switch to palliative care are permitted in several countries, including Brazil (since 2010).

If voluntary euthanasia is forbidden in almost all countries,¹³ what is characteristic—although not exclusive—in the case of Brazil? In a country in which the legislation on matters of life and death remains highly controversial (abortion is still forbidden, with the exception of life-threatening cases, rape, or pregnancy of anencephalic babies), the legalization of voluntary euthanasia appears unlikely. The influence of the Catholic Church in Brazilian society and politics is still considerable. In 2014, Pope Francis reiterated that: "the predominant school of thought sometimes leads to 'false compassion,' which holds that it is a benefit to women to promote abortion; an act of dignity to perform euthanasia; a scientific breakthrough to 'produce' a child"¹⁴ (par. 5). Abortion, euthanasia, and in vitro fertilization are evils to be eradicated from the medical practice, according to the Pope's authoritative viewpoint.

Other important religious groups in Brazil, the Pentecostals, express their preoccupation: only God, they believe, can decide when it is time to go. As Gomes and Menezes put it, "os modos de administração do início e término da vida são os mais diversificados e dependem das crenças compartilhadas elaboradas por cada grupo social" (n.p.). Religion in Brazil still seems to weigh heavily on public opinion and public policy. When Brazilian citizens are asked to express a personal position on euthanasia, such as on TV programs,¹⁵ God is likely to be mentioned by many as a deterrent to an open discussion on this practice. Moreover, the cynical use of religion by conservative politicians and the trivialization of assisted suicide are, as almost everywhere, impediments to an informed public debate on the issue.

Regarding jurisprudence, the arguments against the legalization of euthanasia and assisted suicide are based respectively on the Articles 121 ("Matar alguém") and 122 ("Induzir ou instigar alguém a suicidar-se ou prestar-lhe auxílio para que o faça") of the *Código Penal Brasileiro*. The *Lei Estadual n. 10.241* (March 17th 1999) of the State of São Paulo was a precursor in precisely addressing the right for a patient to refuse end-of-life painful medical treatments ("XXIII—recusar tratamentos dolorosos ou extraordinários para tentar prolongar a vida" and "XXIV—optar pelo local de morte"). Orthothanasia is now considered legal.

Since 2012, Brazilian citizens can write a living will (*testamento vital*) in which they declare whether (in the case of a terminal illness) to accept continuous and often painful medical treatment or to suspend them and switch to palliative

care (VFM 995/2012).¹⁶ The *Código de Ética Médica* recommends the administration of palliatives in the case of “situações clínicas irreversíveis e terminais” (XXII). The latter is clearly distinguished from passive euthanasia, as doctor José Eduardo de Siqueira, ex-president of the Sociedade Brasileira de Bioética, defends: “eutanásia ativa é pegar e injetar cloreto de potássio ou outra coisa no paciente. Eutanásia passiva é você deixar de tratar a pessoa. Ora, nos cuidados paliativos você trata a pessoa, é ativo. A ortotanásia não está nem na categoria da eutanásia ativa nem da passiva. Simplesmente não é eutanásia” (Brum, “Testamento Vital”).¹⁷ Precision in terminology helps to advance a meaningful public debate that minimizes generalizations and misunderstandings.

Paternalism and the Medical Profession in Moacyr Scliar and Dráuzio Varella

The topic of euthanasia is occasionally mentioned in interviews and film reviews in Brazilian newspapers and magazines. For example, in the interview with French anthropologist David Le Breton, appearing in *O Estado de São Paulo* on July 11, 2015,¹⁸ the choice to euthanize is associated with the loss of “meaning” in someone’s life. Brazilian academic studies on literary and filmic representations of euthanasia and assisted suicide focus largely on foreign cultural production.¹⁹ Indeed, Brazilian intellectuals, artists, and writers have dedicated little attention to this theme so far.

Popular culture came first. In *Os gigantes*, the *novela das oito* directed by Régis Cardoso and Jardel Mello and broadcasted on Rede Globo in 1979—and one of the most notable flops in the history of Brazilian television—a renowned international journalist returns home to see her twin brother in a coma and fed artificially. In what she regards as a gesture of compassion, she turns off the machine that keeps her brother alive. The *novela* turns into a long familial and legal drama and it ends with the conviction and suicide of the leading character. Despite this rather moralizing closure, the opening credits of *Os gigantes*, accompanied by the music “Horizonte aberto” by Sérgio Mendes, associate the image of the tormented female protagonist—the actress is shown performing melodramatic facial expressions—with the symbol of the dove, a traditional icon of purity, peace, and renewal in the Catholic tradition. The overall production of the *novela* was complicated and its public reception controversial.²⁰

With elements of both engagement and entertainment, the *crônica* is a genre that consistently provides commentary on societal changes, cultural tendencies, and ideological antagonisms within Brazilian society. Among these debates, we must consider ethical issues related to the medical profession. Moacyr Scliar, a physician, was among the authors that more consistently reflected in the *crônica* genre about the links between the practice of medicine and literature.

Scliar's "Literatura e medicina: o território partilhado" provides a general understanding of the importance of bridging medicine and literature in order to grasp the "cultura do ser humano em sua totalidade" (248). According to Scliar, students of medicine would benefit from reading works of literature that represent illness and the emotional responses to pain. As Mathiasen and Alpert put it, "a knowledge or science of suffering can be acquired . . . health professionals . . . can learn about this feeling vicariously through literature and art" (135–6). Learning means developing a sensitivity towards empathy, a quality which, according to these authors, "can enable the physician to imagine what the patient is experiencing, without becoming the patient" (141). While the psychological conditions of terminally-ill patients are of course imperfectly understood by healthy people, literature—including memoirs, and hybrid texts—can train medical professionals to consider emotions and dilemmas that sick subjects might experience. One of these ethical cross-roads is certainly the right to die.

In 2006, Moacyr Scliar penned the *crônica* "Discussão dolorosa—mas necessária," in which he described "o estranho doutor Jack Kevorkian" (Scliar). Kevorkian became a personality in the U.S. medical debates of the 1990s. He was famously associated with the practice of assisted suicide and helped many people to die in a country in which legislators, medical professionals, and the larger public still feel very uneasy about addressing end-of-life issues. The turning point was in 1998, when Kevorkian decided to push the envelope in a now famous TV interview. After showing a video in which he appeared manually injecting a lethal substance into a patient, Kevorkian was sentenced to prison (where he would spend eight years). This gesture invigorated the debate around end-of-life issues in U.S. society.²¹

Moacyr Scliar summarized Doctor Kevorkian's activity and ethics in these terms, "patologista, o doutor Kevorkian não apenas se oferecia para liquidar pacientes com um aparelho por ele inventado, como uma vez filmou todo o procedimento e exibiu-o na tevê" ("Discussão"). Although Scliar's position on euthanasia is indefinite and dubious, the verb "liquidar" seems to imply moral condemnation of Kevorkian. Moreover, Scliar avoids explaining that Kevorkian filmed his patients several times (and not "uma vez") to document their informed consent, free will, and active participation during the procedure. Video-recording served to prove Kevorkian's indirect, collaborative intervention, excluding the likely accusation of homicide in front of a court. Instead, Kevorkian is reduced—liquidated, to adopt Scliar's term—to the role of a popular culture icon: "não é de admirar que uma banda americana tenha o nome de 'A Câmara de Tortura do Dr. Kevorkian'" (Scliar).

Scliar quotes a few lines of "Do Not Go Gentle into That Good Night" by Dylan Thomas, in which the poet solicits his sick father to resist death. Is this quote meaningful in the case of a discussion of euthanasia? Would it be the ethical, right thing to do, to ask a person in extreme pain to continue living?

Scliar recognizes the dilemma: “seria este o apelo de Dylan Thomas caso o pai estivesse sofrendo barbaramente?” Scliar also mentions orthotanasia as a possible answer. In terms of style and word choice, the conversational tone of the piece softens the author’s seriousness and assertiveness. The simplification of complex debates to reach distracted and occasional readers is a characteristic of Scliar’s medical *crônicas* (the collection *Território da emoção: Crônicas de medicina e saúde* offers several examples).

Making ethical debates relevant for a large number of people is, of course, desirable. Nevertheless, when Scliar oversimplifies the debates on Jack Kevoorkian’s activity of this “discussão dolorosa mas necessária” the risk is to act as a paternalistic and moral guardian who selects what is right to share with his readers and schematically reduces other medical experiences to dishonest and narcissistic acts.

Author of the non-fictional bestseller *Estação Carandiru* (1999) and a popular physician, Dráuzio Varella also expressed a personal view on euthanasia. Varella shows skepticism on the issue. In a 2004 episode of the TV program *Roda Viva*,²² he argued that in Brazil there are already accepted forms of what he calls “eutanásia pacífica,” referring to all those cases in which patients with cancer must wait long periods of time before receiving a medical consultation treatment and/or surgery in public hospitals. When Varella describes cases of voluntary euthanasia abroad, he trivializes the issue, depicting in a few strokes the example of The Netherlands, in which a Dutch patient would ask his doctors, almost capriciously (“olha, eu não quero mais viver, estou cansado de viver”), to end his life. After this short, caricatured portrait (in which a Dutch doctor would respond with a “então, está bom, vamos ligar o soro”), Varella claims that in his long career as a physician, he has only met two or three patients who have requested assisted suicide, deriving the general rule that: “você vai pra cama, fica sofrendo, você fica pelo amor de Deus, pedindo para continuar vivo!” (*Roda Viva*). Although Varella is not assertive and definitive on the matter, his words are not devoid of a certain professional paternalism. Moreover, for Varella, numbers seem especially important. In his lifelong career, only a minority of patients (“dois ou três casos, em trinta e tantos anos”) asked to die. How should statistics be considered in the legislation of voluntary euthanasia? Is Varella suggesting that the limited number of requests should dissuade the public from discussing the legalization of voluntary euthanasia?

When Varella reflects on the palliative sedation of patients in extreme pain, he admits uncertainty as to whether it is a form of benevolent euthanasia. In his record of professional memories *Por um fio* (2004), Varella writes that, although suspending impossible battles against an incurable disease by medicalization might seem like the right thing to do (“muitas vezes, nós, médicos, insistimos em prolongar a vida de pacientes em fase terminal da

evolução de sua doença que melhor estariam se os deixássemos em paz, medicados apenas para controlar os sintomas”), the difficulty of giving a prognosis complicates the matter (“o organismo humano é capaz das reações mais imprevisíveis” [100]).

As it is true for Moacyr Scliar’s short text, Varella’s interview and biographical writing are the expressions of a man who thinks he knows firsthand the complexity of the medical issues of patients in the later stages of life.

Eliane Brum: The Inner Fog of Decision-Making

“Repórter de desacontecimentos,” and “escutadeira” are the expressions Eliane Brum prefers to use in describing her profession.²³ In her reports and columns, Brum listens carefully to her subjects, hoping to find fresh details that will help identify and subvert preconceived ideas. Often, her subjects are working-class people ignored by the big national media outlets, traditionally interested in the problems, interests, and opinions of the Brazilian urban upper middle-class. Brum’s subjects tell impactful personal stories, with a distinctive voice and linguistic peculiarities. They are, according to Brum, parts of the “literatura oral”²⁴ of Brazil.

Edvaldo Pereira Lima characterizes Eliane Brum as an exceptional case of literary journalism in Brazil (158). Brum’s columns, published in *Revista época*, and, more recently, in *El país Brasil*, manifest a strong coherence in the choice of themes and style. Her reports focus largely on “conteúdos universais” (Martinez 69), among which the ethical controversies within the medical world, the condition of patients in Brazilian hospitals, and reflections on dying.

In “Comprei meu túmulo,” Brum mixes humor with matter-of-fact considerations such as the purchase of her coffin and the choice of the perfect location to place her tomb. In “Deus e a eutanásia,” she writes about Flávia, a young girl who spent twelve months in a coma after an accident in a swimming pool. This tragic accident becomes the point of departure for a critical analysis of how Brazilian society reacts to such a tragic episode, with a particular emphasis on how people can quickly express vitriolic comments against the girl’s mother, judging her for opting to keep her daughter, now in a coma, alive. In “Testamento vital” and “Você quer ser pessoa ou paciente?,” Brum solicits readers to reflect on the value of writing a living will and on the advantages of palliative care. The list of examples goes on. Storytelling techniques, such as anecdotes and metaphors, enrich the writing. On the matter of assisted suicide and voluntary euthanasia, Brum reacts against paternalistic and authoritarian impositions, expressing her doubts: “Por que temos tantas certezas sobre o que é melhor para a vida dos outros?” (“Deus e a eutanásia”).

In 2011, Eliane Brum published her first novel *Uma duas*.²⁵ Centered on the long-lasting conflict between an aging mother (Maria Lúcia) and her daughter (Laura), a successful but anxious and emotionally rootless journalist, the novel alternates between a third-person narrative and the fictional testimonies of the two female protagonists. The plot is thin: it revolves around the terminal illness of Maria Lúcia and the emotional turmoil it sets off for both mother and daughter. The relationship between the female protagonists is described as a lifelong struggle that goes beyond the classical generational fight, and becomes a morbid visceral bond. The conflict between them is described with many graphic details, virulence, and grotesque hyperboles; for example, Laura even tears apart her mother's cat with her bare hands in a moment of fury.

When Maria Lúcia is hospitalized, Brum provides unvarnished accounts of the power dynamics among doctors, nurses, and patients. We read examples of medical paternalism (the oncologist “se dirige à mãe como se falasse com uma criança” [130]), arrogance (“ele tem orgasmos com sua própria importância” [129]), and medicalization at all costs (“em medicina, precisamos lutar. Até o fim. . . . Eu preciso fazer tudo o que está ao meu alcance para salvá-la ou posso ser processado por omissão” [130–31]), which is, for Laura, “a forma mais cruel” of treating a terminally-ill patient (136).

The novel received positive, yet similar, reviews. Almost all the reviewers²⁶ praised the subversion of the myth of the benevolent maternal love, but few noted the exposure to end-of-life decision-making in the final chapters of the novel. *Uma duas* certainly offers a long depiction of the contorted and visceral feelings (“quer machucar a mãe com suas unhas até vê-la sangrar, quer quebrar uma unha no osso da mãe. E logo o remorso, o maldito remorso que sempre vem como uma gastura no estômago” [12]), inner conflicts (“odeia e ama aquela mãe com a mesma intensidade, embora só tente odiar” [11]), and inexplicable shifts of mood felt by a daughter toward her irresponsible mother. Nevertheless, this insistent exploration of the nature of a conflict might more accurately be read as a lengthy prologue towards the issue of final decision-making, the assistance that Laura provides to her mother to die (a sort of familial pact of “active euthanasia”). Ignoring this scene impoverishes the (bio-)ethical impetus of this novel, underlined by the obsessive questioning around the body, its drives, wounds, diseases, physiological needs, and deterioration, present since the first page of the novel: “quando digito a primeira palavra o sangue ainda mancha os dentes da boca do meu braço” (7).

Laura's thoughts are opaque and constantly fluid, ranging from furious to commiserative to uncertain; they are graphically represented by text printed in a delicate red color.²⁷ The opacity of Laura's thinking process becomes visible for the readers. Laura is an unreliable narrator, and a traumatized and enraged person; she was the victim of a homicide attempt when she was a

baby, an experience that flashes through her mind in fragments. She writes on the computer to better understand herself, but also to replace her daily life with a new fiction, to edit or replace her unsatisfactory existence with a more suitable and comforting narrative, which is still shapeless (“Eu agora sou ficção. Como ficção eu posso existir. Esta é a história. E foi assim que se passou. Pelo menos para mim” [7]; “Escrevo na esperança de que as palavras me libertem do sangue. Do corpo da mãe” [16]).

Uma duas is not a programmatic novel nor a cautionary tale on euthanasia, but a multilayered representation of the antagonisms within one’s conscience. In the final part of the novel, Maria Lúcia is diagnosed with an advanced stage of liver cancer. After receiving a pessimistic diagnosis, and confronted with the scenario of a long and extenuating surgical battle, she asks her daughter for help to die. Laura’s inner conflict and suspicions emerge in this paragraph:

E agora ela me pede para matá-la. Antes tinha me pedido para salvá-la. E agora que eu tenho autorização para matá-la percebo que essa é a maior vingança não minha, mas dela. Ela quer que eu carregue a sua morte em minha alma para que nunca mais possa me livrar do seu corpo. Para que, em vez de um cadáver, ela seja vida eterna na minha culpa. Minha adorável mãe me pede para ser sua assassina. Será que ela quer que eu apodreça na cadeia por matricídio, separada das outras presas porque meu crime é tão hediondo que nem mesmo as piores criminosas podem admiti-lo? (Brum 135)

In a few sentences, Laura expresses her suspicions about her mother’s real intentions, the fear of having to cope with a life-long guilt and melancholia, and imprisonment. Tatiana Pequeno correctly commented that “é neste ponto que *Uma duas* encampa uma discussão profícua a respeito do que é a vida e, consequentemente, do que é morrer e matar a partir de uma perspectiva antropocêntrica que inviabiliza a prerrogativa científica/biologizante” (178–79). The labyrinth of questioning inherent in this type of decision-making remains for Laura open, indecipherable, and unique. The issue discussed here is not whether voluntary euthanasia has ethical positive value per se, but if the singularity of this case, the doubts and suspicions and wishes originated by these particular circumstances, make euthanasia right. As we see here, discussions on euthanasia are not completely generalizable and applicable to other subjects or situations.

After an initial recoiling, Laura decides to accept her mother’s request, disorienting the reader regarding the true reason behind her ostensibly compassionate gesture. It is at this point that readers enter a labyrinthine and contradictory net of competing emotional desires and drives. The third-person narrator had already informed the novel’s readers that Laura fears and rejects any efforts to arrive at a true understanding of her mother’s reasons:

“[Laura] não quer nenhuma chave que a leve para dentro da mãe” (11). She is not a reliable interpreter of her mother’s wishes. Moreover, in her own notes, Maria Lúcia shares her doubts about Laura’s true motivations. She is also unashamed to reveal the selfishness inherent in her request, careless of the consequences for her daughter:

Não vou suportar essa agonia, Laura precisa me matar de uma vez. E pronto, será como cair morta de repente. Não pensei que Laura tivesse coragem para isso, sempre tão covarde a Laura. Mas no fundo talvez ela sinta prazer em me matar. Laura se ilude de que sou eu o dragão cuspidor de fogo entre ela e a liberdade. É uma boba essa minha filha. Tenho raiva dela agora. Porque ela vai viver, e eu não. Não, eu não daria minha vida pela de Laura, preciso dizer. (Brum 140–41, italics in the original)

As Terry and Williams have argued, “The most useful thing about literature as an approach to bioethics is that the richness of literary portrayals keeps ethics from being merely about concepts or arguments” (19). In fact, *Uma duas* offers a complicated, nuanced, and open representation of what it means to make such an irreversible and emotionally charged decision. Laura suspects that helping her mother to die might create challenging psychological and penal consequences for herself. Compassion, fallacies in interpreting another’s wish, contradictory love, calculated (or unconscious) malevolence and revenge against her mother, and fears are themes that complicate and transcend the simple binary of “for” or “against” the act of assisting someone to die.

Toward the end of the novel, while her mother is at the hospital, laying on a bed and watching *The Sound of Music* on TV, Laura swiftly manipulates her serum. Reading the description of this act, readers must have the impression of an overly perfect scene. Much of this scene seems in fact to occur in Laura’s mind, as if in a dream. All of a sudden, tensions and hate vanish. Laura melodramatically screams: “Não mãe! Eu grito agora. Grito de verdade. Mas é tarde. Sempre foi tarde” [169]). Maria Lúcia dies slowly and peacefully. Finally, a nurse enters, understands what happened in the room, but decides to remain silent.

The end of the novel seems to present a reconciliation. Nevertheless, even this chapter is ambiguous, beginning with a disquieting sentence on the theme of the masquerade (“E à noite todas as feras arreganham os dentes para fora de nós, e as escondemos com pijamas de flanela para que ninguém nos descubra” [165]), leaving shadows on the true meaning of Laura’s gesture. How can severely disabled or ill people trust their potentially unstable and confused, even hostile relatives to honor their true last wish and eventually help them to die peacefully? Should the complicity of the nurse in the novel be considered criminal or an act of piety? And finally, shouldn’t these worries be addressed and defined by legislators?

Carlos Heitor Cony: A “Mental Voice” Against Euthanasia

In 2007, Carlos Heitor Cony, writer and member of the Brazilian Academy of Letters, published *A morte e a vida*, a short novel that received very limited critical attention. The topic of the novel, as the self-explanatory and somewhat banal but also overtly ambitious title indicates, is the most universal of all: death and life. It is perhaps worth noting that the inversion of the natural order of stages prompts readers to give emphasis on the second term (life), as if suggesting an idea of a possible awakening.

More than Brum’s *Uma duas*, this work centers on euthanasia in a direct (and almost exclusive) way. Although the condition and the near future of the semi-comatose patient Maria Emília (laying on a hospital bed with an incurable brain tumor) is interspersed with generic short cuts about the lives of other cardboard characters (Maria Emília’s husband and Ipanema playboy Edmundo, her mother Olga, and nurse Vilma, among others), the novel rarely abandons the focus on terminal illness and end of life.

Contrary to what critic Adilson Barbosa argued in a review of the novel, *A morte e a vida* does not offer a “cortina multifacetada” (162) on euthanasia, nor a confrontation of positions among complex, non-stereotypical characters. In fact, what can be more stereotypical than the cynical and bored *carioca* Don Juan who ends up seducing even his wife’s nurse?

Tired of visiting an almost nonresponsive Maria Emília and of wasting money for her treatments, Edmundo is straightforward in his plan to facilitate his wife’s death. Economics and selfish calculus as the motivations to accelerate the death of comatose patients correspond to what philosopher Jean-Yves Goffi described as “*euthanasie*” (2004). On the other end, the character of the mother Olga (weakly) incarnates Edmundo’s opponent. Rightly predicting the “conspiracy” against her daughter, Olga judges euthanasia—in this case an *involuntary* euthanasia—as criminal, but she is also characterized as naïve. For example, she is certain that Maria Emília’s cancer originated from her husband’s continuous infidelity, lack of affection, and sexual frustration (“não foi à toa que ela teve este tumor na cabeça” [146]). If Edmundo represents schematically the selfish calculus, Maria Emília’s mother, described as a domineering presence, does not offer a convincing argument against the practice of euthanasia. In fact, if she is so naïve, unscientific, full of preconceived ideas, and temperamental, can we relate to and rely on her when she judges euthanasia to be a crime?²⁸

Resisting Edmundo’s request to perform euthanasia on his wife, nurse Vilma is the incarnation of an imperative to persevere with all medical means: “lutar contra a morte enquanto a luta for possível” (150). The novel sympathetically portrays Vilma as the ethical guardian against the “lei da selva” and “intervenções assassinas” practiced by certain doctors (19, 87). She

is Edmundo's second ideological antagonist. It is never clear in the novel, though, if her defense of life at all costs would include requests of voluntary euthanasia.

Through Vilma's act of resistance, euthanasia is revealed to be a temptation or a specter that haunts medical professionals throughout their careers. Vilma explains her sudden transference to another medical unit because, she says, "quiseram me envolver num caso de eutanásia . . . ou melhor, dessa semi-eutanásia cada vez mais comum" (46). She has no doubts, she identifies herself with her professional role: "não tenho opinião firmada sobre a eutanásia. O que tenho firmado é o meu compromisso com a vida . . . independente do que penso pessoalmente sobre o assunto, cumprirei meu compromisso até o fim" (137).

The words "independente do que penso pessoalmente" sinisterly, paradoxically (and certainly involuntarily) echo the imperative to "follow the orders" on the matter of the life or death of others, suspending any personal philosophical belief and agency. "Compromisso com a vida" is too generic to mean anything at all and reflects a vision of death as an absolute state of "otherness" that only competes—almost as an adversary to be defeated in a fight—with the biological life.

Beyond a schematic presentation of euthanasia and its stereotypical characters, the novel becomes more interesting when it attempts to shed light on the thoughts of the semi-comatose Maria Emília, with a form (vaguely) comparable to blank verse poetry (Barbosa 161). Even if responding to the necessity to differentiate the patient's thinking process to that of the other characters, this choice is an easy strategy to elevate Maria Emília's point of view as "lyrical," "purer," and wiser:

Muita confusão na minha cabeça,
Sei mais ou menos o que estão discutindo
Não dou importância, nem parece que é comigo.
O que decidirem, decidido está.
O que conta é que estou viva.
Não sei mais para que, mas estou viva,
Terrivelmente viva,
Eles é que parecem mortos,
Embora tenham a certeza de que estão vivos.
Ponto de vista de uma doente com tumor na cabeça.
Tumor que faz a cabeça não pensar, pensando. (106)

Not only conscious, but also capable of comparing her state of apparent "death" to the fake life of the sane, Maria Emília defends her condition ("o que conta é que estou viva") against the pragmatic and utilitarian vision of life's goal-oriented and productive condition ("não sei mais para que, mas estou

viva"). The character recognizes all her hospital visitors, listens attentively, ("escuto" [68]), and shows agency ("a voz que ouço é nova mas já é antiga para mim. / Torna a dizer que vou abrir os olhos. / Mas não quero abri-los. / Embora sinta as pálpebras tremerem. / É bom ficar assim" [37]). Her mental capacities are also active ("como me sinto lúcida" [102]) and pain is absent ("Nem mesmo sinto dor alguma. / É como se não tivesse corpo" [33]).

Through the unusual point of view of Maria Emília, Cony offers a counter-narrative to those who defend the "good death" and who define coma and artificial nutrition as an annihilation of human dignity. Even if apparently unresponsive and in a limbo, Maria Emília is still eager to feel alive. This representation seems to reflect the position of several Disability Studies scholars. They argue that euthanasia is, in all cases, a disrespectful and authoritarian practice that takes for granted the meaninglessness of the lives of physical and psychologically vulnerable individuals. If involuntary euthanasia is always condemned, voluntary euthanasia could also be criticized as a choice falsely dependent on the free will of the patient and influenced by societal or familial pressures. The rhetoric of an empowering "end-of-life autonomy" might hide, according to Braswell "discrimination against persons with disabilities" (2011). The shadow of the Nazi euthanasia program is often mentioned as a sinister precursor in history (Andre 2003), a comparison²⁹ that does not take into consideration the informed choice and the complete agency of terminally-ill patients.

The radical condemnation of euthanasia appears at times motivated by a generic distrust of human beings' agendas ("people being what they are, its uses will expand far beyond 'mercy killing' or 'assisted suicide' of patients who are both terminally-ill and willing to die" Andre). According to some authors, a "pro-euthanasia lobby" is always at work in capitalist society: "'Killing is cheaper than caring' for the economic machine" (Davis). Capitalist ideology is also responsible for spreading and reinforcing ideas on the absolute value of health and productivity against disease and dependence. "When you're disabled, there's always a price on your head," as disability activist Linda Andre put it (Andre). Societal pressure might induce suffering people to seek assistance with dying. Another recurring objection to the legalization of euthanasia is that decisions to take extreme measures derive from depressive states more than physical conditions of pain. Some scholars argue that a patient's decision to die might be changed by psychiatric or other therapeutic interventions.

In Cony's novel, a husband calculates the economic value of his wife's life. Representing a privileged class in Brazilian society (he is nearly fifty but spends most of his time at the beach with his buddy), Edmundo's thoughtlessness is underlined by his absolute lack of ethical questioning. He simply "Googles" the word "euthanasia" out of curiosity. There is no doubt that if

such a delicate and complex issue is left in the hands of frivolous and self-centered individuals, society is heading toward medical barbarism. But Cony's novel does not escape from a trivialization of the issue, tracing a straight line between the innocence of Maria Emília, the cynical calculus of Edmundo, and the rigidity of Vilma.

The natural death of Maria Emília takes place at the end of the novel. The sentence "foi uma morte serena, com todo o equipamento ligado" comes unsurprisingly (153). A third-person narrator reiterates that a peaceful death is possible, even if (or maybe because) life was still depending on artificial ventilation. Before the conclusion (at which point Vilma baptizes a new-born child with the name of Maria Emília in honor of the recently deceased patient, a cliché that seems stolen from a telenovela), a third-person narrator describes a symposium on euthanasia that gathers Brazilian doctors and politicians. One of the participants, a secondary character throughout the book, "declarava-se a favor da eutanásia, mas como hipótese futura e regulada cientificamente" adopting the overly used diplomatic strategy of acknowledging the relevance of an issue in words and, at the same time, postponing the debate for a generic future (155). It remains unclear if, through the impersonality of his third-person narrator, Cony is suggesting a critique of the rhetoric of this strategy or is reproducing it for the sake of his own ideological agenda.

Conclusions

Through this essay, I have shown how the international debate on the ethics of euthanasia and assisted suicide is reflected, adapted, and problematized in recent Brazilian nonfictional and fictional writing. Journalistic pieces, interviews, memoirs, and *crônicas* by Moacyr Scliar and Dráuzio Varella tend to present issues in a straightforward way and make their experiences as medical professionals count as a warrant of competence. While underscoring their own concerns and belief systems that lean toward a medical, paternalistic approach, Eliane Brum's columns tend to privilege a non-judgmental approach to listening to her subjects, revealing through real-life anecdotes obtuse, schematic, or bigoted mentalities.

The fears and ideological antagonisms on end-of-life issues that circulate within Brazilian society are also at the core of the novels *Uma duas* by Eliane Brum and *A morte e a vida* by Carlos Heitor Cony. Early examples of Brazilian fiction on euthanasia, these novels are quite distinct in their respective approaches and aesthetic achievements, but share the attempt to show how fragmented and dividing this issue can be, staging clashes of visions, particularly between medical professionals and severely ill patients and their relatives.

While Brum tries to illuminate the contradictions in the minds of a daughter and her sick mother, linked by a hateful relationship and the impossibility

of a perfectly Cartesian approach to the issue, Cony chooses to consider the unusual point of view of a semi-comatose patient, although he schematically polarizes the issue through the elemental psychology of the “healthy” characters in the novel. In depicting the end-of-life scenario from the inside, Cony requires more empathy from his readers. As Spiro put it, “the eye is quicker than the ear; yet, the patient’s experience is more complicated and variable than the disease visible to the doctor” (10).

These works ask readers to pay attention to other points of view, even the ones that appear bigoted or authoritarian. In this sense, they constitute a corpus of texts that may function very well in the context of a class on “literature and medicine” in which students are solicited to debate bioethical challenges and recognize the value of engaging in a respectful debate as citizens with different belief systems. Readers who are sympathetic to end-of-life freedom of choice can recognize and acknowledge the existence of a multiplicity of meanings and idiosyncrasies upon which their choice was formed (*Uma duas*). The reading of literature provides, in other words, an opportunity for introspection and anticipation of a possible scenario in which readers are called to make a decision for us or for our loved ones. Cony’s novel and Scliar’s and Varella’s *crônicas* offer the chance to train and refine personal arguments in favor or against euthanasia, either recognizing and dismantling obviously schematic arguments that circulate in society (represented in *A morte e a vida*), or paternalistic approaches more typically found within the medical community (shown in the cited *crônicas* and interventions). If loneliness is inevitable when we are called to be responsible for another suffering person, literature can at least make bioethical themes relevant for us *now*, reflecting and substantiating our anxiety through the written words, and prompting the maturation, with time, of a personal reflection on the emotionally intricate issue of the end of life.

Nicola Gavioli

Florida International University
Department of Modern Languages
Building DM-482A
11200 SW 8th Street
Miami, Florida 33199
ngavioli@fiu.edu

Notes

I would like to thank Sandra Wassilie for her feedback on this essay.

1. The direct experience of illness is the main point of departure to critically reflect on issues of suffering and mortality. Even health professionals—physicians and

nurses—realize that curing severely ill patients does not make them more understanding or prepared to face pain, death, and end-of-life dilemmas. The collective volume *Dall'altra parte* (2006) organized by Paolo Barnard, the memoirs *O médico doente* (2007) by Dráuzio Varella and *When Breath Becomes Air* (2016) by Paul Kalanithi offer examples of real stories in which doctors understand for the first time the experience of being ill through a personal trauma. With Nietzschean echoes, in the *crônica* “O médico doente,” Moacyr Scliar refers to the knowledge through physical pain as “uma experiência transcendente” (55).

2. See Souza’s “Sô Candelário’s Inheritance.”

3. My *corpus* includes texts that directly focus on end-of-life decision making. This selection does not have the ambition of being exhaustive. See, for example, other literary works such as, the novel *Hanói* (2013) by Adriana Lisboa and Lygia Fagundes Telles’s short story “Boa noite, Maria” (in *A noite escura e mais eu*, 1998).

4. To name a few: *Les invasions barbares* (2003) by Denis Arcand, *Mar adentro* (2004) by Alejandro Amenábar, *Bella addormentata* (2012) by Marco Bellocchio, *Miele* (2013) by Valeria Golino, and the short documentary *Extremis* (2016) by Dan Krauss, an Academy Award nominated film. In the 2015 edition of the Cannes Film Festival, the movie *Chronicle* by Michel Franco—telling the story of the relationship between a male nurse (Tim Roth) and a group of terminally-ill patients and offering a meditation on euthanasia—obtained the award for Best Screenplay. Brazilian cinema is still missing a film that might contribute to the international debate on end-of-life decision-making.

5. Theater director Cesar Brie offered a rereading of the classical myth of Orpheus and Eurydice through the lens of current bioethical debates (*Orfeu ed Euridice*, Italy, 2014).

6. Among the websites in Portuguese which address the end-of-life issue, I mention a special section of *El país Brasil* (<http://brasil.elpais.com/tag/eutanasia/a/>), the column in the Portuguese newspaper *Público* by Laura Ferreira dos Santos, founder of *Direito a Morrer com dignidade* (<http://www.publico.pt/autor/laura-ferreira-dos-santos>), and the column *Morte sem Tabu*, in *Folha de São Paulo* (<http://mortesemtabu.blogfolha.uol.com.br>) by Camila Appel.

7. See Vallejos.

8. See the documentary *24 and ready to die* on Youtube: <https://www.youtube.com/watch?v=SWWkUzkfj4M>.

9. The story of DJ Fabo—Fabiano Antoniani—appears on *BBC News* (February 27, 2017): <http://www.bbc.com/news/world-europe-39117472>.

10. The collective volume *Libre acceso* represents a valuable recent contribution to Disability Studies and Latin American cultural production.

11. The semantic difference between voluntary active and passive euthanasia is intuitive: while in the first case a doctor provokes dying, based on the informed will of the patient, through the injection of a deadly substance, in the second the doctor interrupts a therapy essentially allowing a patient to die. The participation of a doctor and the free will of the patient are fundamental (otherwise we could not talk of “voluntary euthanasia”). In *Lasciatemi morire*, pro-euthanasia activist Piergiorgio Welby

wonders if the creation of a new term would help to better explain what assisted end of life is (103). “Assisted suicide” (a practice in which a doctor provides the substances to a patient who, autonomously, performs the injection) is currently legal, with significant differences, in the Netherlands, Belgium, Luxembourg, Switzerland, Canada, Colombia, and the U.S. (in the states of Oregon, Washington, Vermont, California, Montana, and Colorado).

12. The term “orthothanasia” is used to describe situations in which the condition of a patient is certified as incurable by doctors and in which the traditional medical therapies are substituted by palliative care aimed not at saving lives but at alleviating the suffering.

13. The most common reasons against the legalization of euthanasia are: the misleading association with the euthanasia program as practiced by the Nazis; the Nuremberg Code (established after World War II to limit the power of doctors); the Hippocratic Oath (“I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect”); the argument of the “slippery slope,” for which the legalization of euthanasia would gradually and inevitably be followed by the extermination of all the economically indigents, old, and sick considered as a burden in a hyper-capitalist dehumanized society. Contemporary philosopher Alain Badiou has also expressed his concerns on the legislation of euthanasia (again, it is the precedent of the Nazi program that Badiou mentions) in *Léthique. Essai sur la conscience du mal* (2003). Moreover, the French philosopher defends that the expression “bioethics” is per se a disquieting concept.

14. The official English translation of the speech of Pope Francis is available here: https://w2.vatican.va/content/francesco/en/speeches/2014/november/documents/papa-francesco_20141115_medici-cattolici-italiani.html.

15. This happens, for example, in the episode “Direito de morrer” (broadcast on April 22, 2013) of *SBT Repórter*. The program opens with the close-up of a needle accompanied by dramatic music. Even if diverse opinions are shown during the program, this rhetoric choice seems to reveal a (not too) hidden agenda. The ideological affiliation of the TV channel must of course be taken into consideration when analyzing the reportage. Moreover, there is also a curious mistake: Portugal is listed as one of the countries allowing voluntary euthanasia.

16. I am very thankful to Doctor José Marques Filho, first secretary of the Sociedade Brasileira de Bioética, who generously informed me about the legal aspects of the discussion on end-of-life matters in Brazil (February 2017).

17. Dr. José Eduardo de Siqueira’s words are taken from a 2010 interview conducted by Eliane Brum for the magazine *Época* (“Testamento vital” published on July 12, 2010). The text “Bioética no Brasil: uma década de conquistas (2002–2012)” by Léo Pessini and William Saad Hossne offers a synthesis of the major changes in bioethics recently taken place in Brazil. Léo Pessini is one of the most active scholar on bioethical issues in Brazil, having single-authored articles, monographs, and co-edited volumes on the issues of euthanasia, dysthanasia, and palliative care. He penned the entry “Eutanásia” in the collective *Diccionario latinoamericano de bioética* directed by Juan Carlos Tealdi (UNESCO 2008).

18. I would like to thank Jaime Ginzburg for indicating this article to me. The interview by Mônica Manir (“A duras penas”) was occasioned by the translation of David Le Breton’s book *Anthropologie de la douleur* (originally published in 1995). “Meaning” is a key term in Le Breton’s research.

19. For example, essays on the film *Mar adentro* (Pessini, 2008) and *You Don’t Know Jack* (Da Costa e Fonseca, 2012).

20. Technical information about *Os gigantes* is available on the website “Memória Globo:” <http://memoriaglobo.globo.com/programas/entretenimento/novelas/os-gigantes.htm>.

21. Barry Levinson directed in 2010 the HBO biopic *You Don’t Know Jack*, a film based on Doctor Kevorkian’s legal cases and legacy, starring Al Pacino in the leading role.

22. *Roda Viva* is a program of interviews broadcast by TV Cultura since 1986. Seemingly artificial and intimidating, the format of the program is its own distinguishing mark: the interviewed personality sits at the center of a white oval studio—a literal “arena”—surrounded by journalists and experts who alternate in asking questions. It is one of the most important TV programs of Brazilian journalism: writers José Saramago, João Ubaldo Ribeiro, Mia Couto, Mario Vargas Llosa, and Amos Oz, among many others, appeared on the program.

23. Eliane Brum names her website *Desacontecimentos*. Here, she describes herself: “sou uma escutadeira que escreve” (<http://elianebrum.com>).

24. Eliane Brum: “sou influenciada tanto por toda a literatura escrita que li, a literatura do cânone, como pela literatura oral que tive o privilégio de acessar como repórter. O brasileiro tem uma linguagem extremamente sofisticada, constituída de invenções de palavras e achados de linguagem” (Candra).

25. I would like to thank Idelber Avelar for steering me toward *Uma duas*.

26. Several reviews of *Uma duas* are available on Eliane Brum’s official website *Desacontecimentos*.

27. The novel alternates, in a metafictional way, chapters printed in opaque red color (Laura’s notes on the computer: “escrevo com o sangue pingando,” [15]), in bold red (corresponding to the auto-fictional novel Laura writes camouflaged under the guise of an omniscient narrator), and in red italics (Maria Lúcia’s secret notes).

28. A closer look at the novel reveals that the etiological link between personal unhappiness, guilt, and the growth of cancer is also established by other characters, including nurse Vilma, for whom “passiva, carente, dominada pela prepotência da mãe e mais tarde pela leviandade do marido, Maria Emília *fizera o tumor* e ali estava, estável diante da vida, estável diante da morte” (Cony 116, my emphasis). Another character with medical training affirms that: “o que sei é pouco mas há uma teoria, ou melhor, uma hipótese, esses tumores, o câncer de maneira geral, não nasce sem mais nem menos, há sempre uma causa . . . uma causa anterior . . . O câncer é uma doença aqui de dentro” (Cony 52–53).

29. The inevitability of the “slippery slope,” the fear of bringing back a Nazi mentality was represented by Swedish writer Carl-Henning Wijkmark in *Modern Death: The End of Humanity* (1978), a novel in theatrical form in which experts gather to discuss “solutions” for an aging and unproductive population in Europe.

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