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DEMENTIA NARRATIVES IN BRAZIL: CAREGIVER MEMOIRS

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Abstract

Auto/biographical writings by authors who have become caregivers for people with dementias, such as Alzheimer's disease, have been published since the 1980s, particularly in the United States, the United Kingdom, and Europe. Similar Brazilian texts, however, have begun to appear with greater frequency only over the past decade. This study seeks to provide the first comprehensive survey of all works of this kind published in Brazil, with attention to the referential and representative nature of the corpus in relation to statistical data on caregivers of people with dementia. Accordingly, we will examine issues of gender, location and conditions of care, race or ethnicity, and social class of the authors and their relatives, along with a brief commentary on the paratextual resources found in the works. We will then propose two primary modes for classifying caregiver narratives—a tragic mode and a pragmatic mode—in order to discuss, in a more didactic manner, the formal configurations of this subgenre and the key questions raised in similar texts, such as the presumption of identity loss in the person with dementia and the ethical tensions involved in narrating and reflecting upon the burdens of the caregiving experience without reproducing culturally pervasive stigmas and stereotypes surrounding dementia and ageing, nor violating the privacy of someone incapable of understanding or consenting to their participation in the process. Finally, we will undertake a more detailed analysis of Elaine Tavares's *Boa noite, seu Tavares* (2025), which will serve both to exemplify the characteristics of the two modes discussed above and to offer a glance into the ethical/social paradigm of life writing. Along the way, we will seek to systematize the main theoretical contributions that have addressed

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similar objects, with the aim of facilitating the further development of these questions in future research.

Keywords: life writing; auto/biography; caregiver memoirs; dementia; Alzheimer's disease

Introduction: Initial Definitions

"It was on the day my daughter left home that my mother went mad."[1] thus begins the memoir by Heloísa Seixas (2007, 9), which recounts part of her life following her mother's diagnosis with Alzheimer's disease. The line recalls the famous opening of Camus' *The Stranger*: "Mother died today." Together, the initial statement and its literary echo condense many of the central concerns of auto/biographical accounts that narrate the dementia of close relatives. A rupture is created from the moment of the diagnosis; the time of normality is fractured by a catastrophic event. One questions the status of the ill person—from sanity to madness, from rationality to dementia—thus setting in motion a journey of mourning-in-life which the witness/writer must accompany. As rationality shatters, it is the narrator who must both recount and reflect upon their experience. Unlike traumatic injuries and strictly physical ailments, the meaning-making capacities of those with cognitive impairment are ignored, particularly when the afflicted are elderly. The chronological order in the diegesis functions as a normalizing measure against a lived reality of repetitions, false beginnings, disregard for past contracts, and, more radically, the collapse of linear causality. Like Annie Ernaux, such narrators take on the role of "archivists" (1992, 15) of an increasingly unreliable memory. How, then, in the midst of such striking imbalances of power, are the tensions within these intimate accounts articulated? How do established hierarchies—between mothers and daughters, grandmothers and grandchildren, spouses—endure the breakdown of routines and the erosion of the most basic relational assumptions, such as mutual recognition, individual agency, and autonomy? What would be the ethical breaking points of representing limit experiences, particularly when those at the very threshold of vulnerability can no longer consent to, or even comprehend, their transmutation into narrative characters? In other words, why tell? And for whom?

By no means it is our intention, in this brief space, to answer all of these questions, which have already been the focus of research for some decades. Our aim is to offer an overview of how Brazilian writers-caregivers have approached the task of representing their experiences in auto/biographical accounts. To that end, before turning to the actual description of our objects ("Overview of the Works"), and to a discussion of their main literary features through a simple typological framework ("Two Modes of Narrating Dementia"), we must outline a few preliminary definitions and methodological choices.

Alzheimer's Disease or Dementia(s)?

In terms strictly consistent with the recent medical consensus, dementia is a progressive neurodegenerative syndrome characterized by a set of cognitive and behavioral symptoms that interfere with daily activities and cannot be attributed to psychiatric disorders (Smid et al., 2022, 2). While the most familiar complaints relate to memory loss and language impairment (dysphasia or aphasia), it is the decline in the executive function (Ropper et al., 2023, 1058)—planning and carrying out sequential, goal-directed actions such as preparing a simple meal, bathing or dressing—that most directly leads to the person with dementia requiring intensive support.

Dementia lies at the end of a continuum that begins with cognitive decline and includes mild (or light) cognitive impairment (Smid et al.). The term, however, also encompasses several distinct conditions with different etiologies, among them vascular dementia, frontotemporal dementia, Lewy body dementia, and, most prominently, Alzheimer's disease. The criteria for the pathophysiological diagnosis of Alzheimer's are continually being revised (McKhann et al., 2011) and require histological, genetic, and neuroimaging analyses. In clinical practice, however, the diagnosis typically relies on cognitive tests and evaluative tools, such as the Clinical Dementia Rating, or CDR (Hughes et al., 1982),[2] which are considered sufficient for establishing possible and probable diagnoses.

There is a long history—extensively explored by, among others, Gubrium (1986) and Ballenger (2006)[3]—regarding the reasons that led Alzheimer's disease, first identified and named in 1907, to become so widely recognized by the public in the 1980s, to the point of reshaping our entire understanding of aging and of the so-called senile dementia.[4] These authors analyze shifts in the dominant concepts of aging, the influence of research funding in biochemistry, and the rise of support and advocacy organizations, such as the Alzheimer's Association in the United States, to explain how the disease's name came to achieve its current level of visibility and cultural resonance.

In the works examined here, although some authors include brief explanations about other types of dementia, the terms "Alzheimer's disease" or "Alzheimer's" (in Portuguese: *doença de Alzheimer* or *Alzheimer*) are widely used, and we assume the majority of the family members portrayed as characters have received this diagnosis. Accordingly, we have opted to use "dementia" and "Alzheimer's disease" interchangeably. However, we have also retained the plural form "dementia*s*" to indicate the heterogeneity of the condition's manifestations and causes, and to underscore the fact that its diagnosis is neither straightforward nor uncontroversial as is often assumed.

Literary Genre

The discussion regarding the definitions of the literary genres associated with biographical writings, such as autobiography, memoir, and the intimate journal, take up much of the critical work in the field. Therefore, we offer only a concise account of how we employ the terms that designate the genres and subgenres that are most relevant to our analysis.

Following Sidonie Smith and Julia Watson (2010), we consider "life writing" as the set of discourses that comprise a wide range of subgenres. At the end of their book, these authors establish almost 60 classifications (253–86). Among these subgenres, we are particularly interested in the "illness narrative" (Vickers, 2016), as established by foundational authors Arthur Frank (1995) and G. Thomas Couser (*Recovering Bodies*, 1997; *Vulnerable Subjects*, 2004; *Signifying Bodies*, 2009), among others. Within illness narratives, we focus specifically on "relational autobiographies" (see Bitenc, 2019, 129), which center not only on the life of the writer/narrator, but on their relationship to the ill person, often a family member. More narrowly still, our corpus consists exclusively of "caregiver memoirs," the most representative type of such narratives (Bitenc 128). We also employ the term "auto/biography", following Couser (*Vulnerable Subjects* ix) and Falcus and Sako (2019, ch. 1), in order to underscore the interpersonal dimension inherent in all autobiographical writing—a genre that necessarily engages not only the self, but the other. It is distinctively the special position of caring and narrating the other, in an intersubjective relationship always on the brink of becoming exploitative, yet also leaving the author of the narrative exposed, that constitutes one of the main interests of this specific genre, as we shall see.

Scholarship

Projects comparable to the one we pursue here are recent,[5] and nearly all of them have been written in English and published in the United Kingdom, the Netherlands, and Germany, where most established research groups are based. Most of the scholars navigate in the departments of Literature and Health, or Medical Humanities, and adopt multidisciplinary frameworks drawing on Literary Theory—most often within Life Writing—along with Cultural Studies, Disability Studies, and Film Studies.

The main monographs we shall use as reference are those by Martina Zimmermann (*Poetics and Politics*, 2017; *The Diseased Brain*, 2020), Rebecca Bitenc (*Reconsidering Dementia Narratives*), Crystal Yin Lie (*Entangled Stories*, 2019), and Sarah Falcus and Katsura Sako (*Contemporary Narratives of Dementia*). While Lucy Burke has not yet published a full-length study devoted to the topic, her articles—as well as the website of her UK Research and Innovation-funded project (Burke, "Alzheimer's Disease in Contemporary Literature and Culture", 2016)—constitute essential points of reference. In addition, four significant collections of essays have been published in English (Krüger-Fürhoff et al., 2021; Maginess, 2017; Ringkamp et al., 2017; Swinnen and Schweda, 2015) and gather essays by these scholars and by numerous others.

In Brazil, up to the present moment, little has been written on the literary representations of dementia. Among the few studies available, a notable contribution is a chapter from Renata Dalmaso's doctorate dissertation (*Disability and Metaphor in the Graphic Memoir*, 2016), written in English and published previously as an article ("The Visual Metaphor of Disability in Sarah Leavitt's Graphic Memoir Tangles: A Story about Alzheimer's, My Mother, and Me", 2012), which examines the graphic novel *Tangles: A Story about Alzheimer's, My mother, and Me* by Sarah Leavitt (2012). Another relevant work is a chapter in the Master's thesis by Caroline Peres Martins (*Memória, Trauma e História*, 2021), later reworked into an article ("As Representações Do Corpo Em Marcelo Rubens Paiva", 2022), which analyzes *Ainda estou aqui* [I'm Still Here] (2015), by Marcelo Rubens Paiva.

All of these studies address dementias in the context of literature and other arts, and they frequently compare autobiographical, biographical, and fictional works, including poetry, novels, documentaries, and fictional films. It is worth noting that in Brazil we have identified only two prose narratives focusing on the experience of a character with dementia: Homero Fonseca's *À espera do tio Alois* [*Awaiting Uncle Alois*] (2016) and Flavia Cristina Simonelli's *Ausência* [*Absence*] (2017). In addition, in Brazil no exclusively autobiographical works have yet been published: there is not a single narrative in which an individual suffering the early or moderate states of dementia, with our without assistance for writing and editing, records their experience.[6] For this reason, among the theoretical sources we engage, we draw most consistently on scholarship that examines non-fiction caregiver narratives.

Another relevant perspective concerns narratives by people with dementias and their caregivers. For this reason, we include here references from Social Anthropology, Applied Linguistics, and Discourse Analysis, fields that focus on the oral production of spontaneous, situated discourse. It is within these disciplines—often in collaboration with Aging Studies—that we find most Brazilian academic research engaged with a broader understanding of narrative, the construction of subjectivity, and dementia (Bastos and Biar; Costa; Fernandes; Fronza and Cruz; Mira and Custodio). Our principal reference here is the dissertation by Daniela Feriani (2017), in Social Anthropology, which offers an extensive meditation on the discourses surrounding Alzheimer's disease, ranging from medical interviews to analyses of patient-written blogs. The concepts, examples, and questions emerging from these fields provide perspectives that would be inconceivable were we to confine ourselves to a strictly literary framework.

Overview of the Works: Facts and Representativeness

The 12 works[7] that make up the corpus were located through Brazilian university library catalogues, bookstores, academic references, dementia-related websites, and recommendations in support groups, both online and in-person, for families of people living with dementia. Although the result list is likely not exhaustive, it currently provides the most complete overview of Brazilian books on the subject published either in print (10 titles) or in digital form-only (1 title).

With the exception of one volume (Pinto), all were available for purchase in bookstores or second-hand vendors at the time of writing (July-December, 2025).

We have opted to exclude from the corpus texts published exclusively on blogs or social-media platforms, such as X, Facebook, Instagram, Wordpress and Substack, as well as oral narratives transcribed in academic studies, though we refer to some of these materials in later sections. The primary rationale for this choice is that the book format allows for comparison with works published prior to the rise of the internet and with international publications in equivalent formats; it also facilitates long-term access for future researchers and stable citation practices. Nonetheless, we stress the arbitrariness of choosing the traditional book-format, edited and published as a single, self-contained oeuvre. There is a clear need for further research on other forms of life-writing, particularly in those circulating on social-media. It is within online support-group posts that one encounters a substantial portion of the daily struggles of caregivers and, at times, of individuals living with dementia themselves. It is also on these forums one finds accounts from social backgrounds with limited access to the specialized technical apparatus of writing, publishing, and marketing more substantial literary works.

As Neil Vickers (388) and Thomas Couser (*Signifying Bodies* 3) observe, illness narratives were uncommon before 1950 and only gained prominence in the 1980s. The earliest memoir by a caregiver writing specifically about a relative's senile dementia, *Chronicle of My Mother*, appeared in 1975. It was translated to English in 1982 (Inoue, 1982), a decade that witnesses works of fiction (Bernlef, 1984; Forster, 1989), journalistic accounts (Roach, 1983), and an autobiography, *My Journey into Alzheimer's* (Davis, 1989), the first to bring the word Alzheimer's in its title. This rise mirrors the broader history of the disease, which established itself in the public discourse only through the efforts of organized advocacy groups, such as the Alzheimer's Association, in the 1980s, as described by Ballenger (ch. 5). However, it is only in the second half of the 1990s that we observe the editorial consolidation of the genre we analyze here: memoirs of authors who write about their experiences caring for relatives with dementia in a context already shaped by the widespread biomedical definition of Alzheimer's disease. The third and last volume of memoirs about philosopher and novelist Iris Murdoch, written by her husband, John Bayley (1999), and the diary of Annie Ernaux, *I Remain in Darkness* (1999), which deals with her mother's Alzheimer's,[8] are representative examples of works by prominent authors—a "*somebody* memoir", in Couser's terminology (*Signifying Bodies* 1)—who unexpectedly found themselves in caregiving roles. "*Nobody* memoirs", on the other hand, works written by previously unknown or insignificant authors , are exemplified by titles such as *Alzheimer's: A Love Story: One Year in My Husband's Journey* (Davidson, 1997) and *Where Did Mary Go? A Loving Husband's Struggle with Alzheimer's* (Wall, 1996).

The first Brazilian volume published is *Alzheimer's Disease: The Color of Pain* (Elias, 1998), written by a then-amateur author whose later works attracted little attention. It is only from 2015 onward that the substantial majority of publications occur: 9 out of 12 books in our corpus came to light within the last decade. Several factors may explain this. First, the Brazilian publishing market is considerably smaller than the English-language equivalent (WIPO, 2023). This means there is less space for debut authors in major publishing houses. Note that only Heloísa Seixas and Marcelo Rubens Paiva are nationally known and celebrated by their literary and journalistic works, and are the only authors in the list represented by major publishers. All the others published independently or through smaller presses, possibility covering the costs of print out of their own pocket, a practice that has become more viable in recent decades. Second, we propose the hypothesis that the internet played a significant role in prompting authors to elaborate in writing their experiences as caregivers. Of the 12 authors, 5 began writing on social networks, in the form of diaries or chronicles, and only later assembled the texts in printed format (Pinto, Aguzzoli, Moraes, Rufino Júnior and Tavares). It is also possible to suggest that there was a delay in relation to the United States and Europe in the perception of senile dementia as a singular pathological experience distinct from the normal process of aging. This means that the discourse about Alzheimer's and dementias in general took longer to reach all layers of the Brazilian population. Finally, we also ask whether the sense of individual burden experienced by caregivers increased over the last decades. In this respect, both the aging of the population and its migration to urban zones with smaller nuclear families are relevant facts. None of these hypotheses, however, can be developed in this space, since doing so would require, at minimum, a historical understanding of the internet's impact on genres of life writing, a study of the population's general perception of Alzheimer's, and a comparison with countries more similar to Brazil in publishing infrastructure and demographic patterns.

Additional facts about the works can, taken together, provide a general idea of the corpus before we turn to questions of the memoirs' more narrative and literary aspects. In terms of *kinship*, most accounts (8 works) concern parents; 2 center on spousal relationships, and 2 come from (male) grandchildren writing about their grandmothers. With respect to *gender*, [9] 7 memoirs are authored by women caregivers and 5 by men; 10 describe the experiences of women with dementia, and 3 those of men. [10] As for *race/color*, none of the narratives identify their authors or their subjects as Black, Brown (*pardo*), Asian or Indigenous—a significant absence that will be discussed at the end of this section.

Age also provides insight: the average age[11] of writers is 49,[12] while those with dementia average 79. The period described between the first appearance of the first symptoms and either the death or the end of the narrative averages 8 years. Five narratives span 10 to 14 years (Elias; Leal, *O Alemão Veio Nos Visitar*; Leal, *O Alemão Pegou o Bonde*; Leal, *O Alemão Voltou Para Casa*; Paiva; Seixas; Silva), another five cover from 5 to 9 years (Aguzzoli; Pinto; Rufino Júnior; Tavares; Xavier), and two narratives describe periods shorter than 5 years (Barros; Moraes). In five narratives, the person with dementia was still alive at the time of publication.

In most cases, from the moment of the diagnosis, the authors take on the role of *primary caregivers*, receiving varying degrees of support from paid, specialized professionals. The exceptions are Aguzzoli and Rufino Júnior, who were 17 and 23 years old, respectively, when first confronted with their grandmothers' illness and who only gradually assumed primary caregiving responsibilities, always with family assistance.

Concerning the *geographic location* and the *setting* of the narratives, all take place in Brazilian capital cities or in large metropolitan zones. One narrative unfolds primarily in the North Region (Pinto), two in the Northeast (Leal; Xavier); two in the South (Aguzzoli; Tavares), and seven in the Southeast. Almost all accounts narrate care provided within a household shared by the writer-caregiver and the family member living with dementia. Some narratives, however, open with the individuals living in separate homes (Aguzzoli; Paiva; Rufino Júnior) and recount the subsequent transition into a shared dwelling. Only Leal manages to keep her mother in her own apartment, albeit in the same building as her daughter's, allowing for intensive daily contact. Pinto and his siblings are the only authors who place their mother in an institutional geriatric setting—a charitable facility in Belém do Pará.

Although the corpus and publicly available information do not allow for definitive conclusions, the *social class* represented in most of these narratives aligns broadly with what is commonly understood in Brazil as "middle-class," even if the financial circumstances, and the resulting forms of care available to the person with dementia, may vary. Marcelo Rubens Paiva, for instance, could be classified as a member of the "elite" and relies on a network of lawyers, physicians, physical therapists, and professional caregivers, along with cooks and housekeepers employed in his home. A similar, though somewhat precarious, situation appears in the narratives of Rosana Leal and Jaime Xavier. By contrast, writers such as Valmi Elias Carneiro, Míriam Moraes, Lúcio Flávio Pinto, and Elaine Tavares describe financial constraints that prevent them from securing extended professional assistance, thereby positioning them as full-time caregivers who often need to conciliate this task with a full-time regular job outside the home. Despite these differences, the socioeconomic profiles portrayed remain relatively homogeneous and consistent with middle-class *values* and standards of living, without significant extremes in either direction. The authors typically hold higher education degrees or work in professions associated with such training: they are public servants, engineers, professors, researchers, journalists, writers, and businessmen.

The data concerning the ages of the people with dementia and their caregivers in the works analyzed is consistent with statistics reported in the executive summary of the National Report on Dementia in Brazil, or ReNaDe 2024 (Brasil, 2024), as well as with the findings of meta-analyzes and academic studies that profile caregivers in the country (Dadalto and Cavalcante, 2021; Santos et al., 2024). Even so, three elements raise questions about how representative these narratives truly are in relation to certain aspects: the *gender* of the caregivers, the *setting* in which care is provided, and the *racial or color* identifications of those involved—something that also requires a brief reflection on *social class*.

Gender

Official data reported in ReNaDe indicate that 86 percent of caregivers in Brazil are women, while in the corpus examined here male caregivers appear in disproportionately high numbers (41 percent).[13] As Zimmermann notes (*Poetics and Politics*, ch. 3), in the chapter dedicated entirely to memoirs, photographic essays, films and narratives authored by men, one may reasonably hypothesize that the burden experience by male caregivers—in a society that grants males a higher expectation of autonomy and deprives them of a care-centered education—would encourage a more tragic framing of a condition that undermines precisely the independence and rational agency culturally associated with masculinity. Xaiver's memoir (2019) exemplifies this dynamic. The author is a retired executive accustomed to a high standard of living. After becoming his wife's primary caregiver, he recounts the experience in an overtly tragic, even melodramatic register, underscoring his impotence to halt the disease's progress, the "absolute impossibility of bringing her back to life," and what he calls his "greatest defeat as a human being," a "clear affirmation of [his] insignificance" (Xavier 14). The memoir's subtitle, "the journey of hopelessness," encapsulates the general narrative posture, which centers on the sense of failure of a man who had otherwise accomplished all he set out to achieve. The narrator's wife, despite his efforts to reconstruct her biography, is repeatedly reduced to idealized notions of femininity, now destroyed by the illness: "the 'girl' she once was, innocent, pure, joyful, talkative, now unable to express herself clearly [...] the beauty she always had and the sweetness with which she always behaved, little by little slipping away into apathy and sadness" (Xavier 14).

Most male-authored narratives, however, do not adopt this stance. In Marcelo Rubens Paiva's account, the dominant image is that of one of the most significant women in Brazil's recent history, Eunice Paiva. This is achieved by the reconstruction of her life before the illness and the description of her role in investigating crimes committed during the military dictatorship of the 1960s-1980s, which occupy more than half of the book. Such an approach corresponds to what Zimmermann terms an "identity-affirming patient presentation" (*Poetics and Politics* 49), which contrasts with the attitude of "remov[ing] the patient's agency" (*Poetics and Politics* 72). The younger writers, Aguzzoli and Rufino Júnior, are the most humorous and the most willing to confront the disease in an affectionate, light-hearted, and pragmatic manner—as we shall discuss in the next section. By contrast, women writers such as Elias, Seixas, Silva, and Morata, as well as Ernaux, tend toward markedly tragic tones. In this regard, we concur with Zimmermann's conclusion that the degree of available support is more predictive of a narrative's emotional register than gender itself: Xavier and the women authors mentioned above bear the weight of primary caregiving with little to no assistance from family or professionals, whereas Aguzzoli, Rufino Júnior, and Rubens Paiva rely on extensive help.

Caregiving Setting

Across Brazilian narratives, the underrepresentation of individuals with dementia who have been institutionalized at any point in the account is striking.[14] Unfortunately, Brazil lacks statistical data indicating the proportion of diagnosed dementia cases broken down by place of residence. Nonetheless, Gorzoni and Pires (2006), in a literature review that compiles data on dementia syndromes and symptoms in long-term care institutions in Belo Horizonte, São Paulo, and Rio de Janeiro, estimate that between 19.9 and 73.7 percent of institutionalized older adults show signs of dementia, depending on the criteria and the age brackets used in each study. These figures suggest that a substantial share of elders living in nursing homes and geriatric institutions have dementia, and yet there are no narratives in the country dedicated to explore the relationship between the family caregiver and the institutionalized relative, with the exception of Pinto—whose account, however, begins in the family home and offers little sustained reflection on institutional conditions.

Whatever the reasons might be, the fact remains that works in our corpus are situated within the domestic sphere, where the contact between caregivers and people with dementia is continuous and intensive. The narrators sleep in the same room—often in the same bed—as their relatives during the final stages of the illness, and they are frequently responsible for all household maintenance as well as the most intimate forms of personal care. Once again, the practical constraints of daily life and the limits imposed by the caregiving role, reinforce the sense of tragedy that emerges from the painstakingly detailed accounts of routines consumed by tasks of mere subsistence.

The underrepresentation of institutional care in these narratives also means that Brazilian works differ from accounts such as Alan Bennett's "The candlewick way of death" (2005), who chronicles visits to his mother in a long-term facility in England and reflects on his guilt for stepping back from the dementia process, as well as on the structural issues affecting public nursing homes in the country. Nor does it echo Sylvia Molloy's *Dislocations* (2022), where vignettes arising from frequent visits to a friend with Alzheimer's lead to meditations on the language and poetry of dementia, as well as on the nature of identity and memory as concepts by themselves. Susan Schultz (2008) and Dana Walrath (2013) also probe into the psychological and philosophical dimensions of dementia, modes of inquiry arguably enabled by their relative distance from full-time caregiving and by a broader distribution of care within professional support networks. In sum, evidence again suggests that the heavy burden of individual caregivers with little familiar or institutional support constrains the works' range to either a tragic or a pragmatic description of progressive symptoms of dementia in the domestic environment.

Race/Color and Class

Although the National Report on Dementia in Brazil indicates that 39.3 percent of people with dementia and 45 percent of caregivers do not identify as white (Brasil 7, 10), all the works examined in this study are written by, and concern, white individuals. This disparity places the Brazilian corpus squarely within a broader international pattern of marked absence of nonwhite representation in memoirs about dementia and illness and disability more generally. Martina Zimmermann notes she has not encountered a single dementia narrative in English, French, German, Spanish, or Italian authored by a nonwhite caregiver or referring to individuals identified as such (*Poetics and Politics* 15). Rebecca Bitenc underscores that the text she studies cannot be regarded as representative along axes of ethnicity, race, or class (30). These observations echo longstanding insights by illness narrative scholars, such as G. Thomas Couser, who stresses the unavoidable and inherent lack of representativeness in auto/biographical accounts of HIV/AIDS analyzed in his first work (*Recovering Bodies* 170). He points out that access to adequate material conditions of writing and publishing, as well as medical care, and financial support, characteristic of an educated, securely employed white middle class—that is, authors who write from a position of relative privilege—reinforce the tendency of shaping the "best" possible stories, the "*best case scenarios*" (*Recovering Bodies* 170), which stand in stark contrast to the broader realities of illness, especially those experience by Black communities in the United States. More recently, Avrahami concluded her study by remarking that the authors she examines are "predominantly white and middle-class professionals" (159), benefitting from private health care and from extended leaves in order to produce their narratives.

In the field of Critical Dementia Studies, exemplified by the volume edited by Ward and Sandberg (2023), we are beginning to witness scholars interrogate the connections between medical, sociological, and ethnographic research, and the racist, colonial, and Eurocentric assumptions embedded in the very idea of "ethnicity." Such ideas aim to foster active antiracist stances both in academic works and in the implementation of public policies regarding detection and prevention of dementia in minoritized populations (Zubair, 2023). In the field of Disability Literary Studies, a similar effort can be seen in Sami Schalk (2018), whose *Bodyminds Reimagined* articulates intersections between speculative fiction, disability, and race. These few exceptions aside, we may still ask—as Chris Bell does in his provocative essay "Is Disability Studies Actually White Disability Studies?" (2017, 406)—whether dementia life-writing amounts, in practice, to life-writing of white dementia. Thus, as far as Zimmermann and Bitenc assess, this seemingly insurmountable barrier of race remains evident in Brazil as well, given the corpus currently available.

The fact that Alzheimer's disease is represented in exclusively white, middle-class memoirs is also linked to the institutional history of the earliest support groups, as told by Ballenger. He cites the "exemplary cases" (128) that became the emblems of the Alzheimer's Association's institutional public outreach campaigns: individuals were often portrayed as victims who were previously "intelligent, vigorous, and active […] at the pinnacle of, or retiring from, successful middle-class careers" (130). Such portraits reinforced the "American myth," according to the author, of a respectable middle-class, whose values and attitudes cohered around what it means to be a healthy and fulfilled individual (134). This discourse likewise supplied a crucial narrative template later adopted by many life writings about dementia: the tragedy aspect of the stories is emphasized by its stark contrast between an autonomous and mentally sound personality who, after the onset of symptoms, becomes dependent and loses mental acuity. Fictional works engaging with dementia often reproduce this pattern. In Lisa Genova's widely read *Still Alice* (2009), and Alice Laplante's *Turn of Mind* (2011), for instance, the protagonists are scientists whose professional expertise falls on language and neuroscience, respectively, a fact that ironically underscores the disease's corruption of speech and cognition. Caregiver memoirs' frequently draw the same contrast: Heloísa Seixas characterizes her mother as "strong" (17), "self-sufficient" (25), and endowed with a "sharp mathematical reasoning" (2007, p. 67), while Rosana Leal juxtaposes her bedridden mother to the "image of a strong woman" she had always pictured (*O Alemão Voltou Para Casa* 118). Such examples reiterate a central point throughout the scholarship: one of the main impacts of dementia strikes at the sustaining fiction of *autonomy*—an idea that grounds the worldview most often shared by the liberal-minded, privileged classes of Brazil. Individuals who once imagined themselves as autonomous and fully rational, with absolute domain and control over their actions, and who had little prior experience relying directly on kin networks or public assistance, suddenly find themselves enmeshed in webs of aid and dependence. For many others, who never enjoyed the illusion of full autonomy or financial self-sufficiency, such entanglements possibly feel much more familiar.

The absence of dementia narratives written by authors of other racial and ethnic backgrounds, or from lower socioeconomic classes, should be considered a crucial gap in the field. Not only for reasons of a supposed statistical referentiality (as if writing could "represent" reality directly), but because it deprives us of alternative perspectives through which to understand and depict dementia and caregiving beyond those offered by a relatively homogenous group. Nevertheless, we do not refrain from emphasizing that at least the present study—and others that will follow—broadens the corpus available to readers and scholars by incorporating twelve distinct works that differ markedly from those typically examined in the Global North. Despite being constrained by narrow perspectives of color, race, and class, these texts are Latin American and would, in fact, scarcely be considered as "white" within the Western/Eurocentric framework dominant in the United States and Europe. At least regarding the people with dementia portrayed in these narratives, unlike their authors, some of them are elderly individuals with limited formal education, who originate from the most impoverished regions of the country.

Auto/Biographical content and paratexts

The caregiver memoir most frequently encountered takes the form of a retrospective biographical reconstruction of the life of the person with dementia, followed with a detailed account of the daily routine of care after the diagnosis or the start of a more intense interpersonal contact. Usually, the author includes reflections on the emotional repercussions of the disease, which may appear as foreshadowing in the initial chapters, or after narrating the onset of symptoms. Although it is common practice, the story does not necessarily adhere to a conventional chronological account. Marcelo Rubens Paiva and Heloísa Seixas, for instance, interweave descriptions of the routine care they provided their mothers with scenes drawn from earlier periods of their lives. Valmi Carneiro Elias, Jaime Xavier, and Ana Valéria Silva adopt a more linear structure, narrating details from the childhood, the marriage, and the careers of both their beloved and themselves. What matters most here is the subgenre's affinity with the classic auto/biography, which seeks to impose narrative coherence to a complex and multifaceted human existence, thereby generating a strong sense of identity and continuity (Rimmon-Kenan). With the onset of dementia, that sense of identity is challenged. The tragic mode, as we shall examine next, is prevalent in narrators such as Seixas, Elias, and Xavier, who cannot but approach the period of illness as disruptive: the ill person becomes the embodiment of their symptoms, a "living corpse" who acquires a sudden "new personality," or is possessed by an "entity"—"Your mother does not exist anymore. What exists is an entity that has taken her place" (Seixas 91). Other narrative modes—"more ethical", as Zimmermann argues (*Poetics and Politics* 49–51)—allow to discern a continuity between pre- and post-dementia personalities, treating the daily labor of care as an authentic encounter with the other, a rich opportunity for learning and for emotional fulfillment.[15]

The second most prevalent structure is the diary form, which consists of entries written in close temporal proximity to the events described. In contrast to Annie Ernaux (*I Remain in Darkness*), none of the Brazilian authors claim to have maintained a personal journal. Lúcio Flávio Pinto, Míriam Morata Moraes, and Elaine Tavares—those who adopt this form—published their entries directly on blogs and social-media platforms. On the one hand, the diaristic mode does not offer the retrospective distance afforded by the biography form, which frequently refashions a coherent meaning selectively. Moreover, the emotional impact of receiving a diagnosis, confronting the onset of more severe symptoms, or managing daily challenges may therefore emerge in a less controlled fashion when writing concurrently to the events; Ernaux's diary is exemplary in this sense. On the other hand, posting on social media, especially within online support groups, as Moraes and Tavares do, often demand a more measured and uplifting tone, given the public exposure of the posts, and the expressed intent to aid members of the group undergoing similar circumstances. In such writing, extended biographical reconstruction of a period prior to the disease tends to be limited: Tavares refers to aspects of her father's past within the vignettes themselves, while Pinto and Moraes include independent prefaces that briefly summarize their relatives' earlier lives. Yet even in more conventional narratives, such as those of Rosana Leal, the author may devote little attention to the pre-illness biography and instead center the story on the family's experience from the moment of diagnosis onward.

Fernando Aguzzoli, in the latter half of his book, relies exclusively on short, comic dialogues between himself and his grandmother, a stylistic choice that also shapes Sônia Barros' narrative in its entirety. By adopting this strategy, both authors bring their texts closer to a form of dramatic fiction[16], disrupting the novelistic linearity typically associated with classical auto/biographical writing. The repetitive nature of the jokes and the overtly nonsensical exchanges between characters—most often triggered by some lapse of memory—foreground the altered temporality of dementia, privileging the immediacy of the present while placing it in comic disjunction from the past. These instances thus constitute formally deviant examples that invite us to consider the importance of experimenting with nontraditional narrative structures in order to articulate such unique experiences.

Across nearly all the works,[17] albeit with considerable variation, we encounter chapters or paratextual sections explicitly designed to inform readers about Alzheimer's disease and to provide guidance on caregiving practices. In this respect, the genre moves into the terrain of self-help. Leal, Rufino Júnior, and Silva are the authors most explicitly invested in offering practical advice, mobilizing personal narratives as anecdotal demonstrations of the strategies they recommend. Rufino Júnior includes informational boxes differentiated by the layout; Silva titles most of her chapters in an instructive manner; and Leal structures her narrative entirely around the concrete measures she took to resolve the practical problems that emerged as her mother's symptoms intensified.

Even more traditionally biographical works include such paratexts. In what is arguably the first Brazilian publication of this kind, Elias opens with a preface entitled "Alzheimer's Disease: Clinical Diagnoses" in which she explains the disease with reference to medical sources. Xavier concludes his account with a chapter entitled "Practical Tips and Care." Rubens Paiva, in the chapter "The Unpronounceable German" (225–47), offers a concise history of the discovery of Alzheimer's and its physiopathology, and playfully revisits the disease's stages and the eleven caregiving guidelines publicized by Drauzio Varela, a well-known Brazilian physician. His treatment of the matter elaborates on each stage and its correspondent guideline, supplementing them with humorous commentary and personal anecdotal examples.

Of the twelve works examined, four include family photographs interspersed throughout the narrative or gathered in separate sections. In the books by Rufino Júnior and Aguzzoli, the incorporation of photographs reflects the authors' origins, as both first gained public visibility by documenting on Instagram their daily routines of caring for their grandmothers. In this sense, the photographs may also oblige to the expectations of their initial readership, who knew the authors primarily through social media. In Leal's three volumes, portraits of the mother—usually smiling and looking at the camera—occupy full-page spreads at the opening of each section. Daniela Feriani (271) highlights the significance of the represented face in "counter-narratives" of Alzheimer's disease that depart from the strictly biomedical model more focused on the symptoms and the neurological decline. For the researcher, as for Bitenc (67), the inclusion of photographs and films depicting close-ups of faces restores individuality and fosters empathy, helping people with dementia resist objectification and the stigmatizing reduction they may suffer in caregivers' narratives. In these three writers, the photos align with an explicit desire to produce a narrative countering the dominant image of the suffering one typically associates with severe illness: the daily caregiving is portrayed with light-heartedness, humor, attentiveness, and affection. Finally, in Pinto's work the photographs appear within the brief biographical section reconstructing his mother's life before the illness, whose progression is narrated in the diary proper.

Two Modes of Narrating Dementia

The division proposed below, between a tragic mode and a pragmatic mode of narrating the experience of caregiving in the context of Alzheimer's, is intended chiefly as an analytical aid. It allows us to group the Brazilian works into two broad tendencies and to sketch the theoretical issues that cluster around them. The tragic mode raises questions about how the identity of the person with Alzheimer's, and even the very criteria by which personhood is defined, are (re) conceptualized. The pragmatic mode, by contrast, allows us to understand how the narrative fashions itself around the idea of "triumph" and is directed toward readers seeking practical guidance. This is not to suggest that pragmatic accounts lack tragic inflections, or that tragic narratives exclude pragmatic concerns; both tonalities and possible problems traverse all the works to varying degrees. Rather, considering them side by side, and illustrating each tendency with representative examples, clarifies our exposition. As with Arthur Frank's influential models, which serve here as a comparative framework, this division is primarily pedagogical. Once again, it is worth highlighting the more introductory and panoramic nature of this study, and the need for each theme and each individual work to be examined in greater depth in future research.

Tragic Narratives

In his foundational work on illness narratives, Arthur Frank proposes the category of "chaos narratives" to describe accounts in which "troubles go all the way down to bottomless depths" (99). He refers primarily to auto/biographical stories in which any attempt to impose order or meaning—as in the "restitution" or "quest" narratives he describes in chapters 4 and 6—breaks down and turns into a disordered or merely sequential recounting of the hardships. What is most relevant for our discussion, however, is the broader idea that such stories frame illness as an inexorable descent: a steady intensification of suffering for both the person with the disease and the caregiver, regardless of how the narrative arranges chronology. This is why we adopt the term "tragic" in its conventional sense.[18] The adjectives of medical handbooks that typically accompany a dementia diagnosis, such as "progressive", "insidious", "irreversible" (Dalgalarrondo 377), are carried over into the dominant representational mode through which conditions of this sort are culturally represented.[19]

Heloísa Seixas's *The Dark Place: A Story of Senility and Madness* is perhaps the most representative example of a narrative that combines both tragic and chaotic dimensions. The book casts the course of the illness, beginning with the diagnosis, as a "haunted spiral, made of vertigo and pain, spinning ever faster until it effaced reality itself"[20] (11). Even the period just before the illness had been identified is retrospectively reshaped as the onset of an unavoidable decline: "She [the mother] had already been living, unknowingly, a single step away from the precipice, from the dark ravine that would soon engulf her"[21] (24). Other expressions such as "the unnameable terror" that "kept growing by the hour, by the day" (77), the "nightmare" (103) and the "astonishment, horror, disgust"[22] (128), further illustrate the extreme end of what we are calling tragic mode.

In similar fashion, even though it is written in diary form, Míriam Morata Moraes' first book, *Alzheimer: Diary of Forgetting* (2016), reiterates the association between Alzheimer's disease and insanity, along with recurring motifs of horror, in a progression that underscores the powerlessness of all subjects involved:

> "My heart recognizes only *cruelty* in the *absurd condition* in which my father now lives" (227, emphasis added).
>
> "A common truism circulates widely: people like to claim they are 'crazy.' Madness is a sign of daring, irreverence, genius, or inner freedom… No! *Madness s prison. Confinement, paralysis, pain…* (313, emphasis added).
>
> "the illness performs the cruel task of revealing the true scope of our power—none whatsoever" (740).
>
> "My heart is constricted, and I feel numb, without the strength to continue witnessing this *horror film*" (1469, emphasis added).
>
> "Our *descent into hell* began on 14 December 2014" (1679).[23]

More chronologically structured and strongly biographical, since they meticulously reconstruct the life histories of those involved, the narratives by Valmi Carneiro Elias, *Alzheimer's Disease, the Color of Pain* (1998), and by Jaime R. C. Xavier, *Take Care of Me, My Love: The Journey of Despair* (2019), likewise adopt tones of horror and tragedy once the authors begin to describe the intensive caregiving their partners come to require. Elias describes the final five years of her husband's illness as the "most traumatizing and painful [*mais traumatizantes e dolorosos*]" (133) years of her life, repeatedly emphasizing the inevitable and predestined character of events that had left her "without options and without alternatives [*sem opções e sem alternativas*]" (223). As early as in his preface, Xavier warns he has no "pretension of bringing any hope to those who undergo this nearly unbearable experience, knowing that even total dedication of one's strength and resources should yield no expectation"[24] (8).

What stands out most in narratives of this kind are the accounts of behavioral changes and physical symptoms that accompany the evolution of the disease, interwoven with the caregivers' subjective reflections on their own circumstances. In every example cited, the authors serve as the primary caregivers and live in near-complete domestic confinement, receiving little to no outside assistance. Under such conditions, they portray their relatives in embarrassing moments, when cognitive debilitation and loss of bodily control require intimate physical interventions, particularly in relation to eating and excretion. Seixas notes that her mother would at times play with her own feces (28); Elias describes the procedure of manually evacuating her husband's bowels (206); and Xavier, more reserved in these depictions, relates spending an entire night washing the body towels his wife used after a bowel movement (88).

It is practically a consensus in the scholarly literature to point out the ethical concerns of such representations. Zimmermann, in *The Poetics and Politics of Alzheimer's Disease Life-Writing*, argues that early Alzheimer's narratives, as well as caregiver accounts more generally, were shaped by mainstream cultural discourses that tend to stigmatize dependency by framing it as a "burden" and by casting the person with dementia as passive and vulnerable. Drawing on Burke, Bitenc interprets scenes involving nudity or the scatological as instances of symbolic violence (Bitenc 168; Burke, "On (Not) Caring"). Such violations of privacy, they contend, reflect the diminished social status and the effective de-personalization imposed on individuals living with dementia.

The ethical concerns surface consistently in scholarship on auto/biographical writing. Foundational works such as John Paul Eakin's *The Ethics of Life Writing* (2004) and G. Thomas Couser's *Vulnerable Subjects* remain touchstones, repeatedly invoked by critics across the field. In a study specifically addressing literature and dementia, Rebbeca Bitenc (192) expands this discussion and situates it within a broader intellectual lineage that includes Hanna Meretoja's *The Ethics of Storytelling* (2018) and Martha Nussbaum's *Women and Human Development* (2007), among others. Lucy Burke, in particular, has been especially attentive to questions of privacy surrounding the person with dementia (See "Oneself as Another"; "Dementia and the Paradigm of the Camp", 2019).

The tragic mode illustrated in these narratives foreground the profound rupture that dementia inflicts on notions of personal identity, individual rights, and even the very criteria by which we understand what constitutes a person—

one's *personhood*. The topic around the "loss of identity" in people living with dementia—often linked to larger questions about what it means to remain human under such conditions—is certainly the most prevalent in the theoretical literature. Every scholar cited in the introduction dedicates at least one chapter to this issue. We particularly recommend two collections of essays for thinking beyond literary representation: Hydén, Lindermann, and Brockmeier's *Beyond Loss: Dementia, Identity and the Person* (2015), and Hughes, Louw, and Sabat's *Dementia: Mind, Meaning, and the Person* (2006). Chapter Six of Ballenger's *Self, Senility and Alzheimer* offers a useful comparison between the biomedical framework that imagines the self as "destroyed," various constructivist approaches that emphasize intersubjective processes in the shaping of subjectivity, and postmodern accounts that accommodate the notion of self as inherently fluid or fragmented. Many scholars also turn to the "personhood movement," associated above all with Tom Kitwood, as a model for ethical caregiving that resists strictly medicalized readings of dementia—readings that too easily strip individuals of agency and personhood (See Burke, "Oneself as Another"; Burke, "Dementia and the Paradigm of the Camp"; and Costa, 2022, for both the influence of Kitwood and critiques). Although Disability Studies are not the central concern of Caroline Peres Martins' dissertation, she does examine Rubens Paiva's language, an author who constantly describes his mother in the past tense, even though she was alive at the moment of the book's publication. This detail is striking, for his work remains the only Brazilian narrative to engage the idea of "disappearance" in both the individual and collective contexts of a degenerative illness and the military dictatorship, the two main nuclei of his account.[25]

At a certain stage, the afflicted subject becomes a kind of living dead:[26] "when he forgets, my father will have died, and in his place there will remain only a familiar body inhabited by a soul utterly estranged from my own. […] There will no longer be any possibility of contact"[27] (Moraes 152). Annie Ernaux remarks, in *A Woman's Story*, that her mother's story "stops here for there was no longer a place for her in society [*dans le monde*]" (*Uma Mulher* 51; *A Woman's Story* 74). Scholar Lucy Burke summarizes:

> In their starkest expressions, the tropes of 'physicalist,' biomedical models of brain, mind and person discursively strip those with dementia of all vestiges of humanity or personhood, either by way of the familiar attribution of vegetable or "cabbage-like" qualities or by construing these subjects as animals. [...] Alzheimer's [...] becomes a monstrosity, an object of both fear and loathing [...] ("The Poetry of Dementia" 65).

A more adequate response, according to Zimmermann (*Poetics and Politics*), would be narratives produced by the subjects themselves, or at least rooted in conceptions of identity and personhood that move beyond the biomedical paradigm. The author identifies a positive gradual shift from the early stigmatizing accounts of the 1980s and 1990s toward the narratives we have today. In the corpus under examination, however, such a historical evolution is not evident;

instead, what emerges are distinctive narrative modes shaped by the specific circumstances and subjectivities involved in each particular life story.

In any case it must be emphasized once again that, following Zimmermann, we do not condemn the authors of these tragic narratives. The written expression of their suffering is largely conditioned by the concrete material constraints imposed by the lack of access to professional care, as well as by the dominant cultural stigma surrounding aging and dementia. Even when such accounts reiterate stereotypes or reinforce stigmatizing representation, they nevertheless offer a meaningful venue for articulating suffering, and they do so in ways that are often unexpectedly nuanced and sensitive.

The works of Elias, Seixas, and Xavier—preceded in this regard by Ernaux—textualize an experience lived tragically in their contexts. They reflect closely the most painful realities that continue to surface in contemporary caregiver groups. While ethical concerns remain central—especially those related to the privacy and the dignity of individuals with dementia—the affective force of these narratives cannot be dismissed. They voice feelings of helplessness, overwhelming burden, and the reflections caregivers derive from these. Moreover, as exemplified by Elias and Seixas, the intricate circumstances of care make possible a biographical reconstitution of the persons involved, one that leaves readers with a vivid and enduring sense of who they were. Although Elias' husband and Seixas' mother are undeniably subjected to a high degree of exposure, the narratives nonetheless preserve a complexity of character absent from the more affirmative and celebratory accounts to be examined in the next section.

Pragmatic Narratives

The pragmatic narratives discussed in this section can be situated within a broader corpus of "counter-narratives" (Bamberg and Andrews, 2004; Bitenc 103), understood as works that explicitly seek to challenge the culturally dominant images—or, in Bitenc's image, "master narratives" of dementia (104)—that operate the dehumanization of individuals with the condition and depict caregiving as an unbearable burden. In *Who, Me? A Grandmother, a Grandson, a Lesson in Life,* Fernando Aguzolli describes his motivation for writing as a direct response to the discouraging accounts of Alzheimer's disease he had encountered:

> I saw that all the available material ultimately encouraged family members to abandon the elderly person suffering from the disease. […] Wow, how horrifying! Every image related to the subject showed a sad, wrinkled old lady in the dark corner of a room. (9)[28]

In contrast to Valmi Carneiro Elias—who offers a detailed account of the abuse she endured from her husband in the early years of her marriage (52–85)—Aguzzoli deliberately introduces a narrative ellipsis, shielding the readers from the particulars of what appears to have been his grandmother's abusive marital relationship in her youth (20).[29] Instead of dwelling on grievances and sorrow, he prescribes "love and humor [*amor e humor*]" (10).

Rosana Leal, in the series of books inaugurated by *The German Came to Visit Us: Welcoming the Unwanted Guest*, likewise counters the prevailing negative depictions of caregiving for an Alzheimer's family member. A professor, engineer, and writer, Leal states her aim is to "demystify the idea that the person with Alzheimer's Disease is a sufferer or a burden to the family" (*O Alemão Veio Nos Visitar* 7),[30] so she tries to keep her style "light, soft"[31] (*O Alemão Veio Nos Visitar* 14). Although she narrates the most intimate details of the care routine less elliptically than Aguzzoli, her narrative still incorporates numerous scenes that depict joy in the shared life, something that is almost entirely absent from the tragic narratives: "The days have been wonderful. I would say happiness knocked on our door, came in, and is now rolling around in the living room" (*O Alemão Veio Nos Visitar* 189).[32]

Using Arthur Frank's framework, the model for these narratives can be understood as a hybrid between the "restitution" (Frank, ch. 4) and the "quest" (Frank, ch. 6). Both are grounded in the paradigm of life as a "journey" (see Zimmermann, *Poetics and Politics* 13), culminating in either a restoration of health or in the articulation of a renewed existential purpose. Dementia narratives foreclose the possibility of recovery, but the journey described by the authors points toward a persistent attempt to "win the battle" against the situation of vulnerability and to find an ever-renewable equilibrium through the resourcefulness of the caregiver. Simultaneously, the narrators negotiate a new meaning for their lives when they actively and enthusiastically embrace the role of caregivers, in contrast to the posture of victimization that typifies the tragic accounts.

Here we nonetheless emphasize the pragmatic dimension of these counter-narratives, as they consistently orient themselves around the production of advice and practical strategies whose efficacy is demonstrated through the authors' anecdotal accounts of their everyday life. Raul Rufino Júnior's *Never Forget to Smile: A Story of Love and Humor that Will Stay in the Memory* (2022) is exemplary in this regard. He truly synthesizes the way to face the increasingly complex challenges of his grandmother's illness in a single expression: "to hack Alzheimer's [*hackear o Alzheimer*]" (141). This means devising clever maneuvers and shortcuts to handle symptoms and unexpected scenarios. Like Aguzzoli and Leal, the overall tone is lighthearted and consist of only two basic principles: "love" and "good humor", which ultimately enable him to claim having "defeated Alzheimer's [*vencido o Alzheimer*]" (59).

Rosana Leal's work could arguably be considered the most emblematic instance of a narrative form that intertwines anecdotal life writing with a sustained commitment to mitigating the challenges of caregiving through concrete, pragmatic strategies. She "creates support schemes [*cria esquemas de suporte*]" in a kind of "war operation [*operação de guerra*]" (*O Alemão Veio Nos Visitar* 62, 63), aided by an "*elite troop* [tropa de elite]" (*O Alemão Veio Nos Visitar* 98) of women professional caregivers whom she personally recruits and oversees. We follow the narrator closely in an array of logistical undertakings: orchestrating a pool bath, changing a mobile phone plan, relocating apartments, selecting and purchasing a wheel chair, a hospital bed, and a pneumatic mattress, as well as monitoring interventions by physical therapists, dentists, personal trainers, and doctors, including laser treatment of her mother's salivary glands. Even the geriatrician who pens the preface of Leal's second volume complements her "training in engineering and the exact sciences [*formação em engenharia e ciências exatas*]" and the exemplary conduct of someone who follows a "practical and linear reasoning [*raciocínio prático e linear*]" (*O Alemão Pegou o Bonde* 29). During the narrative's most emotionally taxing moments, the author insists that "pain must not overpower rationality [*a dor não poderia suplantar a racionalidade*]" (*O Alemão Voltou Para Casa* 124).

Nearly every author in this corpus employs the "list" format—"ten tips for hacking Alzheimer's [*dez dicas para hackear o Alzheimer*] (Rufino Júnior 141)"—as well as direct, instructional questions— "How to keep them active? [*Como mantê-los ativos?*] [...] Should I give the news that a close relative has passed away? [*Devo dar a notícia de que alguém próximo faleceu?*] (Silva 38, 78). Yet, within the pragmatic narrative mode, a rational and instrumental tone dominates, superseding accounts of frustration or emotional turmoil. When discussing the challenges of personal hygiene, for instance, Silva resorts to a managerial and procedural lexicon: "Any motivation is valid in order for the *process to be concluded successfully and without undue strain* [*Qualquer motivação é válida para que o processo seja concluído com êxito e sem desgaste*]" (Silva 64, emphasis ours).

In subsequent works, we will analyze and discuss pragmatic narratives in more detail, including their assumptions and the issues they entail. At present, however, it suffices to offer preliminary considerations on some aspects of this mode. Certainly, counter-narratives arise in response to the concrete needs of caregivers and individuals living with dementia, who seek models and guidance to navigate the challenges that emerge in daily life. These texts counter the tragic, pessimistic paradigm prevalent in the accounts previously discussed. By foregrounding the caregiver' agency and acknowledging moments of joy that persist even in the later stages of dementia, they may foster a more hopeful and ethically attuned understanding of the caregiving experience.

Conversely, exemplary narratives whose spotlight shines on the ingenuity and resilience of caregivers, leaving the broader context—that is, the material and social conditions that render such "operations" feasible—in the shadow, ultimately privilege individualized and procedural solutions at the expense of tragic, albeit illuminating, articulations and expressions of vulnerability. Although ethically challenging, as we examined, tragic narratives expose the self as fundamentally relational, bound to others, to its own corporeality, to the surrounding environment, and to its inescapable emotional dilemmas. In this regard, the valorization of "love" and "humor," coupled with the stylistic lightness through which the experience is conveyed, risks converting into prescriptive *remedies* what are, in truth, the very *preconditions* that allow for a loving and humorous caring environment. Affection, lightheartedness, and pragmatic resourcefulness flourish more readily where economic stability, familial networks, and preexisting bonds of mutual care are already in place. One must therefore ask: how are caregivers without Rosana Leal's resources, or without the familial support enjoyed by Rufino Júnior and Aguzzoli, to make practical use of such tips and tricks? How would they avoid the pitfalls of self-help discourse?

Towards a Third Mode: Elaine Tavares and the Ethical/Social Chronicle

Despite their contrasting pessimistic or optimistic inflections, the earlier narrative modes operate within what G. Thomas Couser (*Signifying Bodies* 16) characterizes as the medical/individual paradigm of disability, wherein a natural or biological condition befalls individuals who then must shoulder the burden of adaptation in society. In tragic accounts, that burden dominates; in pragmatic ones, it is partially mitigated through a reconciliation or negotiated balance with the condition. Couser proposes a recent and less widespread alternative, the social/cultural paradigm, as a more productive framework for conceiving disability (and, by extension, illness in general) as socially constructed. This shift relocates the onus of adjustment from the individual to society at large. Although the works examined here briefly acknowledge issues of infrastructure and social support, they generally remain confined to the domestic sphere and adhere to the conventions of auto/biographical writing, which presuppose an autonomous, rational subject as the locus of agency and interpretation.

In this regard, Elaine Tavares' *Boa noite, seu Tavares* (2025) markedly departs from the narrative models discussed so far. Rather than aligning Alzheimer's disease with madness—a recurrent trope in tragic accounts—Tavares associates it with the experience of aging and with the precarious social position of older adults in Brazil. This allows her to foreground the structural impositions shaping her circumstances as she assumes the care of her father, Nelson Tavares. Her narrative documents material obstacles, such as her neighborhood's inadequate sidewalks, and extends into the public discourse through an open letter addressed to the administrators of Brazil's public Unified Health System (*SUS*), on which she depends (192–94). To the reflections pertaining to the intimate sphere, she adds more general observations about contemporary society:

> The capitalist world teaches us to be in a great hurry, to eliminate the obstacle, the different, the annoying. (51)
>
> In the world of labor, of capital, [the elderly person] is useless. (123)
>
> Who said it is necessary to produce all the time? Who said one must

> fulfill a protocol of usefulness in order to be a person? (123)
>
> [The elderly person] deserves to live without the pressure of being useful. (125)[33]

Such observations move toward a conception of illness that resonates with contemporary debates distinguishing *impairment* from *disability*. Impairment refers to the condition of illness or injury in its individual dimension. Taken alone, the concept confines us to a biomedical framework which demands the individual to adapt to existing structures such as they are. The social character of the concept of disability, on the other hand, is understood here as the interplay between the symbolic mode through which the term circulates—the negotiated/arbitrary definitions delimiting what counts as normal or abnormal—and the material conditions of public policy and infrastructure that restrict the autonomy of those who live with cognitive decline.

Our working definitions draw on Couser (*Signifying Bodies* 23), who provides succinct explanations of impairment and disability within the context of illness narratives, grounded in the social model of disability and articulated most influentially by Michael Oliver (1990), a foundational figure in Disability Studies. Shakespeare, Zeilig and Mittler (2019) examine and problematize the applicability of the social model to the specific case of dementias, yet maintain that such conditions ought to be included within the category of disability in order to enable concrete political mobilization. Burke ("Thinking about Cognitive Impairment") focuses specifically on diseases and cognitive forms of disability, reaffirming the relevance of the term impairment to underscore losses in "cognition, attention, behavior, language, and memory" ("Thinking about Cognitive Impairment" i) experienced by affected individuals and to validate their perception of the loss. She also addresses the burden of care under neoliberalism, arguing that it is futile to pursue "biographical solutions to systemic contradictions" ("On (Not) Caring" 604)—a point that Tavares acknowledges, as subsequent excerpts will illustrate.

Tavares' narrative persistently oscillates between these two poles. It acknowledges the family's intimate struggles in caring for Nelson, while also identifying systemic causes that exacerbate their burden, such as shifting family dynamics,[34] and the utilitarian ethos of capitalism, mentioned in the previous citation. More than addressing exclusively Alzheimer's disease, her work interrogates the social status of older adults in general, exemplified by a chapter pointedly titled "There Are More Older People in Brazil, and They're Fucked [*Há mais velhos no Brasil, e eles estão fodidos*]" (35).

Broadly speaking, caregivers' narratives must balance three forces in constant tension. First, they are expected to remain faithful to the lived experiences of all participants, especially the caregiver whose dominant voice expresses emotional responses and introspective remarks follow closely the vicissitudes of care. Second, they often seek to instruct the broader community—whether members of support groups or the wider reading public—through practical strategies tested under the specific anecdotal accounts. Finally, the narratives must uphold an ethical commitment to the person being represented, which entails not only acknowledging their biographical identity prior to cognitive decline but also affirming their agency and rights in later, post-diagnosis stages, including rights to privacy and to the control of their own image.

With respect to the last factor, the authors offer little, if any, explicit theorization about the ethical implications of exposing their relatives while recounting scenes that may be humiliating or compromising. Rufino Júnior—already a social-media figure prior to the book's release as author of an Instagram profile featuring photos and videos of his grandmother—responds defensively to critiques of this practice: "I didn't want to be answering this kind of question. The idea was just to have fun with my grandma […] are they suspicious of me?" (107)[35] Rosana Leal likewise addresses the dilemma of digital exposure, noting that she and her sister agreed not to publish images of her mother, except in rare circumstances where such dissemination could be justified by the informational relevance of the image (*O Alemão Pegou o Bonde* 134). Yet the book is saturated with photographs and intimate accounts of caregiving. The ethical problem, therefore, becomes structurally tensioned by the two previous factors: the more detailed the episodes and the intimate considerations—even when framed as pedagogical—the greater the degree of involuntary exposure imposed upon the vulnerable subject.

In exemplary fashion, once again Tavares moderates the inclination to dispense advice with a measured sobriety that grants full expression to the tragic erosion of her father's cognitive abilities. She refuses any romantic veneer: "it's shit […] a roller coaster, a gallop without brakes [*é uma merda [...] É uma montanha russa, um galope sem freio*]" (19). Particularly in the final stages, her testimony conveys a profound testimony before the inexorability of neurocognitive decline: "Alzheimer's is a sad disease because, in the end, there is no cure. There is no medicine, no therapy, nothing. Everything is palliative, and the sentence is cruel: things will only get worse" (176).[36] Even so, the book's cumulative effect resists a tragic conclusion. Taken together, the individual vignettes do not lead toward catastrophe, and, as we argue below, several factors help explain how Tavares produces such an outcome.

Foremost among Tavares' strategies is a marked capacity for self-reflection. Drawing on Arthur Frank's typology, her writing aligns less with the restorative logic of "restitution" than with the existential openness of the "quest." Accepting the irreversibility of her father's decline, she renounces the fantasy of reclaiming a former equilibrium—achieved by pragmatic fixes—nor does she offer ready-made prescriptions. Instead, the moment she acknowledges her position of daughter-as-caregiver, she reorganizes the trajectory of a life previously anchored in relentless labor and political engagement, endowing it with a newly discovered meaning:

> "Time to learn slowness again, in a life that was so full of things to do." (27)
>
> "It's like this, with patience, letting things sort themselves out, that we keep going." (41)
>
> "It is a kind of learning, this thing of caring for someone who forgets." (61)
>
> "In the end, our elders are not nuisances, much less punishments from God. They are a window into our deepest humanity." (73)
>
> "Thus, we become better people. The other is always paradise when he already exists within us." (73)[37]

Tavares seems to ground her ethical stance not in a logic of identity but of alterity. The appeal to an ontology rooted in alterity and difference, especially in the terms developed by Emmanuel Lévinas—and the ethical implications derived from breaking with an ontology of identity, recurs frequently throughout the specialized scholarship (See, among others, Bitenc 143; Burke, "Oneself as Another" 30; Oyebode and Oyebode; Rabelo et al. 30). When applied to old age and dementia, such an ethics entails more than acts of care, but also an attunement to a different temporality—slower, denser, and more humane.

A further strategy lies in Tavares' refusal to reconstruct her father's pre-dementia biography in any detail. The vignettes begin only once the symptoms have become unmistakable enough to prompt the diagnosis and a change of residence. Consequently, the text avoids staging a dramatic discontinuity between an autonomous, rational individual and the supposedly monstrous subject that would emerge after the clinical verdict. The impulse to restore a stable and coherent identity—Frank's "restitution" narrative—is deliberately foreclosed, allowing the father's persona to remain fluid. Nonetheless, his presence anchors the work from the outset: his name appears in the book's title—something that only occurs in Pinto's self-published brochure—, and his portrait is illustrated on the cover. More significantly, he *makes himself heard* in the dialogues, often ending with the last word:

> [Elaine:] 'Do you need anything, darling?'
> 'I do.'
> 'What?'
> 'Attention.' (79)[38]

In contrast to a widespread trope in the genre, the text refuses to conflate dementia with mental degradation—"old people are slow, but they are not idiots [*os velhos são lentos, mas não são idiotas*]" (35)—and the author likewise resists the commonplace infantilization of the ill subject:

> Old people are not children, so one cannot apply the rules of child-rearing to them. It is necessary to give them autonomy, to make them feel capable, to respect their choices and wishes. It is an intense and difficult process. (71)
>
> I try not to treat [my father] like a child, but as an adult person who needs to know what is going on. (185)[39]

Even the absence of recognition, so central in other memoirs, weighs less: "He no longer knew who we were, yet he knew he was loved and that he could trust us. This remained true until his final breath"[40] (25).

The candor of these chronicles makes room for scenes that would otherwise be considered too embarrassing—among them, the father's struggle with fecal incontinence and his refusal to wear adult diapers. Such episodes are never framed as shocking or traumatic. Instead, the body and its functions appear with an almost disarming naturalness. The father's interjections, cutting through the narrator's reflections, undo the burden of the moment through a strain of comic absurdity. The excerpt that follows, for instance, unfolds just after the narrator discovers the bedroom smeared with feces in the first hours of the morning:

> We get that feeling of desolation! I take a deep breath, and so as not to make him nervous, I put on a surprised face.
> 'Good grief, Dad, who could have done this?'
> And he looks at me with that innocent little face.
> 'That's outrageous, I don't know. A guy came by here, and another one over there, and another one over there,' and he pointed to the little piles of poop, as if each one had been made by a different person, 'They came by and then left.'
> 'Wow, those scoundrels, right?'
> 'Yeah,' and he walks away as if nothing had happened.
> What remains is the cleaning, which is no easy task. And he rests on the porch, quite pleased with himself. Such are the mornings at the Tavares house. (137)[41]

The game of question-and-answer fostered by the daughter—despite her awareness of the actual facts—infuses the episode with a sense of playful banter. Mr. Tavares emerges as a shrewd figure whose whimsical inventiveness and good-natured cynicism allow him to have the last word. In the narrator's remarks, she betrays her own intimate feelings: desolation, fear of setting him off, the burden of a difficult cleaning job ("no easy task") which is probably recurrent ("such are the mornings"). However, her performative stance, addressed simultaneously for her father and for the reader, deflects direct confrontation, rendering a testimonial that maintains a balance between tragedy and comedy.

Just as we saw in Rufino Júnior, Tavares insists that "joy is the best of remedies [*a alegria é o melhor dos remédios*]" (209). But in no way this maxim is prescribed as a mandate or an imposition. It is not even a practical strategy attainable by anyone. On the contrary, she underscores the structural condition that make such a disposition possible: "All I wanted was for people to have the time to care for their elders [*Tudo o que eu queria era que as pessoas pudessem ter esse tempo para cuidar de seus velhos*]" (149). Crucially, she recognizes that her own situation is not a model to be replicated but rather an exception:

> I have been learning with my father. It is not easy. I think I am still lucky to count on the help of those who live with me, my nephews, and my partner. But it distresses me to know that in this god's-big-world there is a load of little old people lost and alone, because families have no condition whatsoever to care for them. One must provide for life, one must work, one must grind the body in the wheel of capital. It is no one's fault; it is the damn life that opens no exits. (39)[42]

In many ways, Tavares' narrative is not exceptional, but rather exemplary. Practically all the elements listed above are present, to some degree, in other Brazilian works. Aguzzoli and Barros, for instance, adopt comparable uses of dialogue, granting the person with dementia a meaningful voice while tempering the burden of caregiving with vignettes of comic relief. In Barros' dramatic dialogues, remarks resembling stage directions mark her fatigue and despair—"(asking strength from the heavens) [*(pedindo força aos céus)*]" (14); "(I take a deep breath) [*(respiro fundo)*]" (60)—yet the spoken exchanges, much like those in Tavares, invariably elevates the mother's humorous tone. Whether in the most active and pragmatic caregiver, such as Rosana Leal, or in the more plaintive voice of Moraes, these narrators acknowledge the structural conditions that exceed individual agency (Leal, *O Alemão Veio Nos Visitar* 119; Moraes 1855). And Rufino Júnior, like many of the more solution-oriented voices in the genre, describes caregiving as a profoundly transformative encounter, as in the excerpt in which he credits the grandmother with restoring his emotional equilibrium after a severe depression (Rufino Júnior 85–86).

Tavares also does not refrain from providing lists of practical recommendations, though she presents them only in abbreviated form (89). Her pragmatism aligns less with the engineer's methodical logic than with the aerial poise of a tightrope walker. As the physician who introduces the volume observes, Tavares' most distinctive contribution to perspectives that uphold health and hygiene as absolute standards, is the fact she portrays a caregiving practice "open to risk [*abertura ao risco*]" (16)—as an improvised dance which does not require the rigidness of predetermined formulas and axioms.

Taken together, all these elements render Tavares' text simultaneously emblematic of the dominant tendencies in contemporary Brazilian caregiver memoirs, and also singular. Rather than privileging either a tragic voice or a pragmatic ethos, the work entwines both modes with a reflective discourse on aging, illness, and caregiving, situating each within the structural forces that shape the vulnerabilities of all involved. The individual success or failure of the caregiver is not reduced to a journey narrative but weaves personal experience and social critique in a sensitive and complex way.

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Notas finais

1. *"Foi no dia em que minha filha saiu de casa que minha mãe enlouqueceu."* All translations of Brazilian works throughout this article, unless otherwise noted, have been provided by the author.
2. See Macedo Montaño e Ramos to verify the applicability of the CDR in Brazil. Full reference: Macedo Montaño, Maria Beatriz M, and Luiz Roberto Ramos. "Validade Da Versão Em Português Da Clinical Dementia Rating." *Revista de Saúde Pública*, vol. 39, no. 6, Dec. 2005, pp. 912–17, https://doi.org/10.1590/S0034-89102005000600007.
3. See also Leibing, who discusses the Brazilian context regarding the history of the "rediscovering" of Alzheimer's disease and its meaning towards the contemporary understanding of aging. Leibing, Annette. "Olhando Para Trás: Os Dois Nascimentos Da Doença de Alzheimer e a Senilidade No Brasil." *Estudos Interdisciplinares Sobre o Envelhecimento*, vol. 1, 1999, pp. 37–56, https://doi.org/10.22456/2316-2171.4650.
4. Ropper et al (1056) regards as "outdated" the practice of attributing a different status to Alzhimer's disease and senile dementia, along with the more severe forms of cognitive impairment in elderly populations.
5. Zimmermann (*Poetics and Politics* 25) considers Woodward as the first paper by a literary scholar to deal with Alzheimer's. However, longer monographical studies have appeared only in the last two decades. Woodward, Kathleen. "Reminiscence and the Life Review: Prospects and Retrospects." *What Does It Mean to Grow Old? Reflections from the Humanities*, edited by Thomas R. Cole and Sally Gadow, Duke University Press, 1986, pp. 135–63.
6. Zimmermann (*Poetics and Politics*, ch. 4 e 5) focuses on the earliest first-person accounts of Alzheimer's disease. In Brazil, translations of at least two autobiographical works written by patients themselves are available: Graham, Chris, and Wendy Holden. *Minha Aventura Contra o Alzheimer*. Translated by Bruno Alexander, Globo, 2018. McGowin, Diana Friel. *Vivendo No Labirinto: O*

Mal de Alzheimer Na Visão Do Paciente. Translated by Miriam Groeger, Record, 2003.

7. The complete list of works accompanied by a literal working translation of their titles can be found at the beginning of the Works Cited section. Although there are 16 individual works in the corpus, we chose to count the two 3-book series by Míriam Moraes and Rosana Leal as single works.

8. The subject was also addressed by Ernaux in *A Woman* (Ernaux, *Uma Mulher*), whose final sections were composed from the diary entries, later published in *toto*—according to the author—in *I Remain in Darkness*.

9. We adopt the conventional binary division of gender, "women" and "men," since none of the narrative problematizes questions of gender identity. In all works cited, the individuals discussed identify as cisgender women or men and there is no mention of sexual orientation.

10. Moraes' work portrays both her father and her mother.

11. We calculated the average age in the following manner: (a) for *authors*, we used the mean of their ages in the year their relatives' symptoms first appeared and in the year the (last) works conclude their diegetic timelines or reach publication; (b) for the *individuals with dementia*, we used the mean of their ages from the onset of symptoms to the year of death, the end of the narrative period, or the publication of the memoir (when the individual was still alive at the time of publication). In the case of Moraes, we employed a single mean based on the ages of both parents, for the sake of simplicity.

12. This average increases to 54 if we exclude the two narratives about grandmothers (Aguzzoli; Rufino Júnior), published by authors who were 23 and 31 years-old, respectively.

13. The report's figures include in this percentage 16.4 percent professional caregivers, which renders any direct comparison with our study—concerned exclusively with family caregivers—somewhat imprecise. Even so, since caregiving within the domestic sphere continues to fall primarily on women (Santos et al. 174–75), the discrepancy between the corpus and broader national patterns clearly stands.

14. According to data from 2020, the United States had 1.3 million adults over the age of 65 living in long-term care facilities, amounting to 2.3 percent of the nation's elderly population. By contrast, according to the 2022 Census report, Brazil has only about 160 thousand people over the age of 60 residing in nursing homes (Agência Brasil), a figure that corresponds to merely 0.49 percent of the national population in that age group (IBGE). The comparison, albeit imperfect, nonetheless helps illuminate the underrepresentation of narratives involving institutionalized elders.

15. It is worth noting that the distinction between more or less ethical forms of narration, in Zimmermann's view, does not constitute a moral evaluation of individual authors. Instead, it reflects the material and structural conditions of care made possible by public policy. When caregivers collapse under the burden of overwhelming responsibility without no governmental support, tragic narrators are often deprived of the circumstances necessary to establish more positive relationships with the ill person.

16. In the case of Sônia Barros, as noted earlier, the book was published as a work of fiction, even though we are choosing to read it as memoir.

17. The books by Heloísa Seixas, Sônia Barros and Lúcio Flávio Pinto form the exception.

18. We have also in mind the idea of tragic as an "irreconcilable opposition," as

proposed by Goethe. See Szondi (48). Szondi, Peter. *Ensaio Sobre o Trágico.* Translated by Pedro Süssekind, Jorge Zahar, 2004.

19. Zimmermann (*Poetics and Politics*), particularly in the introduction of her volume, and Swinnen and Schweda are authors who try to outline the hegemonic, or mainstream, representation of dementia in popular culture.

20. *"uma espiral assombrada, feita de vertigem e dor, que giraria cada vez mais rápido, apagando o real."*

21. *"Ela [a mãe] já vivia, sem saber, a um passo do precipício, do desfiladeiro escuro que a tragaria em pouco tempo."*

22. *"o terror inominável", "ia crescendo a cada hora, a cada dia" (77), "pesadelo" (103), "assombro, horror, nojo" (128)*

23. *"Meu coração só consegue enxergar crueldade na situação absurda em que meu pai se encontra." (227) / Existe uma bobagem muito popular, as pessoas adoram dizer que são "loucas". Loucura é sinal de ousadia, irreverência, genialidade, liberdade interna... Não!* Loucura é prisão. É reclusão, imobilidade, dor... *(313) / a doença tem a tarefa cruel de nos mostrar a exata dimensão do nosso poder — nenhum! (740) / Meu coração está apertado e sinto que estou anestesiada, sem força para continuar assistindo esse* filme de horror. */ (1469) Nossa* descida ao inferno *começaria nesse dia 14 de dezembro de 2014. (1679)"*

24. *"a pretensão de trazer qualquer esperança, [sic] a quem vivencie essa quase insuportável experiência, sabendo que, mesmo que se dedique com todas suas forças e recursos, nada deverá esperar."*

25. In Argentina and Chile, this interplay of personal and collective disappearance has been powerfully explored in the films *Tiempo suspendido* and *La memoria infinita*. For an extended discussion of these and related works, see works by Raquel Medina. *Cinematographic Representations of Alzheimer's Disease.* Palgrave Macmillan, 2018. "Forgetting and Remembering in Post-Dictatorial Argentina. Tiempo Suspendido and the Ethics of Documentary Filmmaking Featuring People Living with Dementia." *The Politics of Dementia: Forgetting and Remembering the Violent Past in Literature, Film and Graphic Narratives*, edited by Irmela Marei Krüger-fürhoff et al., De Gruyter, 2021.

26. See Behuniak's work for an examination of the "zombification" of the individual with Alzheimer within cultural discourse. Behuniak, Susan M. "The Living Dead? The Construction of People with Alzheimer's Disease as Zombies." *Ageing and Society,* vol. 31, no. 1, 2011, pp. 70–92, https://doi.org/10.1017/S0144686X10000693.

27. *"quando esquecer, meu pai terá morrido e em seu lugar haverá um corpo familiar, com uma alma completamente estranha ao meu coração.* [...] *Não existirá possibilidade de contato."*

28. *"vi que todo o conteúdo disponível acabava incentivando o familiar a abandonar o idoso que sofre com a doença.* [...] *Uau, que horror! Toda imagem referente ao assunto mostrava uma senhora triste e enrugadinha no canto escuro de um quarto."*

29. Ana Valéria Pereira de Almeida Silva in *You Want to Leave Me and I Can No Longer Hold You* (2021) also makes extensive use of narrative ellipses. The author summarizes the burden of daily caregiving and the manifestation of her mother's symptoms in less detail than the tragic narrators. For example: "After a long time, lots of stress, sleepless nights, and days when the atmosphere at home was awful, I decided to change strategies. *[Depois de muito tempo, muitos estresses, noites sem dormir e dias com o clima da casa péssimos, resolvi mudar de estratégia]*" (63).

30. *"desmistificar a ideia que a pessoa com Doença de Alzheimer é uma sofredora ou um fardo para a família."*

31. *“de um jeito leve, suave.”*

32. *“Os dias têm sido maravilhosos. Diria que a felicidade bateu à nossa porta, entrou e está rolando na sala.”*

33. “O mundo capitalista nos ensina a ter muita pressa, a eliminar o entrave, o diferente, o chato. (51) / *No mundo do trabalho, do capital, ele [o idoso] é um inútil.* (123) / *Quem disse que é preciso produzir o tempo todo? Quem disse que há que se cumprir um protocolo de utilidade para ser uma pessoa?* (123) / *Ele merece viver sem a pressão de ser útil.* (125)”

34. “It is painful. Old age can be a beautiful moment if the elderly person has health and is surrounded by people who love them. But this is not true for everyone. After all, families today are small and many are unable to establish a routine of care. There are others who find no other option but to institutionalize [the elderly]. And they suffer from this as well. *[É doloroso. A velhice pode ser um momento bonito se o velho tiver saúde e pessoas que o amam a sua volta. Mas, isso não é válido para todos. Até porque, hoje, as famílias são pequenas e muitas não conseguem estabelecer uma rotina de cuidados. Outras há que não encontram outra forma senão asilar. E sofrem com isso também.]*” (Tavares 46)

35. *“Eu não queria estar respondendo a esse tipo de questionamento. A ideia era apenas me divertir com a minha vó [...] estão desconfiando de mim?”*

36. *“O Alzheimer é uma doença triste, porque, ao fim, não tem cura. Não tem um remédio, nem terapia, nada. Tudo é paliativo e a sentença é cruel: as coisas só vão piorar”*

37. *“Hora de aprender a lentidão outra vez, numa vida que foi tão cheia de coisas para fazer. / É assim, na paciência, deixando que as coisas se acertem por si, que vamos levando. / É um aprendizado isso aí, de cuidar de quem esquece. / Por fim, nossos velhos não são incômodos, muito menos castigos de deus. Eles são uma janela para nossa mais profunda humanidade. / Assim, vamos ficando melhores pessoas. O outro sempre é o paraíso quando ele já existe dentro de nós.”*

38. *“— [Elaine:] Precisa de alguma coisa, querido? / — Preciso. / — De quê? / — De atenção.”*

39. *“O velho não é criança, então não dá pra aplicar as regras do trato infantil com ele. É preciso dar autonomia, fazer com que se sinta capaz, respeitar suas escolhas e vontades. É um processo intenso e difícil. / Procuro não tratá-lo como criança, mas como uma pessoa adulta que precisa saber o que se passa.”*

40. *“Ele não sabia quem a gente era, mas sabia que o amávamos e confiava em nós. Foi assim até o último suspiro.”*

41. *“Dá aquela sensação de desolação! Respiro fundo e para não o deixar nervoso, faço cara de surpresa. —Barbaridade, pai, quem será que fez isso? E ele me olha com aquela carinha de inocente. / — Mas sabe que eu não sei. Passou um cara aqui, e outro ali, e outro ali — e foi apontando os cocozinhos, como se cada um deles tivesse sido obra de uma pessoa diferente / — Passaram aí e foram embora. / — Puxa vida, que safados, né? / — É — e sai andando como se nada. / Sobra a limpeza, coisa nada fácil. E ele descansa no alpendre, bem faceiro. Assim são as manhãs na casa Tavares.”*

42. *“Com meu pai tenho aprendido. Não é fácil. Penso que eu ainda tenho a sorte de contar com a ajuda dos que vivem comigo, meus sobrinhos e meu companheiro. Mas me angustia saber que nesse mundão de deus tem uma carrada de velhinhos perdidos e sozinhos, porque as famílias não têm a menor condição de cuidar. Há que prover a vida, há que trabalhar, há que moer o corpo na roda do capital. Não é culpa de ninguém, é a porra da vida que não abre saídas.”*

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