Care, dementia, and the fourth age in Erica Jong’s later work

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Abstract

Background and Objectives: This article addresses the representations of dementia and caregiving in the fourth age as depicted in Erica Jong’s later-life work. It shows how the experience of parental care leads to the discovery of new ways of human interaction and expressions of personhood.

Research Design and Methods: Framed within literary-cultural age studies, the article shows how humanities-based inquiry can illuminate important aspects of aging and care of the oldest old, which are significant and revealing, but often hidden under the dark shadow of dementia.

Results: Newly discovered ways of communication challenge the notion of the loss of agency as they demonstrate that the body itself has the power of creative and intentional capacities and self-expression.

Discussion and Implications: Care-related narratives offer new insights into aging, dementia and subjectivity that can help pursue a better analysis of the ‘deep’ old age, strengthen collective solidary and manage increasing ageism, especially pronounced during the Covid-19 pandemic.

Keywords: Cultural-literary gerontology, Humanities, Literature, Oldest old.
Introduction
This study employs cultural-literary gerontology as the main framework to address the issue of caring for the oldest old whose agedness and both physical and mental frailty are associated with declining cognitive impairment, as represented in contemporary American writer Erica Jong’s (1942) later work. Specifically, the article focuses on the author’s latest novel to date, *Fear of Dying* (2015), which deserves particular attention because, in contrast to her previous writings, it is primarily about aging, losses and death. This coming-of-age story depicts a 60-year-old actress, Vanessa Wonderman, who is faced with caregiving duties of her dying parents, her husband’s impotence, and the fear of her own aging, the loss of youthful looks and rationality, and mortality. With her honesty and witty humor, Jong brings her readers closer to age-related challenges, and questions the meanings of life, death and growing older in contemporary society. Although, in the novel, old age is accompanied by pain, dependency, bodily decay and, ultimately, deaths, Vanessa also discovers that the perplexing experience of aging and carework, as well as the proximity of death, can yield remarkable insights about later-life stages and make the fictional character less fearful of aging and the end of life. Jong’s novel also examines parent narratives that elicit different subjectivities, and give voice to the often-silenced social and psychological realities of human aging. It tackles the problem of conveying the meaning of personhood in old age when faced with gradual mental decline, which is especially difficult to capture and represent (Barry & Vibe Skagen, 2020). The author’s later writing, very often autobiographical in nature, also contributes to a growth of literary texts that only recently are beginning to portray older people living with dementia in contrast to the many accounts that witness dying of our beloved ones. Finally, this study aims to demonstrate how humanities-based inquiry can illuminate important aspects of the fourth age and caregiving experiences that are both challenging and revealing, but often underappreciated and hidden under the dark shadow of dementia and the ‘deep’ old age.
The ‘black hole’ in age(ing) studies

There is a substantial body of theory on the so-called third age, closely related to the retirement age of the now aging baby-boom generation; yet, the last stage in life, commonly known as the fourth age, has not been the object of so much attention and has even been considered a ‘black hole’ in age(ing) studies (Gilleard & Higgs, 2010; Higgs & Gilleard, 2021). This phase in life is usually marked by numerous emotional and bodily illnesses, dementia and deaths, and is linked to dependency and the loss of mobility and cognitive capacities (Gilleard & Higgs, 2010; Lloyd, 2015). As Lloyd observes, this life-stage is usually regarded as “a troublesome concept, an inevitable outcome of the emergence of the third age as a period of personal growth and active engagement” (2015, p. 261). The importance given to the third age masks the darker aspects of social realities of the fourth age, which is hidden “behind the screens of nursing homes and geriatric wards” (Blaikie, 1999, p. 110). As Barry and Vibe Skagen contend, aging is a non-linear “inexorable process with no dramatic arc” that becomes even more complex in the fourth age, especially when looked at through the lens of the “intractable materiality,” which manifests itself when we are faced with the mismatch of our material selves and our inner perceptions of ourselves (2020: pp. 1-2).

The concept of the fourth age, also known as the deep of old age (Featherstone & Hepworth, 1989), is closely related to carework. Although care is especially needed in the first years of life as well as in case of illnesses, it becomes much more pronounced when older people, often infantilized and perceived as a homogeneous group, start to require daily assistance and support because of illness, loneliness, dementia, and/or disability (Gilleard & Higgs, 2010; Fine, 2015; Twigg, 2000). In today’s fast-aging society, challenges related to care of older individuals are becoming high-priority issues for families, caretakers, practitioners, policymakers and scholars working in these fields (Furstenberg et al., 2015; Katz & Lowenstein, 2019; Vincent & Velkoff, 2010). Cognitive impairment is one of the major sources of caregiver burden and reasons for institutionalization of older adults (Bannon et al., 2020; Friedman & Kennedy, 2021; Reinhard et al., 2008; Sheehan et al., 2020; Strommen et al., 2020; Voutilainen et al., 2018). Those living with dementia, especially, are assumed to lack meaningful participation and interaction, and are often regarded “as major sources of burden to family carers, formal care providers, and the healthcare system” (Kontos & Grigorovich, 2018a, p. 719).
Although the fourth age is seen through rather negative lens, it can offer us significant discoveries about growing older, subjectivity and human interaction (Beard et al., 2009; Hennelly et al., 2021; Kontos & Grigorovich, 2018a, 2018, 2019; Lee et al., 2020; Skinner et al., 2018). A humanities-based approach to care-related stories serves as a powerful tool to give meaning to old age, and offers significant insights into the aging experiences and care relationships (Chivers & Kriebernegg, 2017). Care narratives not only “capture the rich interplay of subjectivities and the complex relationships”, but also provide us with “a cultural repository for fears and hopes about an aging population” (Chivers & Kriebernegg, 2017, p. 17). Additionally, the narrative inquiry allows us to find the meaning of life and make our lives meaningful by telling stories because “humans are fundamentally storytelling creatures,” and life narrative is “the paradigm for human time” (Randall & Kenyon, 2004, pp. 333-334, emphasis in original).

Cultural-literary gerontology
During the last decades, there has been a visible growth and interest in age(ing) studies from interdisciplinary perspectives that go beyond the traditional field of gerontology. Scholars working in these disciplines argue that collective cultural-literary perceptions of later-life are imperative to better comprehend the current realities of aging, and bridge the gap between the social and medical sciences and humanities (Barry & Vibe Skagen, 2020; Calasanti & King, 2015; Casado Gual et al., 2016; de Medeiros, 2016; Falcus, 2016; Twigg & Martin, 2015; Zeilig 2011). Since the so-called longevity revolution (Butler, 2008), literature that explores the dynamics of aging has proliferated – there are more people writing into older age because they “remain well enough to reflect on the experience” and, thus, can share their compelling stories in many different ways, which also connects to the wider tradition of self-help and life writing (Barry & Vibe Skagen, 2020, p. 3; Amigoni, 2020). Literary approaches to later-life broaden the gerontological scholarship as they show that aging is a dynamic process that constitutes multifaceted meanings of older age, and allows to explore the depths of agedness that move beyond the reach of narrative as we approach the limits of life and the sociocultural representations of old age (Barry & Vibe Skagen, 2020; Casado Gual et al., 2016; de Medeiros, 2016; Falcus, 2016; Hepworth, 2000; Zeilig 2011). Lately, there has been an increasing number of fictional and personal narrative accounts that address the relationship between care, dementia and age (Barry & Vibe Skagen, 2020; Beard,
2016; Chivers & Kriebernegg, 2017; Clare et al., 2008; Falcus & Sako, 2019). Broader knowledge about these issues is becoming especially important because of a fast aging society and the growing need of caregiving services for older adults (Furstenberg et al., 2015; Katz & Lowenstein, 2019). As Chivers and Kriebernegg argue, care of older people is “at the crux of age/ing studies. Changing the meaning of care stands to substantially change what it means to ‘age well’” (2017, p. 20).

This article contributes to the growing interest in parental care narratives and tries to illuminate the ‘black hole’ in age(ing) studies. In her later works, Erica Jong, a spokeswoman of the American post-war generation women, highlights both anxieties and significant discoveries about the oldest old, and calls for a rethinking of the fourth age and the moral imperative of care. Today Jong’s writings continue to be as significant as they were during the feminist movement (c. 1960-90), when her groundbreaking novel, Fear of Flying, was published in 1973. In her early works, Jong openly discussed intimate experiences and professional aspirations of young women, and illustrated the sociocultural and political climate of the seventies in the USA, characterized by the sexual revolution, social upheavals, and the second-wave women’s liberation movement. Yet, the issues regarding older women, dementia, and old age have not been addressed in the feminist agenda of that period. As King states, there was “a significant silence regarding women’s ageing, a lacuna which deserves examination” (2013, p. xvi). This is exactly what Jong does as she grows older – by incorporating the voices of the female representatives of the baby-boom generation, she examines the ways they approach their latest-life stages and explore the often silenced aspects of parental caregiving.

**Aging and care narratives**

In Fear of Dying (2015), a middle-aged protagonist Vanessa struggles with parental care, and observes that her parents “have deteriorated drastically in the last few months” (Jong, 2015, p. 9). The fact that Jong does not place Vanessa’s aging parents in a nursing home can be interpreted as the author’s belief in dignified care at home, which, in contrast to residential care, may appear “as an unquestioned ideal” (Chivers & Kriebernegg, 2017, p. 20). The choice of home might also suggest the importance that the writer grants to family bonding in later-life and her critique of the medicalised institutions that have invaded the intimate home space (Blaikie, 1999). Additionally, being taken away from home can be seen as a betrayal, and may cause pain and
disappointment to aging individuals (Blaikie, 1999). The vital energy that Vanessa’s parents used to possess decreases as they grow older. Her parents’ frequent bad mood, their anxiety, unpleasant smells, and the sick-like atmosphere propel the daughter to wish that people did not get as old and ill as her parents:

[they both wear diapers – if we’re lucky. Their apartment smells of urine, shit, and medications. The shit is the worst. It’s not healthy shit like babies produce. It seems diseased. Its fetid aroma permeates everything – the oriental rugs, the paintings, the Japanese screens. It’s impossible to escape – even in the living room (Jong, 2015, p. 9).

In her novel, Jong does not shy away from explicitly describing care-related challenges, but exposes her readers to the often hidden aspects of the fourth age and the negativities of aging bodies, which are often neglected in the field of gerontology. Twigg (2000) states that caregiving for older people is often a missing dimension in gerontological research since it represents the human dirt, low status, and agedist and gendered accounts in contemporary culture: “carework is about dealing with human wastes: shit, pee, vomit, sputum; and as such involves managing dirt and disgust” (2000, p. 395). Jong gives a special focus to smell, which, as she writes, permeates the whole environment and even seems to linger upon her own body. Smell is especially present and significant in care for older individuals as it “extends the patient’s corporeality in such a way that intrudes and seeps into others’ spaces. Odours by their nature cannot be easily contained; they escape and cross boundaries” (Twigg, 2000, p. 397). Gilleard and Higgs also point to the ‘dirty work’ performed by caregivers that is often unseen and unvoiced, but which has a huge impact on caretakers’ emotions and the management of their own personhood and moral identity (2017, p. 235). Playing down the issue of the human dirt and, instead, stressing care and emotional aspects reveals the contemporary inability to accept aging realities and negotiate an aging body (Twigg, 2000). Repugnance generated by sagging and smelly aging bodies also reveals the fear of contamination and moral pollution, which has become especially problematic in contemporary society that is based on individualism, self-management and “the construction of persons as self-contained, bounded entities” (Twigg, 2000, p. 396).

The negativities of the sagging bodies of Vanessa’s aging parents and the shadow of the daily ‘dirty work’ hinder the daughter’s relationship with them and generate troubled feelings. The protagonist tries to avoid seeing the body of her aging mother – “the crepey neck, the sagging arms, the bunioned feet” – because it reminds
her of the ravages of time and presents a vision of her own future of aging (Jong, 2015, p. 9). Therefore, the heroine secretly wishes not to get as old as her parents. Vanessa confesses that she has to force herself to look at her mother’s aging body because it generates anxiety, the fear of growing older, and makes her feel uneasy. Being middle-aged herself, Vanessa becomes even more aware of her own aging body and confronts the unpleasant truths of growing older:

Her cheeks are sallow and crosshatched with a million of wrinkles. Her eyes are rheumy and clotted with buttery blobs. Her feet are gnarled and twisted, and her thick, ridged toenails are a jagged mustard color. Her nightgown keeps opening to reveal her flattened breasts (Jong, 2015, p. 10).

Although Vanessa is also exposed to the bodily deterioration of both her mother and father, her mother’s physical decay is more visible and more explicitly described, while her father’s aged body is hidden under the blankets. The disclosure of her mother’s body alone suggests Jong’s critical standpoint in terms of the female aging body politics and the rigid ideals of beauty and attractiveness that are based on youthful images and, thus, the discriminatory representations of older women, which reveals the ‘double standard’ of aging (Sontag, 1972). In fact, contemporary anti-aging-oriented society does not provide us with many bodily images of aging women, especially those stepping into the ‘deep’ old age (Silver, 2003; Twigg, 2000; Wolf, 2002). Even if we have become more open in the treatment of the naked aging body in modern society, only slim, fit and youthful-looking older bodies are allowed to be visible (Twigg, 2000, p. 397).

Contrary to her mother, whose sagging breasts are seen through the nightgown that keeps opening, Vanessa’s father is described as a little mummy that is immobile and almost invisible: “[h]is wasted body takes up remarkably little space under the blankets” (Jong, 2015, p. 11). His smallness, calmness and practical nonexistence are also shown in his disconnection from the exterior world. Because of his impaired hearing he can no longer follow conversations and communicate. However, according to Vanessa, even if he could be helped by a hearing aid, he would not be interested in talking, because he “prefers to spend the day sleeping” (Jong, 2015, p. 11). After a cancer surgery, he has become even more enclosed in his inner world: “[j]ust six months ago, before his cancer surgery, he was a different man” (Jong, 2015, p. 11). As Vanessa’s father approaches his death, he becomes more negative, nihilistic and bored with everything to the point that he even considers life as a big joke. If, in his younger
days, her father thought that competition and fighting for goals were important, aging and the presence of death made him realize that he was fooling himself only to stay active and functional. According to him, all the things “you were so passionate about don’t mean a thing. You only did them to keep busy” (Jong, 2015, p. 25). His comments make the daughter rethink her pursuit of personal goals and her life choices. Yet, the heroine refuses to see life as a joke: “[p]lease tell me that life is worth living. Please tell me that all the hassle of getting up, getting dressed, is worth the trouble. I don’t want to believe that life is only a joke. I don’t think parents ought to tell that to their children” (Jong, 2015, p. 26). Yet, although Vanessa’s father is nihilistic about life when still alive, he becomes more positive when he appears in her dreams after his death. In them, he encourages his daughter to keep on living and writing:

And the strangest thing is this: When he was alive, I thought all our conversations were partial, frustrating – unintelligible. But once he was dead, we really began to talk. We talked through all my dreams. We talked every night till the small hours of the morning. Alive, he was closed and careful. Dead, he told me everything. I think he may be dictating to me now (Jong, 2015, p. 126).

The cancer operation of Vanessa’s father also makes her realize the inevitability of the end of life and the insignificance of human body. Even though the cancer tumor was successfully removed from her father’s body, he could not prolong his life because “the anesthesia invaded his brain,” thus, showing that “if death can’t march in the front door, it’ll sneak in the back” (Jong, 2015, p. 21). Vanessa believes that Americans disregard death unless it manifests itself through a grieving chain of deaths: “[w]e have trouble with death. We think it’s un-American. We think it won’t catch us” (Jong, 2015, p. 134). This observation points to the popularity of the idea of successful aging in Western countries and, especially, in the USA, where this model was originated in the second half of the twentieth century (Calasanti, 2016; Katz & Calasanti, 2015).

Successful aging discourse, aimed at replacing the narrative of decline (Gullette, 2004), according to which aging individuals are seen as dependent and frail, disseminated the idea that it was possible to avoid disease and illnesses in later years by actively engaging in life (Rowe & Kahn, 1998). The main idea behind this model was that as long as older people were able to enjoy life, maintain healthy habits, and enthusiastically participate in social circles and leisure activities, they were aging in a successful and gracious way (Calasanti, 2016; Katz & Calasanti, 2015; Katz, 2000). Equated with the current concepts of happiness and well-being, Rowe and Kahn’s
model continues to heavily influence our daily lives and social trends to the extent that getting and looking old is considered immoral, unethical or even “heretical” (Katz, 2000, p. 135). Hence, Vanessa’s statement that death is ‘un-American’ can be seen as a response to the powerful influence of successful aging discourse and anti-aging tendencies. Closely related to neoliberal rationality and capitalist ideology, this model ignores the diversity of the experiences of aging and, in its stead, imposes new pressures and requirements for older adults who are held responsible for their own aging, wellbeing and ‘failures’ (Calasanti, 2016; Katz & Calasanti, 2015; Katz, 2000). Furthermore, Katz (2017) observes that the idea of successful aging has also invaded the governance of human minds, which have become quantified and measured by the use of digital technologies and brain sciences. Online brain-game performance or ‘bio-games’ promise to optimize people’s brain health and “cognitive fitness,” which is now regarded as an indicator of a successful adaptation to societal expectations and successful aging. In this way, according to Katz, individuals are made responsible for their own cognitive performance and, consequently, become “align[ed] to capitalist standards of productivity, efficiency and speed” (2017, n/p), which is also visible in dementia-related research and treatment.

**Dementia and the new colors of life**

Progressive neurodegenerative conditions affect approximately 46.8 million people around the world and create significant limitations that obstruct their social participation and interaction (Portacolone et al., 2021; Skinner et al., 2018). Alzheimer’s disease and related dementias are chronic illnesses that increase with age and affect a person’s capacity to manage one’s life and make meaningful decisions (Lee et al., 2020; Portacolone et al., 2021). Yet, Alzheimer’s is not only about rendering older individuals forgetful and dependent; rather than that, it “represents a malignant forgetfulness that causes people to lose their sense of who they are and what is most important to their sense of self […] and their place” in the world (Gilleard & Higgs, 2017, p. 232). As Gilleard and Higgs argue, it gradually lessens not only people’s social interaction and participation, but also “their connections to themselves and their ‘individual representations’ of their personal past” (2017, p. 232). Therefore, the possibility of developing Alzheimer’s is regarded as one of the most fearful aspects because it represents a loss of one’s cognitive capacities, selfhood, power, social status and attractiveness (Gilleard & Higgs, 2017). Katz (2017) also observes that the growing
preoccupation of dementia contributes to the use of innovative anti-aging-oriented
digital technologies and, accordingly, equates people’s cognitive abilities with
successful aging and global capitalist ideologies. The scholar highlights that the fear of
dementia, similar to that of aging, is now seen as a contagious disease that can only be
cured by “the brain enterprises”. As a result, our society has generated “a new
dimension of ageism that equates hypercognitive abilities with successful aging” (Katz,
2017, n/p).

The challenges related to dementia are also present in Jong’s later work. The
writer expresses Vanessa’s worries and difficulties when caring for her aging mother
who lives with Alzheimer’s disease. The fictional character observes how her mother’s
progressive cognitive impairment impacts her mood, communication and her
relationship with the outside world. The heroine ponders if her aging mother is even
aware of her “near extinction of consciousness” and the fact that “she’s ending her
days” (Jong, 2015, pp. 224-225). Vanessa confesses that many times she prayed for her
mother to die sooner because she could no longer stand the sight of her mother’s loss of
rationality and her silent suffering in a smelling room that embittered her own life:
“[t]here were many times I prayed for her to die. She was so frail and so sad that I often
couldn’t bear to visit her. I always preferred to be with my daughter and grandson rather
than with her” (Jong, 2015, p. 237). The protagonist even thinks that the pain of the
dying should not be prolonged, because “[I]nterminable may be much worse” than dying
(Jong, 2015, p. 175). Yet, Vanessa observes that sometimes her mother seems to have
some glimpses of consciousness and is aware of the burden she places on her daughter:

‘[w]hat are you thinking about?’ my mother asks.
‘Nothing,’ I say.
‘You’re thinking you never want to get as old as I am,’ she says. ‘I know you’
(Jong, 2015, p. 11).

Even if faced with caregiving struggles and coping with dementia, Vanessa, as the
narrative unfolds, learns new ways of interacting with her aging mother. The daughter
realizes that language is not the only means to connect with the external world: “[w]hen
dementia has been with us a long time, the means of communicating change” (Jong,
2015, p. 226). Although the protagonist confesses that sometimes she was not “alert
even to her new ways of communicating,” her mother has taught her that senses,
colors, tastes, smells, sounds, and body language can be as powerful and efficient as the
spoken language: “[m]usic delights her, though I think she doesn’t hear. Chocolate slides on her tongue like love” (Jong, 2015, p. 228). Gradually, Vanessa realizes that:

[w]e are so unaware of different languages – not Latin and Greek, but the language of color, the language of food. We hardly know all the different kinds of human music. My mother could speak without speaking, laugh without laughing, sing without having voice. The parents of special-needs kids know this and so do the children of the dying (Jong, 2015, p. 229).

Through her body language, her mother tries to show her approval of Vanessa’s clothing, which reminds her of her younger days and makes her happy, even if she cannot verbalize her emotions:

[s]he sits up and tries to exclaim at the color of my shirt – red and purple with mossy green. An Etro confection she might have worn when she was young. Her taste in clothes was always over the top, ahead of her time, widely artistic. But she can’t speak. She croaks like a frog that might sit on mossy green ledge, then dive swiftly into the water. She lifts her shoulders strongly, though by now she can’t sit up. She exclaims without exclaiming. I know she is approving of my colorful colors – so like those she wore in her salad days. She has found a new sort of speech that is wordless (Jong, 2015, pp. 228-229).

The challenges of caregiving and old age are not only represented in Jong’s fiction, but also in her more personal accounts, in which the author writes about her parents’ longevity and her experience with parental care. In her essay “Breaking the final taboo,” which precedes Fear of Dying, Jong states:

[w]hen I tell people my mother is a hundred and a half, that my grandmother lived to ninety-eight and my father to ninety-three, they look at me approvingly and say ‘You’ve got good genes’ as if they are about to find a new reason to be envious. They have no idea what they’re saying (Jong, 2014, p. 84).

Jong, likewise her fictional character Vanessa, discovers her mother’s alternative ways of communication and self-expression. The author explains that during her mother’s last days, she would only react to color, which made Jong realize the power of non-verbal communication and the complexities of living and aging with dementia:

[i]n the last few days, she was alert enough to respond to color, though she could not speak. I came to realize that I had underestimated her grasp of language. Color was her language, and a bright shirt I wore to sit by her side and tell her I loved her evoked a passionate response (Jong, 2014, p. 92).
In a poem “Dying is not black” (2014) the writer again emphasizes the newly found ways of interaction with her dying mother. The caregiving experience allows Jong to reestablish their conflicting relationship (Stońcikaitė, 2016) and reconnect emotionally through color, touch and wordless language:

[t]ouch, words, color, / my expiring mother / notices the red & purple of my shirt / with delight. / Color is her language / though she taught me / both painting & poetry / interlocking languages for her / & now for me. / She has no words for my shirt / but exclaims nonsense syllables / of joy, her only brush now / for the ecstasy of red, / the blue note / of mauve over it, / making plum. / Her sounds become / a damson jam / like her mothers’, / sweet but muddled. / But her love is clear. / Her love assails / my eyes / as if it were / blood glittering / on a knife / aiming for / my heart (Jong, 2014, pp. 92-93).

The power of non-verbal communication is getting more attention in the field of age(ing) studies, especially in dementia-related research and person-centered care, which significantly contributes to improving quality of life and cognitive function of older people and their carers (Dewitte et al., 2020; Hennelly et al., 2021; Kelley et al., 2021). Creativity and arts-based activities, such as painting, music, drama and/or dance can improve the physical, emotional and neurological wellbeing of people living with dementia, and provide them with new ways of social interaction and emotional support (Kontos & Grigorovich, 2018a, 2018, 2019; Li, 2021; Skinner et al., 2018). Such non-pharmacological interventions allow for alternative ways of communication and the creative-expressive power, which help reveal novel opportunities to express people’s thoughts, emotions and capabilities. Additionally, different forms of interaction challenge the notion of the loss of agency, as older people with dementia show that the body itself has creative and intentional capacities and the power of natural expression (Kontos & Grigorovich, 2018a, 2018, 2019; Skinner et al., 2018). Kontos and Grigorovich emphasize the importance of ‘embodied selfhood’ and the persistence of agency even when living with cognitive impairment: “embodied selfhood highlights our intrinsic corporeality of being-in-the-world, which sustains and animates self-expression, and which is always intertwined with a shared world” (2018, p. 718). Even when faced with dementia and a lack of coherent and rational engagement, diverse forms of personhood and sense-making still remain – older people strive to negotiate their everyday lives and incorporate their cognitive decline into their existing self-identities (Beard et al., 2009; Hennelly et al., 2021; Li, 2021).
Personhood as a concept has both metaphysical and moral roots: metaphysical aspects relate to rationality and agency, whereas moral selfhood is linked to equality of all human beings (Higgs & Gilleard, 2016). However, people with dementia are often regarded as nonpersons because they lack these competences and skills (Hennelly et al., 2021). Yet, the problem of conveying selfhood marked by dementia is not only difficult to conceptualize and describe, but is often absent from gerontological research. In her essay “Critical interests and critical endings,” Barry (2020) explores the issue of subjectivity in relation to dementia of the oldest old and those who provide care for them by aligning these aspects with moral philosophical positions on identity and cultural and fictional representations of aging. According to the scholar, although dementia is often related to the end of life story in sociocultural assumptions and, thus, the culmination of a person’s meaningful judgment and significant living, it can also offer alternative narratives marked by new findings and inner transformations for both the carers and those in need of care. Even if darkened by the declining cognitive condition and reduced capacities, people preserve their personhood and autonomy until the end of their existence. However, these significant aspects are often undermined by successful aging discourse and its neoliberal imperatives, which are mainly focused on the third age and cognitive optimization. Therefore, contemporary society fails to reconsider the power of ‘embodied selfhood’ and the traits of personhood in ‘extreme’ years.

In her later work, Jong brings to light these important discoveries, and shows how the experiences of parental care can offer new visions about dementia and subjectivity that are not revealed by ‘bio-games’ or empirical data, but disclosed through the body language and emotional intimacy. Both Jong and Vanessa realize that personhood goes beyond speech or rationality as it manifests through alternative ways of interaction with the outside world. The author also demonstrates that to notice and appreciate these little glimpses of life and the assertion of agency requires patience and love. Caregiving experiences also reveal that the narrative of one’s life is never a single and isolated story, but, as Barry puts it, “a set of causes and effects, memories and influences, that reverberate through and colour one’s own and others’ lives, both past and present” (2020, p. 132). By depicting challenging but also illuminating aspects of parental care and aging realities, Jong also stresses the need for innovative humanities-based approaches to person centered-care and dementia research in order to produce
new knowledge, and improve quality of life for older people, and, at the same time, provide carers with different visions about the suppressed stage of the fourth age.

**Conclusions**

By focusing on Erica Jong’s later-life work, this article has addressed the complexities of parental care shadowed by dementia in the deep old age (Featherstone & Hepworth, 1989; Gillett & Higgs, 2010). It aimed to show how literature can illuminate alternative ways of representing later years and caregiving experiences that are marked by new perceptions of aging and the discovery of the power of non-verbal communication, ‘embodied selfhood’ and emotional intimacy. In her work, Jong exposes the usually silenced and avoided aspects of care, such as ‘dirty work’ and bodily decay, even if they represent the fear of growing older and go against the ideals of successful aging in our modern secular society that emphasizes youth, beauty and self-management (Calasanti & King, 2015; Silver, 2003; Smirnova, 2012; Twigg, 2000, 2012; Wolf, 2002). The writer seems to offer different perspectives about aging in hope to unite her readers in an act of mutual support and solidarity when faced with dementia-related care. Her work also shows that taking care of old parents is an act of gratitude and love, and that only through compassion and resilience can we learn to better understand and appreciate all life-stages. Ultimately, while there are many different opportunities to interrogate the concept of the fourth age and the moral imperative of care in the current cultural imaginary, dementia and parental caregiving accounts can provide us with new perceptions of old age through particular life-journeys of aging individuals and their expressions of agency and personhood, however insignificant or minute they might seem.

This study has also aimed to demonstrate that a humanities-based approach can extend the gerontological framework, and care narratives give voice to those aging individuals who struggle to communicate and are ‘silenced’ in nursing homes that represent the “society’s greatest fears of old age” (Gillett & Higgs, 2017, p. 239). Instead of escaping from the uncomfortable truths and realities of the fourth age, we
should open out the debate because of its relevance and importance today “even if – or most likely because – its resolution is so hard to realize” (Gilleard & Higgs 2017, p. 240). Taking care-related narratives into account would strengthen collective solidary and help manage the increasing anger towards the aging population, which has become especially pronounced during the Covid-19 pandemic (Ayalon et al., 2020). If, before this crisis, older people living with dementia were already at high risk for negative health outcomes and exclusion, the Covid-19 outbreak has acted as a magnifying glass that has exposed increasing ageism and the fear of old age (Ayalon et al., 2020; Portacolone et al., 2021). However, this global tragedy not only uncovered “a story of failed humanity that needs to change,” but has also showed that older people, even made invisible, can teach us what it means to be human and how to “show kindness, love and care,” even “when everything breaks to pieces around us” (Douglas, 2020, n/p).
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References:

Amigoni, D. (2020). Self-help in the historical landscape of ageing, dementia, work and gender: Narrative duplicities and literature in a “Changing place called old age”. In E. Barry & M. Vibe Skagen (Eds.), Literature and ageing (pp. 150–166). D.S. Brewer.

Ayalon, L., Chasteen, A., Diehl, M., Levy, B. R., Neupert, S. D., Rothermund, K., Tesch-Römer, C., & Wahl, H. W. (2020): Aging in times of the Covid-19 pandemic: Avoiding ageism and fostering intergenerational solidarity. Journals of Gerontology: Series B, 76(2), e49–e52. doi:10.1093/geronb/gbaa051

Bannon, S., Reichman, M., Popok, P., Wagner, J., Gates, M., Uppal, S., LeFeber, L., Wong, B., Dickerson, B. C., & Vranceanu, A. M. (2020). In it together: A qualitative meta-synthesis of common and unique psychosocial stressors and adaptive coping strategies of persons with young-onset dementia and their caregivers. Gerontologist. doi:10.1093/geront/gnaa169

Barry, E. (2020). Critical interests and critical endings: Dementia, personhood and end of life in Matthew Thomas’s We are not ourselves. In E. Barry & M. Vibe Skagen (Eds.), Literature and ageing (pp. 129–148). D. S. Brewer.

Barry, E. & Vibe Skagen, M. (2020). Introduction: The difference that time makes. In E. Barry & M. Vibe Skagen (Eds.), (pp. 1–15). D.S. Brewer.

Beard, R. L. (2016). Living with Alzheimer’s: Managing memory loss, identity, and illness. New York University Press.

Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. Journal of Aging Studies, 23(4), 227–235. doi:10.1016/j.jaging.2008.01.002

Blaikie, A. (1999). Aging and popular culture. Cambridge University Press.

Butler, R. (2008). The longevity revolution: The benefits and challenges of living a long life. Public Affairs.

Calasanti, M. T. (2016). Combating ageism: How successful is successful aging? Gerontologist, 56(6), 1093–1101. doi:10.1093/geront/gnv076

Calasanti, M. T., & King, N. (2015). Intersectionality and age. In J. Twigg & W. Martin (Eds.), Routledge handbook of cultural gerontology (pp. 193–201). Routledge.

Casado Gual, N., Domínguez Rué, E., & Worsfold, B. (Eds.) (2016). Literary creativity and the older woman writer: A collection of critical essays. Peter Lang.

Chivers, S., & Kriebneregg, U. (2017). Introduction: Care home stories: Aging, disability, and long-term residential care. In S. Chivers & U. Kriebneregg (Eds.), Care home stories (pp. 17–26). Transcript Verlag.

Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. Gerontologist, 48(6), 711–720. doi:10.1093/geront/g48.6.711

de Medeiros, K. (2016). Narrative gerontology: Countering the master narratives of aging. Narrative works: Issues, investigations, & interventions, 6(1), 63–81. https://journals.lib.unb.ca/index.php/NW/article/view/25446/29482

Dewitte, L., van Wijngaarden, E., Schellekens, T., Vandenbulcke, M., & Dezutter, J. (2020). Continuing to participate in the dance of life as oneself: The lived experience of meaning in life for older adults with Alzheimer’s disease. Gerontologist. Advance online publication. doi:10.1093/geront/gnaa206

Douglas, C. (2020). Lives and deaths with dementia during Covid-19: Our shameful (but hopefully transformative) post-pandemic legacy. Co-existing with Covid-
19: Moving into the post-pandemic world with the social sciences. UCL Medical Anthropology. https://medanthucl.files.wordpress.com/2020/06/cewc_lives-and-deaths-with-dementia-douglas.pdf

Falcus, S. (2016). Literature and ageing. In J. Twigg & W. Martin (Eds.), Routledge handbook of cultural gerontology (pp. 53–60). Routledge.

Falcus, S., & Sako, K. (2019). Contemporary narratives of dementia: Ethics, ageing, politics. Routledge.

Featherstone, M., & Hepworth, M. (1989). Ageing and old age: Reflections on the postmodern life course. In B. Bytheway, T. Keil, P. Allat & A. Bryman (Eds.), Being and becoming old: Sociological approaches to later life (pp. 143–157). Sage.

Fine, M. (2015). Culture of care. In J. Twigg & W. Martin (Eds.), Routledge handbook of cultural gerontology (pp. 269–277). Routledge.

Friedman, E. M., & Kennedy, D. (2021). Typologies of dementia caregiver support networks: A pilot study. Gerontologist. Advance online publication. doi:10.1093/geront/gnab013

Furstenberg, F. F., Hartnett, C. S., Kohli, M., & Zissimopoulos, J. M. (2015). The future of intergenerational relations in aging societies. Daedalus, 144(2), 31–40. doi:10.1162/DAED_a_00328

Gilleard, C., & Higgs, P. (2010). Aging without agency: Theorizing the fourth age. Ageing & Mental Health, 14(2), 121–128. doi:10.1080/13607860903228762

Gilleard, C., & Higgs, P. (2017). An enveloping shadow? The role of the nursing home in the social imaginary of the fourth age. In S. Chivers & U. Krieberneeg (Eds.), Care home stories (pp. 229–246). Transcript Verlag.

Gullette, M. M. (2004). Aged by culture. Chicago: University of Chicago Press.

Henny, N., Cooney, A., Houghton, C., & O’Shea, E. (2021). Personhood and dementia care: A qualitative evidence synthesis of the perspectives of people with dementia. Gerontologist, 61(3), e85-e100. doi:10.1093/geront/gnz159

Hepworth, M. (2000). Stories of aging. Open University.

Higgs, P., & Gilleard, C. (2016). Interrogating personhood and dementia. Aging & Mental Health, 20, 775–780. doi:10.1080/13607863.2015.1118012

Higgs, P., & Gilleard, C. (2021). Fourth ageism: Real and imaginary old age. Societies, 11, 1(12). doi:10.3390/soc11010012

Jong, E. (2014). Breaking the final taboo. In J. Burroway (Ed.), A Story larger than my own. Women writers look back on their lives and careers (pp. 84–93). Chicago University Press.

Jong, E. (2015). Fear of dying. St. Martin’s Press.

Katz, R., & Lowenstein, A. (2019). Editorial introduction: Cross-cultural contexts of eldercare and caring: Theory, research and policy. International Journal of Care and Caring, 3(1), 3–8. doi:10.1332/239788219X15492859621982

Katz, S. (2000). Busy bodies: Activity, aging and the management of everyday life. Journal of Aging Studies, 14(2), 135-152. doi:10.1016/S0890-4065(00)80008-0

Katz, S. (2017). ACT based research on aging and cognito-politics. http://actproject.ca/reflections-from-stephen-katz-on-quantified-ageing/

Katz, S., & Calasanti, M. T. (2015). Critical perspectives on successful aging: Does it ‘appeal more than it illuminates’? Gerontologist, 55(1), 26–33. doi:10.1093/geront/gnu027

Kelley, R., Godfrey, M., & Young, J. (2021). Knowledge exchanges and decision-making within hospital dementia care triads: An ethnographic study. Gerontologist. Advance online publication. doi:10.1093/geront/gnaa216
King, J. (2013). Discourses of ageing in fiction and feminism: The invisible woman. Palgrave Macmillan.

Kontos, P., & Grigorovich, A. (2018). Dancing with dementia: Citizenship, embodiment and everyday life in the context of long-term care. In Katz, S. (Ed.), Ageing in everyday life: Materialities and embodiments (ageing in a global context) (pp. 163–179). Policy Press.

Kontos, P., & Grigorovich, A. (2018a). Integrating citizenship, embodiment, and relationality: Towards a reconceptualization of dance and dementia in long-term care. The Journal of Law, Medicine & Ethics, 46(3), 717–723. doi:10.1177/1073110518804233

Kontos, P., & Grigorovich, A. (2019). A critical narrative on late-life creativity and dementia: Integrating citizenship, embodiment and relationality. In D. Amigoni & G. McMullan (Eds.), Creativity in later life. Beyond late style (pp. 167–181). Routledge.

Lee, K. H., Lee, J. Y., & Kim, B. (2020). Person-centered care in persons living with dementia: A systematic review and meta-analysis. Gerontologist. Advance online publication. doi:10.1093/geront/gnaa207

Li, B. Y. (2021). Cocomposing an aesthetic self through play: Toward a transformative framework for dementia care. Gerontologist. doi:10.1093/geront/gnab021

Lloyd, L. (2015). The fourth age. In J. Twigg & W. Martin (Eds.), Routledge handbook of cultural gerontology (pp. 261–269). Routledge.

Portacolone, E., Chodos, A., Halpern, J., Covinsky, K. E., Keiser, S., Fung, J., Rivera, E., Tran, T., Bykhovsky, C., & Johnson, J. K. (2021). The effects of the Covid-19 pandemic on the lived experience of diverse older adults living alone with cognitive impairment. Gerontologist, 61(2), 251–261. doi:10.1093/geront/gnaa201

Randall, L. W., & Kenyon, G. M. (2004). Time, story, and wisdom: Emerging themes in narrative gerontology. Canadian Journal of Aging, 23(4), 333–346. doi:10.1353/cja.2005.0027

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.), Patient safety and quality: An evidence-based handbook for nurses (pp. 341–404). Agency for Healthcare Research and Quality.

Rowe, J., & Kahn, R. (1998). Successful aging. Pantheon Books.

Sheehan, O. C., Haley, W. E., Howard, V. J., Huang, J., Rhodes, J. D., & Roth, D. L. (2020). Stress, burden, and well-being in dementia and non-dementia caregivers: Insights from the caregiving transitions study. Gerontologist. Advance online publication. doi:10.1093/geront/gnaa108

Silver, B. C. (2003). Gendered identities in old age: Toward (de)gendering? Journal of Aging Studies, 17, 379–397. doi:10.1016/S0891-4067(03)00059-8

Skinner, M. W., Herron, R. V., Bar, R. J., Kontos, P., & Menec, V. (2018). Improving social inclusion for people with dementia and carers through sharing dance: A qualitative sequential continuum of care pilot study protocol. BMJ Open, 8, e026912. doi:10.1136/ bmjopen-2018-026912

Smirnova, M. H. (2012). A will to youth: The woman’s anti-aging elixir. Social Science & Medicine, 75, 1236–1243. doi:10.1016/j.socscimed.2012.02.061

Sontag, S. (1972). The double standard of aging. The Saturday Review, 29–38 Sept 23. Stončikaitė, I. (2016). Erica Jong: From a youthful fear of flying to a more experienced landing in her late years. In N. Casado Gual, E. Domínguez Rué, & B. Worsfold (Eds.), Literary creativity and the older woman writer: A collection of critical
essays (pp. 149–173). Peter Lang.
Stončikaitė, I. (2019). Critical approaches to ageing body politics in the works of Erica Jong. Societies, 9(2), 47. doi:10.3390/soc9020047
Stončikaitė, I. (2020). To lift or not to lift? The dilemma of an aging face in Erica Jong’s later works. Journal of Aging Studies, 52. doi:10.1016/j.jaging.2020.100835
Strommen, J., Fuller, H., Sanders, G. F., & Elliott, D. M. (2020). Challenges faced by family caregivers: Multiple perspectives on eldercare. Journal of Applied Gerontology, 39(4), 347-356. doi:10.1177/0733464818813466
Twigg, J. (2000). Carework as a form of bodywork. Ageing & Society, 20, 389–411. doi:10.1017/S0144686X99007801
Twigg, J. (2012). Adjusting the cut: Fashion, the body and age on the UK high street. Ageing & Society, 32(6), 1030–1054. doi:10.1017/S0144686X11000754
Twigg, J., & Martin, W. (2015). The challenge of cultural gerontology. Gerontologist, 55(3), 353-359. doi:10.1093/geront/gnu061
Vincent, G., & Velkoff, V. (2010). The next four decades: The older population in the United States: 2010 to 2050 (Current population reports). https://www.census.gov/prod/2010pubs/p25-1138.pdf
Voutilainen, A., Ruokostenpohja, N., & Välimäki, T. (2018). Associations across caregiver and care recipient symptoms: Self-organizing map and meta-analysis. Gerontologist, 58(2), e138–e149. doi:10.1093/geront/gnw251
Wolf, N. (2002). The Beauty myth: How images of beauty are used against women. Harper & Row.
Woodward, M. K. (1991). Aging and its discontents: Freud and other fictions. Indiana University Press.
Zeilig, H. (2011). The critical use of narrative and literature in gerontology. International Journal of Ageing and Later Life, 6(2), 7–37. doi:10.3384/IJAL.1652-8670.11627