VIRUS

Beiträge zur Sozialgeschichte der Medizin

Band 16

Schwerpunkt: Orte des Alters und der Pflege –
Hospitäler, Heime und Krankenhäuser

Herausgegeben von

Elisabeth Lobenwein, Sarah Pichlkastner,

Martin Scheutz, Carlos Watzka und Alfred Stefan Weiß
für den Verein für Sozialgeschichte der Medizin

Leipzig: Leipziger Universitätsverlag, 2017



Ulla Kriebernegg

Putting Age in Its Place. Representations of Institutional Eldercare in Contemporary North American Film and Fiction

Deutscher Titel

Dem Alter Raum geben. Altersheim-Darstellungen im nordamerikanischen Film und Roman

Zusammenfassung

Dieser Aufsatz widmet sich einem derzeit im angloamerikanischen und kanadischen Raum immer populärer werdenden Genre, dem Pflegeheimroman ("care home novel"), und beschäftigt sich mit der Frage, welche Rolle die fiktionale Repräsentation von Orten des Alterns und der Pflege für ein sozial und kulturell konstruiertes Altersbild spielen kann. Nach einer überblicksartigen Darstellung der verschiedenen Sub-Genres und ihrer Beispiele wird darauf eingegangen, wie das Heim als Ort des Alterns in solchen Romanen dargestellt wird, wer darin Sichtbarkeit erlangt und wer unsichtbar bleibt. Da Pflege immer auch räumlich determiniert ist, erlaubt eine Analyse der Darstellungsweise des Heimes Aussagen darüber, wie im Pflegeheimroman Fragen der menschlichen Existenz verhandelt werden.

Keywords

Care home narratives, spaces and places of care, fourth age, Aging Studies, Cultural Gerontology, contemporary North American literature, cultural representation, ageism

Introduction

"Her new home, sweet home. But mustn't start on a sour note, or a dubious one. [...] This will be fine. Fine enough. It only takes getting used to, and a little while to get settled. It'll remain a shock for a while, being incarcerated in this genteel, open-doored prison." When Sylvia Lodge, one of the protagonists in Joan Barfoot's 2009 novel "Exit Lines" decides to move into the Idyll Inn, a retirement lodge in a small city somewhere in Canada, she is aware of the fact that this transition may be the last time she moves house in her life—unless she has to relocate from the retirement lodge to a nursing home, "the next step downwards en route to incapacity's

basement",² as she cynically puts it, using the common spatial metaphor of aging as decline. "Currently, nursing homes signal failure—of old people to remain independent and of family members to provide adequate care", Sally Chivers argues and continues, "nursing homes invite fear partly because they house a conglomeration of what people often dread about old age. If old age were not necessarily to conjure up negative opinion, nursing homes may, in turn, not seem or be as threatening".³

The fears Chivers addresses are reflected and processed in literature and film, and fictional representations of institutionalized eldercare are currently booming. When care homes are represented in novels or films, such depictions usually place an emphasis on the fact that such a home is more than simply a building or residence. Rather, it is "a micro-complex of architectural, administrative, financial, clinical, familial, symbolic, and emotional interactions and power relations". In literature and film, the care home often serves as a symbol, a spatial metaphor for the experience, fears, and uncertainties associated with old age. Used as a setting or spatial frame, the care home illustrates the marginalized social position of old age ("over the hill" being one such position). The threat of ending up as inmates of the "halfway houses' between society as we know it and the cemetery" has been mirrored in literary texts since the late 1960s and has become increasingly common up until today. The genre of the care-home novel is currently flourishing, reflecting the wide variety of care-giving models that range from prison-like, infantilizing, and even abusive institutions to hotel-like retirement facilities with luxurious amenities and responsible caregivers. However, texts depicting the home as a place of confinement still dominate the market. The "horrible home", with its parallels to the Gothic novel and the sublime, has become a predominant topos in literary texts, while fiction and film that reflect the increasing variety of today's eldercare options, including its positive sides, have only slowly begun to appear. Today, nursing homes still represent a focal point for society's fear of aging. They are commonly described as terminal places from which there is no exit but death. In recent years, however, the question of how and where to live in old age has become more relevant than ever due to changing demographics:

"In 2011, the first of the baby boom generation reached what used to be known as retirement age. And for the next 18 years, boomers will be turning 65 at a rate of about 8,000 a day. As this unique cohort grows older, it will likely transform the institutions of aging—just as it has done to other aspects of American life. Will boomers redefine this life stage, or will it redefine them?" 6

¹ Joan Barfoot, Exit Lines (Toronto 2009), 16.

² Ibid., 20.

³ Sally Chivers, From Old Woman to Older Women. Contemporary Culture and Women's Narratives (Columbus 2003), 58.

⁴ Stephen Katz, Cultural Aging (Peterborough 2005), 240.

⁵ Richard M. GARVIN / Robert E. BURGER, Where They Go to Die. The Tragedy of America's Aged (New York 1968), 11.

⁶ American Association of Retired Persons, quoted in Bryan Dooley, Profitable investing in an ageing world, in: The Royal Gazette (18th March 2014), http://www.royalgazette.com/article/20140318/BUSINESS/140319777 (04.05.2017).

As the website of the American Association of Retired Persons (AARP) informs us, new forms of eldercare are emerging, and the image of a hospital- or prison-like institution that focused primarily on the management of the old body in terms of a medical model is gradually being replaced by images of modern and comfortable homes that put personalized care and individual needs first. New housing schemes for the elderly are being conceptualized where "leisure and consumption play an important symbolic role in affirming personal identities". As Andrew Blaikie comments, the "land of old age" is being redeveloped in such a way that congregated housing units emulate the appearance of grand-deco hotels and explicitly offer a "hotel lifestyle", while traditional homes for the elderly serve a population of frail elders who are largely excluded from the new construction of the life course and become "marginalized relics".8 Which type of care-giving is suitable, affordable, and accessible for an individual depends, however, on a plethora of parameters that are to a large extent related to aspects of the traditional matrix of "race, class, gender, age, and able-bodiedness".9

Since the emergence of the public old age home in the early decades of the twentieth century, theories of aging as well as concepts of care-giving have changed, yet the "nursing home specter" still lingers on in the collective memory of North American societies. It has been perpetuated, but also challenged, in many novels, plays, short stories, and films that currently mushroom on the literary market: the number of texts dealing with the complexity of housing the oldest old has increased rapidly on both sides of the Atlantic. The last decades have seen a boom in fiction and films set in care homes, indicating that a new sub-genre is emerging: that of the care home narrative, a category which encompasses a large variety of texts including comedy, drama, crime stories, slap stick "geezer lit mystery"/"geezer noir" stories, and novels that Barbara Frey Waxman calls "Reifungsromane", 10 novels of ripening, in which the authors portray their heroes and heroines "as forging new identities or reintegrating fragmented old ones and as acquiring the self-confidence, self-respect, and courage to live the remainder of their lives fully and joyously".11

In her 2010 book "Figurenmodelle des Alters in der deutschsprachigen Gegenwartsliteratur", 12 Miriam Seidler asks whether the care home novel, a type of novel which is primarily associated with places of physical and mental decline, could spark any interest in readers. 13 Six years later, we have a clear affirmative answer: Authors employing the care home as a setting and/or theme have touched a nerve because fiction and films that deal with institutions of longterm care have become increasingly popular, reflecting the growing public interest in topics

⁷ Andrew Blaikie, Ageing and Popular Culture (Cambridge 1999), 175.

⁹ For an excellent analysis of how the material environments of retirement and assisted living communities "frame" their residents in ways that have deep implications for elder identities, identity management, and cultural citizenship (10) especially with regard to class, see Meredith Green Kuhn, The Eye of Beauty. Creating a Place for Elite and Aging Elders, unpublished PhD Dissertation (University of Arizona 2008), http://arizona.openrepository. com/arizona/bitstream/10150/193736/1/azu etd 2700 sip1 m.pdf (11.01.2017).

¹⁰ Barbara Frey WAXMAN, From the Hearth to the Open Road. A Feminist Study of Aging in Contemporary Literature (New York 1990), 2.

¹¹ Barbara Frey Waxman, From "Bildungsroman" to "Reifungsroman". Aging in Doris Lessing's Fiction, in: Soundings. An Interdisciplinary Journal 68/3 (1985), 318-334, here 320.

¹² Miriam Seidler, Figurenmodelle des Alters in der deutschsprachigen Gegenwartsliteratur (Tübingen 2010).

¹³ Ibid., 316.

related to aging and old age. In Germany, Miriam Seidler was the first to explicitly theorize the "care home novel" ("Pflegeheimroman") as a distinct and newly emerging genre. Although her classification in "closed" and "open" care home novels—novels which are entirely set in care homes and those that only partly play within such institutions—only minimally contributes to a better understanding of how such narratives construct old age, in her chapter, Seidler offers a concise overview of the genre in German literature, and addresses questions that are equally useful for an analysis in the context of North American literature. We may ask: Why is this newly emerging genre gaining popularity so quickly? What are the discourses that inform such texts?

In the North American context, Sally Chivers in "From Old Woman to Older Women" first analyzed texts set in care homes in her book chapter "'Here, Every Minute Is Ninety Seconds'. Fictional Perspectives on Nursing Home Care",¹⁴ implicitly pointing out the emergence of the genre by analytically juxtaposing several North American novels, all of which are set in long-term care institutions. In her recently completed PhD thesis entitled "Long-Term Caring. Canadian Literary Narratives of Personal Agency and Identity in Late Life", Patricia Life argues that such a genre has recently been emerging in anglophone Canadian literature. ¹⁵ Analyzing several Canadian twenty-first century texts, Life acknowledges that nursing-home narratives have become "a recognizable genre, under the general umbrella of age narratives": ¹⁶

"[It is a genre] that begins with realism flavoured by the gothic, evolves into mystery edged by black humour, and finally transforms into fantasy with an undercurrent of grim awareness. I compare the image of the dreaded nursing home of mid-twentieth-century texts to its metamorphosed images in late twentieth- and early twenty-first-century texts, and I argue that authors are now beginning to combine narratives of fear of the nursing home, aging, and death with narratives of positive-aging and late-life agency. This mixture has culminated in the birth of new fantasy stories featuring successful escape from nursing homes and aging, although awareness of reality's grim truths also still lurks within them." ¹⁷

In my analysis of the genre's development, a post-doctoral book project ("Habilitation"), ¹⁸ I have come to similar conclusions, but disagree with Patricia Life with regard to the chronological changes she details. Although she is certainly correct in stating that earlier (i.e., mid-twentieth century) novels tended to present the care home as a dreadful place, an observation that is true for both Canadian and US American literature with Margaret Laurence's "Stone Angel" (1964)¹⁹ and May Sarton's "As We Are Now"²⁰ as respective examples, I am not entirely convinced that this is no longer the case in recent publications (see, e.g., John

¹⁴ Chivers, Woman, as in footnote 3, 59.

¹⁵ Patricia Life, Long-Term Caring. Canadian Literary Narratives of Personal Agency and Identity in Late Life, unpublished PhD thesis (University of Ottawa 2014), 4.

¹⁶ Ibid.

¹⁷ Ibid

¹⁸ Ulla Kriebernegg, Putting Age in its Place. Age, Space, and Identity in North American Anglophone Care Home Narratives, unpublished habilitation monograph (University of Graz 2015), accepted for publication (Heidelberg 2017).

¹⁹ Margaret Laurence, The Stone Angel (Chicago ³1993).

²⁰ May Sarton, As We Are Now (New York 1973).

Mighton's play "Half Life"²¹). Life argues that the changes in representation from hospital- or prison-like homes towards hotel-like facilities are paralleled by a development from a decline narrative to narratives of late-life agency:

"While in the past nursing-care institutions epitomised decline, I will argue that now they are often presented as sites where late-life individuals exert agency over their surroundings, further enrich and expand their personal identities, and avoid application of the decline narrative to their own lives. I will also show that early twenty-first-century texts have begun to add a surprising new narrative where residents have acquired so much agency that they are able to walk away from the nursing home and even from old age itself."22

It is certainly true that care-giving institutions have traditionally been linked to a cultural imaginary of old age as a state of decline, but Life's claim rests upon the assumption that novels which present the care home as a prison-like institution do not allow for or transport narratives of late-life agency. As my analysis shows, however, this assumption cannot be confirmed. Whereas on the surface, narratives set in homes that are presented as "total institutions",23 to use Erving Goffman's term, may at first seem to symbolize decline, they often subvert and challenge ageist stereotypes and decline narratives fervently. They do so by offering striking individual narratives of self-determination and agency, representing escape stories or novels set in luxurious retirement lodges. Read as "Reifungsromane"24 or "Vollendungsromane", 25 they narrate resistance, and sometimes even progress, despite adverse conditions.

When almost 100-Year-Old People Climb Out of Windows and Disappear: The Care Home Novel as Road Narrative

When characters walk away from the care home—the escape narrative being a recently emerged sub-genre, as Life rightly observes—this can definitely be interpreted as a sign of self-determination and agency. While newspaper reports sometimes cover incidents of residents who suffer from dementia and walk away unintentionally and accidentally, the escapes narrated in such literary texts are always well planned. Examples of such escape narratives are Clive Edgerton's "Lunch at the Piccadilly", ²⁶ Sarah Gruen's "Water for Elephants", ²⁷ Janet Hepburn's "Flee, Fly, Flown"28 and Oscar Casares's "Amigoland".29 Interestingly, however, it

²¹ John Mighton, Half Life (Toronto 2005).

²² Life, Long Term Caring, as in footnote 15, 4.

²³ Erving GOFFMAN, Asylums. Essays on the Social Situation of Mental Patients and Other Inmates (Garden City, NY 1961), xiii.

²⁴ WAXMAN, Hearth, as in footnote 10, 2.

²⁵ Constance ROOKE, Old Age in Contemporary Fiction. A New Paradigm of Hope, in: Thomas R. Cole / David Van Tassel / Robert Kastenbaum, eds., Handbook of the Humanities and Aging (New York 1992), 241-57, here 245.

²⁶ Clive Edgerton, Lunch at the Piccadilly (New York 2004).

²⁷ Sara Gruen, Water for Elephants (Toronto 2007).

²⁸ Janet Hepburn, Flee, Fly, Flown (Toronto 2013).

²⁹ Oscar Casares, Amigoland (Boston 2009).

is quite irrelevant for the escapees whether their institution is portrayed as a prison-, hospital-, or hotel-like facility. What really matters and usually triggers protagonists' ideas to run away is that they do not feel "at home" in their respective institutions. Why this is the case depends on a variety of aspects. Genre conventions (prison narrative, escape story, quest) definitely play a large role in the protagonists' degree of self-determination. However, the underlying assumption in all these works is that there is a place where we feel "at home".

Long-term care escape narratives can be read as constitutive of an activity narrative, which helps defeat the nursing home specter by promoting a new narrative of resistance. Their protagonists are "declining to decline" and take control of their own destiny. They position themselves as "third agers", rather than "fourth agers", and show readers that even nursing home residents still have hope. Such affirmative narratives explain the popularity of stories such as "The Hundred-Year-Old Man Who Climbed Out of the Window and Disappeared" by Swedish author Jonas Jonasson.

The characters who escape confinement are struggling to acquire a new kind of subjectivity.³² Their spiritual and physical journeys change them forever and challenge the notion of old age as being static and immobile. Thinking about the protagonists' physical and spiritual mobility is one way of theorizing the connections between age, gender, and spatiality. "Lack of movement is characteristic of decrepit age", Kathleen Woodward argues: "If movement bespeaks life, immobility—lack of movement—is akin to death, and inertia verges dangerously on the inert."³³ It can be argued that escape narratives, therefore, counteract the myth of immobility in old age and celebrate the protagonists' resistance to the inertia forced upon them by institutional life.

Horror, Hospital, Hotel, or Home?

The care home novel borrows elements and themes from several other genres. The previously mentioned escape narratives, for instance, are often modeled after road movies. Comedy and romance offer other templates, for instance in Joyce Magnin's "Blame It on the Mistletoe: A Novel of Bright's Pond". Another popular genre is detective fiction, in which elderly residents often slip into the role of the investigator. A prime example is the "geezer-lit mystery" series invented by Mike Befeler, the author of six books featuring "Paul Jacobson, a crotchety octogenarian amateur sleuth", three of which involve long term care institutions, "Retirement Homes Are Murder". Care Homes Are Murder", and "Nursing Homes Are Murder".

³⁰ Margaret Morganroth Gullette, Declining to Decline (Charlottesville 1997).

³¹ Jonas Jonasson, The Hundred-Year-Old Man Who Climbed Out Of The Window And Disappeared (London 2012).

³² Cf. Tanu P. Uteng / Tim Cresswell, eds., Gendered Mobilities (Aldershot 2008), 1–12, here 2.

³³ Kathleen Woodward, Instant Repulsion. Decrepitude, The Mirror Stage, and The Literary Imagination, in: Kenyon Review 5/4 (1983), 43–66, here 53.

³⁴ Joyce Magnin, Blame It On the Mistletoe. A Novel of Bright's Pond (Nashville 2011).

³⁵ Mike Befeler, Retirement Homes Are Murder (Waterville 2007), back cover.

³⁶ Ibid.

³⁷ Mike Befeler, Care Homes Are Murder (Waterville 2013).

³⁸ Mike Befeler, Nursing Homes Are Murder (Waterville 2014).

Resident-detectives also play a central role in M. Scott Peck's "A Bed By the Window. A Novel of Mystery and Redemption", 39 James Moore's "They Should Live So Long"40 and Al Stevens's "Nursing Home Ninjas", 41 suspense stories in which a band of vigorous seniors take it upon themselves to find out who is behind the sudden and unusually high death rate in patients and employees.

Horror narratives are almost as popular as "care-home whodunits". The fourth age as an expression of the uncanny is presented in stories where the oldest old are featured as the "living dead", existing as zombies in a timeless limbo state. This horror setting corresponds to the realm Hazan terms the "twilight zone of human existence" 42 when he talks about the final stages of life in old age. In such horror novels, the "fourth age" is represented as a time of suffering, and is the true horror that haunts newly arrived inmates, who have not yet been initiated into the terrors of the nursing home. The mysteries driving the plot in such novels are usually resolved with recourse to slapstick and comic relief, as in Joe R. Lansdale's short story and movie "Bubba Ho-Tep" in which Elvis Presley meets John F. Kennedy in a nursing home where they have to defeat a "redneck mummy". Other novels containing horror elements are "The Tides" by Melanie Tem, winner of the Bram Stoker Award, or "The Nursing Home" Home by James J. Murphy III., books whose covers feature creepy images of haunted castles, the grim reaper, and the undead. Here, the "nursing home specter" looms large as an expression of the threatening forces associated with old age that need to be kept at bay. Eudora Welty's short story "A Visit of Charity" (1941) is an early example that "borrows repeatedly from the arsenal of the gothic", 47 as Rüdiger Kunow argues, representing the aged "as alien, as totally Other". 48

The Care Home as Prison

One of the predominating themes in the care home novel is that of the home as a prison. In general, it can be said that care home narratives tackle questions of life-course identity and old age, and that a movement to or within the space of the care home is often used to signify transition, change, or crisis. As in the boarding school novel, a character's loneliness and his or her difficulty to cope with a new phase of life away from "home" is placed in the foreground. The nursing home, like the boarding school, is often depicted as a microcosm of society—a disciplinary institution that is often run by overbearing and despotic administrators who rule what

³⁹ M. Scott Peck, A Bed by the Window. A Novel of Mystery and Redemption (London 1994).

⁴⁰ James Moore, They Should Live So Long (Lincoln, NE 2001).

⁴¹ Al Stevens, Nursing Home Ninjas (Waterville 2013).

⁴² Haim HAZAN, Beyond Dialogue. Entering the Fourth Space in Old Age, in: Ricca Edmondson / Hans-Joachim von Kondratowitz, eds., Valuing Older People. A Humanist Approach to Ageing (Bristol 2009), 91-104, here 96.

⁴³ Joe R. Landsdale, Bubba Ho-Tep (San Francisco 2003).

⁴⁴ Melanie Tem, The Tides (New York 1999).

⁴⁵ James J. Murphy III., The Nursing Home (Shrub Oak, NY 2009).

⁴⁶ Eudora Welty, A Visit of Charity, in: Martin Kohn / Carol C. Donley / Delese Wear, eds., Literature and Aging. An Anthology (Kent, OH 1992), 331-335.

⁴⁷ Rüdiger Kunow, The Coming of Age. The Descriptive Organization of Later Life, in: Alfred Hornung / Rüdiger Kunow, eds., Representation and Decoration in a Postmodern Age (= American Studies 94, Heidelberg 2009), 295-309, here 300.

⁴⁸ Ibid., 301.

is often depicted as a panoptical institution in Michel Foucault's sense by using discipline and punishment. In addition to being subject to the institution's regulations, the inmate is also subject to the dynamics of a small social group whose rules have yet to be understood by the newcomer.

The space of the care home, which is at the nexus of public and private, rarely offers space for privacy, and it is difficult for characters who feel lonely and powerless to create any counter-worlds or spaces of agency in which they can create a sense of self-determination or where they can feel "at home". Some care home narratives address this dilemma. One of the central topics in all care home narratives is the question of what it means to be "at home". The institution of the care home, often depicted as a trivialized simulacrum version of home, reveals the difficulties inherent in defining what "being at home" means. By narrating the care home as a professionally constructed home, this existential dimension is foregrounded, especially since moving to a care-giving institution is often depicted as a character's last move during their lives. Against this backdrop, elderly protagonists have to challenge and fight against, sometimes subvert, institutional constraints in order to maintain or renegotiate their sense of self, and regain their independence and agency. In some novels, this struggle may go hand in hand with the need to transgress borders and defy rules and regulations in order to resist becoming a "patient". Tim Sandlin's "Jimi Hendrix Turns Eighty". 49 or Paul Quarrington's "King Leary"⁵⁰ are excellent examples of such narratives. As opposed to boarding school novels where the transitional age of adolescence is highlighted, an age that leads to maturity and adulthood, care home narratives often deal with protagonists' struggle against the transition from adulthood into the culturally constructed state of senescence, and highlight the difficulty of remaining "adult" in the sense of maintaining self-determination and independence. Residents are often victimized and infantilized in such narratives, and the grade of senescence is very often expressed through space: Moving to the next floor in a care home often signifies moving further away from adult life, and eventually into oblivion. The space of the home can be experienced as limiting and confining, but also serves as a space of protection and redefinition of a protagonist's self, such as in Todd Johnson's "The Sweet By and By", 51 Lola Lemire Tostevin's "The Other Sister", 52 Joan Barfoot's "Exit Lines", 53 or Shani Mootoo's "Cereus Blooms at Night".54

⁴⁹ Tim Sandlin, Jimi Hendrix Turns Eighty (Detroit 2007).

⁵⁰ Paul QUARRINGTON, King Leary (Toronto 1987).

⁵¹ Todd Johnson, The Sweet By and By (New York 2009).

⁵² Lola Lemire Tostevin, The Other Sister (Toronto 2008).

⁵³ Barfoot, Exit, as in footnote 1.

⁵⁴ Shani Mootoo, Cereus Blooms at Night (New York 1996).

"Don't Let Them Steal Your mind": May Sarton's "As We Are Now"

As a prominent example, I will in the following briefly sketch how American novelist May Sarton in "As We Are Now" describes life in a nursing home. "I am in a concentration camp for the old, a place where people dump their parents or relatives exactly as though as it were an ash can", 55 May Sarton has her protagonist Caro Spencer complain in her diary, also using the over-exaggerated and inappropriate image of the concentration camp⁵⁶ to express her extreme frustration about the poor standards of the home and her treatment, but also, and more importantly, with her suffering in the foreign and forgotten place. Sarton calls "As We Are Now" "her 'J'accuse" in which she articulates her indictment of society's inhumane treatment of dependent elders. Sarton also offers an explanation for difficulties encountered when writing about old age, and employs a spatial metaphor to emphasize the binary opposition of young and old when she writes, "[t]he trouble is that old age is not interesting until one gets there, a foreign country with an unknown language to the young, and even to the middleaged".58 The strangeness of the other country, which is of no importance until one enters it, is additionally reinforced by the fact that the old are not intelligible to the young. Sarton describes the problem of the binary construction of young and old in her novel, set in the Twin Elms nursing home, a space that houses those who are perceived as "other". The journal Caro Spencer keeps is, as Barbara Frey-Waxman puts it, "a vehicle that transports us to the foreign country of dependent senescence and translates its language into terms that adult readers, regardless of age, can comprehend".⁵⁹ In "As We Are Now", Sarton expresses the inability to communicate the experience of old age to those who have not yet reached the "fourth age", an "era of final dependence, decrepitude, and death". 60 The experience of old age, she implies, cannot be passed on via a common language. Sarton uses a spatial metaphor, the "foreign country", to describe this wordless realm. Caro Spencer feels entrapped both in her own aging body and the dreadful, prison-like nursing home: "I am walled in",61 she describes her situation, "[t]he walls close in on every side. I do not remember things very clearly."62

Caro Spencer's diary (that she eventually hides in a fridge before setting fire to the institution and thus committing suicide) is equated with an open letter that rebels against the inhumane conditions under which old people are forced to live in nursing homes. Her journal is a "life-testimony" that she wants to use to reach out to the world, bringing the perpetrators

⁵⁵ SARTON, As We Are Now, as in footnote 20, 9.

⁵⁶ In "Understanding May Sarton", Mark K. Fulk explains that Sarton frequently uses the Holocaust as a subtext in her writing (Mark K. Fulk, Understanding May Sarton [Columbia 2011], 49, 98, 101). This comparison seems particularly out of place because Sarton refers to concentration camps in other contexts throughout the novel, making it clear that she is well aware of the abject horror of such places. While such comparisons are not uncommon (Joseph P. Shapiro, No Pity. People with Disabilities Forging a New Civil Rights Movement [New York 1993], 237) and extend back to 1930, they are clearly questionable.

⁵⁷ The term 'J'accuse' is attributed to French writer Émile Zola who wrote an open letter in 1898 in the newspaper "L'Aurore" in the context of the Dreyfus affair.

⁵⁸ SARTON, As We Are Now, as in footnote 20, 23.

⁵⁹ WAXMAN, Hearth, as in footnote 10, 140.

⁶⁰ Peter Laslett, A Fresh Map of Life. The Emergence of the Third Age (Cambridge, Mass 1991), 4.

⁶¹ SARTON, As We Are Now, as in footnote 20, 111.

⁶² Ibid., 115.

to trial, as Shoshana Felman theorizes the act of witnessing with regard to the act of writing and reading. "A 'life-testimony' is not simply a testimony to a private life, but a point of conflation between text and life, a textual testimony which can *penetrate us like an actual life*. [...] something crucial takes place which is of the order of a *trial*" (italics in the original). Caro Spencer appoints herself as a witness, and speaks for others to others.

Caro Spencer rebels against the institutional pressures that threaten, as Goffman expresses it, her moral career. In fact, many passages in the novel can be read as descriptions from the inside of a total institution, as if to illustrate Goffman's case studies further: "There is a connection between any place where human beings are helpless, through illness or old age, and a prison. It is not only the heroic helplessness of the inmates, but also what complete control does to the nurses, guards, or whatever", 65 and "[i]f keepers are corrupted by having absolute power, what about those they keep? We learn to ingratiate ourselves", 66 Caro Spencer writes in her diary. "So if I am punished, I deserve it." She has already internalized her guilt—she is guilty of being old.

From the first week of her institutionalization on, Caro tries to defend her sense of self against the humiliating mortification she experiences in the home. Once, after speaking up against the nurses' inhumane treatment of a fellow resident, she is locked in a dark room, which is a devastating experience for her: "They shatter me. I am not worthy, a leper—an old woman without control over herself."68 She is well aware of the processes that endanger her identity ("Don't let them steal your mind"69) and tries to resist being "mortified"70 by writing down her thoughts and experiences as best she can in her little book: "I am forcing myself to get everything clear in my mind by writing it down so I know where I am. There is no reality now except what I can sustain inside me. My memory is failing. I have to hang on to every scrap of information I have to keep my sanity, and it is for that purpose that I am keeping a journal. Then if I forget things later, I can always go back and read them here."71 Caro knows she cannot fully trust herself: "The borderline between reality and fantasy is so thin in this confined, dreadfully lonely place."72 It also becomes clear to the reader that Caro is not always a reliable narrator, and that she oscillates between reality and imagination, rationality, and senility.⁷³ Whether her narration is an accurate description of the nurses' sadistic dictatorship or if this is how Caro conceives and interprets what could merely be sloppiness and carelessness on the nurses' part is not important. What is more important is that the novel reveals the

⁶³ Shoshana Felman, Education and Crisis, Or the Vicissitudes of Teaching, in: Shoshana Felman / Dori Laub, eds., Testimony. Crises of Witnessing in Literature, Psychoanalysis, and History (New York 1991), 1–56, here 1.

⁶⁴ Cf. ibid., 3.

⁶⁵ SARTON, As We Are Now, as in footnote 20, 49.

⁶⁶ Ibid., 74.

⁶⁷ Ibid., 75.

⁶⁸ Ibid., 42.

⁶⁹ Ibid., 29.

⁷⁰ GOFFMAN, Asylums, as in footnote 23, 14.

⁷¹ SARTON, As We Are Now, as in footnote 20, 10.

⁷² Ibid., 26.

⁷³ Cf. Roberta Maierhofer, Salty Old Women (Essen 2003), 331.

significance of her maintaining integrity in that she maintains her identity in life and death and counteracts the fragmentation of self. Caro's journal serves as her map (a repeated image) that allows her to navigate the borderland between rationality and imagination: So, in this way, this path inward and back into the past is like a map, the map of my world. If I can draw it accurately, I shall know where I am. Tagree with Kathleen Woodward, who reads this passage of knowing where I am as a rejection of paternalism and the adoption of a conscious political position. By locating herself on this map, Caro Spencer strives to make the horrible conditions of her existence at Twin Elms, but also the way old people are treated in general, accessible to the public. Caro equates her experience of oppression to that of the African Americans' resistance: I have my own ideas of what those beyond the pale do—the blacks, for instance. They finally come to see that violence is the only answer to oppression. They make bombs, Caro states. Her diary elads to an act of *guerilla warfare* inside the closed world of Twin Elms and, Spencer hopes, may have an influence outside it, Moodward notes. Not death itself is horrible, but a life without dignity preceding death, and this is why Sarton argues for a dignified way of aging in spite of physical and mental restrictions.

Representations of Care-Givers in Film and Fiction

Whereas the previously mentioned texts center around protagonists who are themselves residents/patients in care homes, the last decades have also witnessed the production of texts written from the perspective of adult children or other care-givers, who struggle with decisions of putting loved ones into nursing homes. Some of them are fictional, such as Michael Ignatieff's "Scar Tissue", 80 and some are autofictional or autobiographical, such as Dudley Clendinen's "A Place Called Canterbury". 81 Autobiographical / creative non-fiction accounts also include those of nurses' aides and nurses, for instance "Harvest Moon" by Sallie Tisdale or "Endnotes" by Ruth Ray. In addition, a vast number of advice columns, manuals, how-to-guides and self-help books and specialist reports, as well as a large number of care home ethnographies, are available.

^{74 &}quot;Deutlich wird im Roman, dass es vielmehr darum geht, die Integrität der Identität im Alter und im Tod zu bewahren und der Fragmentarisierung des Selbst entgegenzuwirken" (ibid.).

⁷⁵ SARTON, As We Are Now, as in footnote 20, 10.

⁷⁶ Kathleen Woodward, May Sarton and Fictions of Old Age, in: Janet M. Todd, ed., Gender and Literary Voice (New York 1980), 108–124, here 122.

⁷⁷ SARTON, As We Are Now, as in footnote 20, 107.

⁷⁸ Woodward, May, as in footnote 76, 122.

⁷⁹ Cf. Maierhofer, Women, as in footnote 73, 328.

⁸⁰ Michael Ignatieff, Scar Tissue (New York 1993).

⁸¹ Dudley CLENDINEN, A Place Called Canterbury. Tales of the New Old Age in America (New York 2008).

⁸² Sally Tisdale, Harvest Moon (New York 1987).

⁸³ Ruth Ray, Endnotes (New York 2008).

Only slightly more than 5% of the 65+ population in North America live in long-term care facilities, standard about 70% of these people are women. The novels, short stories, plays, poems, and films I have analyzed in my research mirror this demographic data not only with regard to gender, but also in terms of race and class, so because they almost exclusively depict relatively privileged white residents as recipients of care. Changing demographics show, however, as an increasing proportion of the population ages, an ever increasing number of persons will be in need of professional care. This will also affect demographics within caregiving institutions, and culturally competent care-giving may become even more important in the coming years than it has been in the past. Each of the population in North America live in long-term care facilities, and the stories of the population ages, an ever increasing number of persons will be in need of professional care. This will also affect demographics within caregiving institutions, and culturally competent care-giving may become even more important in the coming years than it has been in the past.

Kathleen Woodward addresses the invisibility of caregivers in her essay "A Public Secret. Assisted Living, Caregivers, Globalization", arguing that they are "shamefully unacknowledged by our society".89 She renders this "scandalous public secret" visible by exploring the

⁸⁴ In Canada (2011), 224.280 residents were living in nursing homes, chronic care, long-term care hospitals and residences for senior citizens. This corresponds to 4.5% of the 65+ population. 2.6% of the 65+ population (127.925) lived in retirement communities. Among the age group 65 to 69, about 1% lived in special care facilities in 2011; among seniors aged 85 and over, the proportion was 29.6% (Statistics Canada, Living Arrangements of Seniors. Families, Households and Marital Status, Structural Type of Dwelling and Collectives, 2011 Census of Population, 5, 7, http://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-312-x/98-312-x2011003 4-eng. pdf [13.01.2017]). The report "A Profile of Older Americans: 2013" states that "a relatively small number (1.5 million) and percentage (3.5%) of the 65+ population in 2012 lived in institutional settings such as nursing homes (Administration of Aging [Administration for Community Living, U.S. Department of Health and Human Services], A Profile of Older Americans: 2013, 5, https://aoa.acl.gov/Aging Statistics/Profile/2013/index.aspx [23.03. 2017]). According to the report "Long-Term Care Services in the United States: 2013 Overview", in the United States on any given day in the year 2012 there were "1,383,700 residents in nursing homes, and 713,300 residents living in residential care communities" (National Center of Health Statistics [Center of Disease Control and Prevention, U.S. Department of Health and Services], Long-Term Care Services in the United States: 2013 Overview [= Vital and Health Statistics 3/37 (2013)], 26, https://www.cdc.gov/nchs/data/nsltcp/long term care services 2013.pdf [23.03.2017]). Assuming a US population of roughly 314.000.000, this would mean that in 2012, 0.44% of the total population lived in nursing homes and 0.23% lived in residential care communities.

⁸⁵ Ibid., 40.

^{86 &}quot;Non-Hispanic white persons accounted for at least three-quarters of users in all long-term care services sectors, except adult day services centers" (ibid., 34). More than 80% of American nursing home residents are White, whereas only ten percent are Black, three percent are Hispanic, and two percent are Asian (Zhanlian Feng et al., The Care Span. Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options, in: Health affairs 30/7 [2011], 1358–1365, here 1364, http://www.ncbi.nlm.nih. gov/pmc/articles/PMC3785292/pdf/nihms-506106.pdf [13.01.2017]). Likewise, Canadian nursing homes are populated by a majority of White, female customers (Chandra Mehrotra / Lisa S. Wagner / Stephen Fried, Aging and Diversity. An Active Learning Experience [New York 22009], 227).

⁸⁷ The report "Long-Term Care Services in the United States: 2013 Overview" says that "recent projections estimate that over two-thirds of individuals who reach age 65 will need long-term care services during their lifetime. Largely due to aging baby boomers, the population is expected to become much older, with the number of Americans over age 65 projected to more than double, from 40.2 million in 2010 to 88.5 million in 2050 [...]. The oldest old [those aged 85 and over] are projected to almost triple, from 6.3 million in 2015 to 17.9 million in 2050, accounting for 4.5% of the total population (U.S. Census Bureau, 2012)" (National Center of Health Statistics, Long-Term Care, as in footnote 84, 3).

⁸⁸ Rüdiger Kunow, Aging Between Two Cultures. Migrants and Old Age, public lecture, C.IAS Brown Bag Lunch Series, University of Graz, Austria, 07.11.2012.

⁸⁹ Kathleen Woodward, A Public Secret. Assisted Living, Caregivers, Globalization, in: International Journal of Ageing and Later Life 7/2 (2012), 17–51, here 21.

representation of caregivers and old people together, suggesting that "one of the most effective modes of advocating for changes in public policy is engaging in people's understanding through stories and images".90 Woodward advocates a new way of representing care-giving—a way that focuses on both the care-giver and old person: "Isolated and separate, caregivers and elders are vulnerable. Together, caregivers and elders are strong. [...] We need scholars without borders in age studies, scholars who understand that it is important not just to think globally and act locally but also to think locally and act globally—and who will call attention to the public secret of the caregivers of frail elders."91

Many care home narratives reflect an increasingly commonly expressed wish for social participation, and in most novels, a resident / patient / inmate is the narration's prime focalizer. The secret Woodward alludes to is in fact publicized in several fictional accounts. Although the abusive "tyrant nurse" modeled after Nurse Ratchet in Ken Kesey's "One Flew Over the Cuckoo's Nest"⁹² can be described as a stock character in many care home novels and films, the representation of nurses is, as I will briefly show in the following, much more nuanced than one might assume. However, the authoritarian nurses are still prevailing, for instance in above-mentioned May Sarton's "As We Are Now".93

There are, however, also counter narratives that depict responsible care-givers. Trinidadian-Canadian author Shani Mootoo's "Cereus Blooms at Night" is an example of nursing home narratives that challenge the assumption that such institutions are merely sites of decline. Through the narrative of Tyler, a homosexual male Afro-Caribbean nurse at Paradise Alms House on the Caribbean island of Lantanacamara, readers learn the life story of his patient, an old woman named Mala Ramchandin. The almshouse, literally a "home over the hill", and its adjacent garden constitute the setting of the story's frame narrative and function as a productive literary "third space" in which both Mala's and Nurse Tyler's life course narratives can be re-written, enabling the marginalized characters to come to terms with their traumatic pasts. The interpersonal and intergenerational encounters that are portrayed in the novel show the importance of nurturing relationships and mutual listening and understanding in order for the characters to develop, as well as for readers to be able to reimagine care homes differently. As Sally Chivers puts it, the depiction "encompasses a reimagination of the possibilities of what most people think of as a last resort in frail old age". 96 Mootoo's novel is one of the few books that place the caregiver in a prominent position. Even though it is not a documentary or an auto/biographical text, a genre which, as Kathleen Woodward argues, might be better suited than fiction to press for changes in social policy because it "draw[s] us closer to what is real", 97 the novel calls attention to the "public secret" of the caregivers, lifting them and the elderly out of "the one-dimensional frame of victimhood. Isolated and separate, caregivers and elders are

⁹⁰ Ibid., 17.

⁹¹ Ibid., 46.

⁹² Ken Kesey, One Flew Over the Cuckoo's Nest (New York 1962).

⁹³ SARTON, As We Are Now, as in footnote 20.

⁹⁴ Моотоо, Cereus, as in footnote 54.

⁹⁵ Homi K. Bhabha, The Location of Culture (London-New York 1994), 37.

⁹⁶ Chivers, Woman, as in footnote 3, 77.

⁹⁷ WOODWARD, Secret, as in footnote 89, 46.

vulnerable. Together, caregivers and elders are strong", 98 Woodward maintains. Both Mala, the old woman, and Tyler, the homosexual male nurse, find a home in the liminal space of the Paradise Alms House.

Another example that centers around the figure of the caregiver is Edna Alford's short story cycle "A Sleep Full of Dreams".99 The stories are linked through a single narrator's perspective, mostly Nurse Arla's, which is refracted in an indirect, sometimes omniscient third-person narrative. "A Sleep Full of Dreams" traces Arla's personal development and her difficulties finding a voice of her own, while coming to terms with her ambivalent feelings towards her exhausting job as a nurse at Pine Mountain Lodge and the stigma that caring for the dying involves. She feels that "just by working with these old women, she carried some kind of curse, some contagion, some odour". 100 Like her charges, Arla is part of institutional regimes, rules, and discourses. The narrative successfully portrays her struggle to find an answer to her boyfriend's question "[i]f you're so upset about it, Arla, why don't you leave?" 101 Pine Mountain Lodge is represented as a threatening place to the elderly women's individual identities, but also challenges Arla's sense of self. She is conscious of the processes and power games at work in the institution, and through her encounters and relationships with the individual old women, she begins to critically reflect on her own life. Through her growing engagement with the women, she finds it increasingly difficult to deal with the central aspects of a nursing home: old age, dependency, and death. Arla's identification with her patients leads her to the painful discovery that she, too, is aging and might one day end up in a similar situation. She questions her own norms and values, both in her capacity as a nurse as in her private life, especially her relationship with her boyfriend, David. As readers, we follow Arla's inner conflicts and personal development until one day, at the end of the book, she decides to quit her

As my analysis has shown, the voice of the care-giver is not as frequently neglected in care home narratives as one would assume. I, therefore, argue that such representations and their analyses, together with an awareness of the problematic situation Woodward addresses, have the potential to change the way we care for frail elders, including raising consciousness for the unjust conditions experienced by the caregivers described above.

⁹⁸ Ibid., 46

⁹⁹ Edna Alford, A Sleep Full of Dreams (Lantzville 1998).

¹⁰⁰ Ibid., 19.

¹⁰¹ Ibid., 21.

Representations of the Care Home in Film Adaptations

During the past two decades, and especially the last few years, movies have also begun to play an important role, adding to the genre of the care home narrative. Most of them have been based on novels, plays, or short stories, such as Kari Skogland's "The Stone Angel" which is based on Margaret Laurence's 1964 novel of the same title, 103 Sarah Polley's film "Away From Her". 104 which is adapted from Alice Munro's famous short story "The Bear Came Over The Mountain": 105 or Nicholas Sparks's novel "The Notebook". 106 which was made into a movie by the same name by Nick Cassavetes. "Away From Her" and "The Notebook" are dementia narratives that deal with the meaning of true love in old age while "The Stone Angel", a family saga, portrays the struggle of a woman at the end of her life to reconcile herself to her past. It tells the life story of 90-year old Hagar Shipley who runs away when her son wants to assign her to a nursing home. Other movies hat center on efforts to keep characters out of long-term care include "Iris", 108 "Cloudburst", 109 "Up", 110 "Robot and Frank", 111 and "The Savages". 112

Two recent and very popular British movies that address the question of where to spend the last years of one's life are John Madden's "The Best Exotic Marigold Hotel", 113 based on Debora Moggach's novel "These Foolish Things", 114 and "Quartet", 115 based on a play with the same title by Ronald Harwood. A variety of short films (e.g. McKenzie, "Rhonda's Party" 116) also deal with the topic of long-term residential care. Furthermore, a number of "cinema verité" documentaries have come out that portray life in the care home, including the award-winning

¹⁰² Kari Skogland, dir., The Stone Angel (DVD 2007).

¹⁰³ Laurence, Stone, as in footnote 19.

¹⁰⁴ Sarah Polley, dir., Away From Her (DVD 2007).

¹⁰⁵ Alice Munro, The Bear Came Over the Mountain, in: Id., Hateship, Friendship, Courtship, Loveship, Marriage. Stories (Toronto 1999), 275-323.

¹⁰⁶ Nicholas Sparks, The Notebook (New York 1996).

¹⁰⁷ Nick Cassavetes, dir., The Notebook (DVD 2004).

¹⁰⁸ Richard Eyre's movie "Iris" (2001) is based on John Bayley's memoires of his wife (John BAYLEY, Iris. A Memoir of Iris Murdoch [London 1998]; ID., Elegy for Iris. A Memoir [London 1999]).

^{109 &}quot;Cloudburst" premiered as a stage play in 2010 and was adapted by its author, Thom Fitzgerald, for the screen in 2011.

^{110 &}quot;Shady Oaks Retirement Village" is the care home featured in the animation films "Up" (2009 by Pete Docter) and "George & A.J." (2009), the bonus film narrating what happens to the two retirement home workers after witnessing Carl Fredricksen's house flying off in "Up".

^{111 &}quot;Robot and Frank" (2012) by Jake Schreiner tells the story of an ex-jewel thief whose increasing dementia causes his children to buy him a care robot that becomes his friend—and partner in crime. In the end, Frank moves to a nursing home in which all care-givers are robots.

^{112 &}quot;The Savages" (2008) is a film by Tamara Jenkins in which the central characters are a brother and sister who have to take care of their elderly father after his girlfriend passes away in Sun City, Arizona. They decide to relocate him to a care home in Buffalo, where he dies.

^{113 &}quot;The Best Exotic Marigold Hotel" (2012) by John Madden tells the story of a group of British pensioners who decide to 'outsource' their retirement to the less expensive and seemingly very exotic India. Instead of a luxurious palace, they arrive at a dilapidated hotel. However, they are all transformed by the shared experience, discovering that they are not too old to live and love.

¹¹⁴ Debora Moggach, These Foolish Things (London 2004).

¹¹⁵ Ronald Harwood, Quartet (London 1999).

¹¹⁶ Ashley McKenzie, dir., Rhonda's Party (2010), http://rhondasparty.ca (25.02.2016).

movie "Room 335"¹¹⁷ by Andrew Jenks, who decides as a young college student to move to a Florida senior residence for one summer; Brad Lichtenstein and Lisa Gildehouse's "Almost Home", ¹¹⁸ which chronicles the daily lives of staff and residents at Saint John's On The Lake, a retirement community in Milwaukee, Wisconsin, documenting the "Culture Change" movement that strives to improve quality of life for residents and staff; Jared Scheib's award-winning film "The Mayor", ¹¹⁹ which tells the stories of several octogenarian long-term care facility residents in Texas; and Gen Silent, ¹²⁰ a documentary that focuses on LGBT elders in care homes. The film "Penelope: The Documentary" deserves special mention because it is the capstone of the groundbreaking "Penelope Project", with an aim to "dramatically raise the bar on activities in long term care". ¹²² The film shows how residents, some with severe dementia or who are wheel-chair bound, collaborate with playwright Anne Basting and the Sojourn Theater to create "Finding Penelope", a play reinterpreting Homer's Odyssey to tell it from Penelope's point of view.

Who Gains Visibility in Cultural Representations of Care Homes, and Who Does Not?

The settings of care-home films and novels range from retirement lodges and assisted living facilities to nursing homes (a true categorization is difficult due to the lack of standardized terminology), and, thus, also include places where around-the-clock care is standard. While "illness narratives", including dementia narratives, have gained popularity as a genre in the second half of the twentieth century, 123 and include pathographies that end with the death of the narrator, the sick and dying oldest old are, interestingly, rarely represented in nursing home narratives. Although a few exceptions exist, such as in Canadian writer Edna Alford's short story cycle "A Sleep Full of Dreams", 124 protagonists who are frail, sick, in pain, or bedridden rarely are given a voice or position from which the action is narrated. Unlike in illness narratives, such characters are often only referred to as "the other" living in the "black hole" of an inaccessible closed ward, such as on the "second floor" in Alice Munro's short story "The Bear Came Over the Mountain", 125 or the "Advanced Living" wing in Margaret Atwood's tale "Torching the Dusties" where, the narrator assumes, "things are different. She hasn't wished to imagine exactly how different". 127 While statistics show that a large number of care-home

¹¹⁷ Andrew Jenks, dir., Room 335 (DVD 2006).

¹¹⁸ Brad Lichtenstein / Lisa Gildehouse, dir., Almost Home (DVD 2006).

¹¹⁹ Jared Scheib, dir., The Mayor (DVD 2011).

¹²⁰ Stu Maddux, dir., Gen Silent (DVD 2010).

^{121 371} Productions, Penelope (2013), http://371productions.com/work/penelope/ (25.10.2016).

¹²² Ibid.

¹²³ Cf. Heike Hartung, Ageing, Gender, and Illness in Anglophone Literature. Narrating Age in the Bildungsroman (= Routledge Interdisciplinary Perspectives on Literature, Basingstoke 2015), 10.

¹²⁴ ALFORD, Sleep, as in footnote 99.

¹²⁵ Munro, Bear, as in footnote 105, 309.

¹²⁶ Margaret Atwood, Torching the Dusties, in: Margaret Atwood, Stone Mattress. Nine Tales (London et al. 2014), 225–268.

¹²⁷ Ibid., 232.

residents need full time care due to various forms of dementia, frailty, and illness, the majority of literary and filmic representations of care homes—with exceptions—include depictions of elderly people who are more or less healthy, and one is sometimes left to wonder why such protagonists are portrayed as living in long-term care facilities at all. Some of them, especially those in care home detective stories, are still "third agers", pensioners without severe physical or mental ailments. While several dementia narratives have actually been written from an agent position, which aims to represent what is going on in the brain as memory slowly disintegrates (e.g., Lisa Genova's "Still Alice" 128), the "representational dilemma" 129 of depicting the frail and sick oldest old living in nursing homes has so far barely been tackled, and the oldest old are usually not developed into full-fledged characters. Heike Hartung approaches the difficulties related to representing frail old age from a narratological perspective in her monograph "Narrating Age. Ageing, Gender and Genre in Anglophone Literatures" and points to the "problem of narrating the unnarratable" 130 in dementia and illness narratives.

The absence of the oldest old in care home narratives may be read as pointing to the taboo of death in care home narratives, the "D-word", as Margaret Atwood's protagonist calls it in the short story "Alphinland": "[T]he D-word: it was there, it loomed over them like a huge advertising blimp, but to mention it would have been like breaking a spell."131 Julia Twigg's argument may also offer an explanation: She asserts that the proximity to death makes old age a cultural taboo. There is "little to say about the stage that precedes it [death]: old age. Death empties old age of meaning. [...] It is hard to invest the body in old age with a stronger sense of subjectivity, when old age itself is avoided as a topic, seen as having no meaning, or at least no meaning other than decay, decline and final absence". 132

Oldest age, decay, decline, and ultimately death also seem to be avoided in most care home narratives, even though the space of the care home itself triggers such associations. They become what Rüdiger Kunow terms an "impossible object", 133 "an object which does exist, but only as something that cannot (yet) be named, a gap or crevice inside the registers of representation". 134 Kunow, with reference to the term's origins in the words of Ernesto Laclau and Teresa de Lauretis, writes: "To call age an impossible object means that it is something which established discourses or hegemonic representational practices promise to describe, yet cannot do so."135

¹²⁸ Lisa Genova, Still Alice (New York 2009).

¹²⁹ Hartung, Ageing, as in footnote 122, 15.

¹³⁰ Ibid.

¹³¹ Margaret Atwood, Alphinland, in: Margaret Atwood, Stone Mattress. Nine Tales (London et al. 2014), as in footnote 125, 1-34, here 15.

¹³² Julia Twigg, The Body in Health and Social Care (Basingstoke-New York 2006), 50.

¹³³ Kunow, Coming, as in footnote 47, 306.

¹³⁴ Ibid.

¹³⁵ Ibid.

What Is It that We Can Gain from Literary Representations of the Space that Houses the Oldest Old?

Hannah Zeilig has formulated two questions in this respect. She asks, "is it feasible to extrapolate from literature in order to gain insight into other fields of inquiry? If so, what can be gained from literature, what is the type of information which it can yield?"¹³⁶ Zeilig's questions have in part been answered by Barbara Frey-Waxman who argues that literature "can take us out of ourselves and our usual settings, making us more conscious of our unexamined beliefs and assumptions and giving us new food for thought".¹³⁷ Because of their fictionality, stories can powerfully characterize the inner world of old individuals and "affirm the contradictions, complexity, and uncertainty that lie at the heart of the experience of aging".¹³⁸ While striving to understand fictional characters, we acknowledge them as being different from, but also similar to, ourselves at the same time; we recognize ourselves in them through a personal and a political act of understanding, as literary philosopher Martha Nussbaum asserts:

"It is for this reason that literature is so urgently important for the citizen, as an expansion of sympathies that real life cannot cultivate sufficiently. It is the political promise of literature that it can transport us, while remaining ourselves, into the life of another, revealing similarities but also profound differences between the life and thought if that other and myself and making them comprehensible, or at least more nearly comprehensible." ¹³⁹

Nursing home narratives draw, in one way or another, readers into the world of the care home, permitting them to identify with their protagonists in their struggles against institutionalization, or in their attempts to redefine themselves in a way that makes sense for them in a new environment. While it is clearly not the task nor the focus of sociological, gerontological, or medical texts to facilitate identification on the reader's part, understanding the "visceral prose" and aesthetics of literary texts can enable readers to identify with a literary character, and experience aging by proxy. This argument resonates with Nussbaum's claim that we as readers gain a better understanding of the world by "learning both to see the world, for a time, through their eyes and then reflecting as spectators on the meaning of what we have seen". As literary gerontologists, however, we can take the matter one step further, as Waxman argues. Literary texts, she maintains, "can affect whole societies and do important work for

¹³⁶ Hannah Zeilig, The Uses of Literature in the Study of Old People, in: Anne Jamieson / Sarah Harper / Christina R. Victor, eds., Critical Approaches to Ageing and Later Life (Philadelphia 1997), 39–48, here 40.

¹³⁷ Barbara Frey WAXMAN, Literary Texts and Literary Critics Team Up Against Ageism, in: Thomas R. Cole / Ruth E. Ray / Robert Kastenbaum, eds., A Guide to Humanistic Studies in Ageing. What Does It Mean to Grow Old? (Baltimore 2010), 83–104, here 83.

¹³⁸ Robert Yahnke, Representations of Aging in Contemporary Literary Works, in: Generations 17/2 (1993), 83–86, here 86.

¹³⁹ Martha C. Nussbaum, Cultivating Humanity. A Classical Defense of Reform in Liberal Education (Cambridge, Mass. 1997), 111.

¹⁴⁰ WAXMAN, Hearth, as in footnote 10, 18.

¹⁴¹ Martha C. Nussbaum, Poetic Justice. The Literary Imagination and Public Life (Boston 1991), 93.

social betterment, even when they are presenting sexist or ageist notions in their characters and plots, precisely because resisting literary critics will interrogate and undermine these sexist or ageist notions in the texts and raise general readers' awareness of how these damaging notions operate both in texts and in society". 142 In recent decades, not only the different types of care facilities have been increasing in North America, which are also mirrored in fictional works, but also the representation of elderly characters in film and fiction has significantly changed from "flat" to "fully round", as Anne Wyatt-Brown points out. 143 Cultural representations have the capacity, as Wyatt-Brown argues, "to create a picture of aging, one that most readers can easily understand and appreciate. Without literary gerontology, however, the representation might be one-sided, the view of the author and few others. Only by combining research with novels and memoirs can we begin to comprehend the varieties of aging experience in our time".144

Now, at the onset of the twenty-first century, the nursing home seems to have been firmly established as a setting, and its residents have been developed into central characters. These developments add weight to the argument that narratives that represent elderly protagonists living in long-term care institutions need to be addressed from the perspective of literary studies and age/aging studies. One of the few scholars who actually do that is Sally Chivers who refers to novels depicting institutional care by arguing that

"[t]hese depictions of institutional care, more than commenting on the possibilities of such facilities to provide improved care, demonstrate the complicated process of forming attitudes toward the frail old and help to counter the impetus to think of age as either positive or negative. They provide examples of how narrative fiction can offer a perspective on the individuality of elderly residents that differs from clinical interaction."145

As Chivers shows, it is important to re-imagine old age in order to reimagine structures of institutional care. In order to develop convincing arguments for such a paradigm change, however, it is also important to analyze why the nursing home specter still looms so large in our minds. Where does the deep-rooted cultural fear of care homes for the elderly come from, and why is it so deeply engrained in our minds?

¹⁴² WAXMAN, Texts, as in footnote 136, 88.

¹⁴³ Anne M. WYATT-BROWN, Resilience and Creativity in Aging. The Realms of Silver, in: Thomas R. Cole / Ruth E. Ray / Robert Kastenbaum, eds., A Guide to Humanistic Studies in Ageing. What Does It Mean to Grow Old? (Baltimore 2010), 55–82, here 57.

¹⁴⁵ CHIVERS, Woman, as in footnote 3, xlvi.

Conclusion

Defining old age as an uncanny and dangerous place also positions the care home as an uncanny site. Therefore, a re-imagination of care homes as sites of meaningful identity development in old age is crucial to be able to counteract ageism. Literary representations of care homes can encourage readers to engage in such redefinitions because many texts portray individuals who have the most important experiences at the latest stages of their lives, experiences which enable them to re-narrate their lives, and arrive at new and meaningful conclusions to their narratives despite, or perhaps even because of, their physical frailty. A re-conceptualization of eldercare through film and fiction also has the potential to challenge the "nursing home specter". "The figure of the 'nursing home', typically as a symbol of cultural failure and a fate worse than death, haunts representations of older adults across the popular culture spectrum, in television, magazines, cinema and newspaper coverage", 146 Sally Chivers argues. Care home novels and films add to these kinds of cultural representations of old age, and in most cases fuel rather than calm the fears of ending up in such an institution.

In contrast to ethnographic research on residential care facilities in which old people can easily be objectified and unintentionally rendered passive, ¹⁴⁷ I would argue that especially through the mediums of art, literature, and film as well as the criticism thereof, this passivity can be counteracted, and a voice can be given to all—care-givers, family members, and old people. The care home as a setting serves to highlight this search for identity, also in old age. Authors consciously employ the space of the care home (instead of, for instance, a hotel or a cruise-ship), precisely *because of* the connotations and cultural assumptions linked to it. While many texts (seemingly) reaffirm these assumptions, others challenge them openly. All of them produce an alternative spatiality of old age and offer the possibility to overcome its negative interpretations. The problem of the "double marginalization" of old women crystallizes in such narratives.

As American Studies scholars in the field of literary gerontology, we can contribute to changing traditional ways of reading such texts by resisting conventional interpretations of life in the care home as decline narratives. We need to contest readings that link agency solely to a person's own "home", and see "aging in place" as necessarily preferable to institutional long-term care. Only by interpreting the care home in such narratives literally and metaphorically as a space in which self-determination and agency are possible can we achieve an understanding of experiences of old age as meaningful at all times in all places. Having agency in old age should not be undermined by interpretations that are guided by preconceived and stereotypical

¹⁴⁶ Sally Chivers, "Blind people don't run". Escaping the "Nursing Home Specter" in Children of Nature and Cloud-burst, in: Journal of Aging Studies 34 (2015), 134–141, here 134.

¹⁴⁷ Robin Kearns / Gavin J. Andrews, Placing Ageing. Positionings in the Study of Older People, in: Gavin Andrews / David J. Phillips, eds., Ageing and Place. Perspectives, Policy, Practice (London 2005), 13–23, here 20.

notions of age and aging as decline. Interpretations of care home novels as disempowering, because they victimize frail, elderly people, are often ageist readings. What remains is the challenge of understanding representations of the "fourth age", and the spaces associated with it, not as "black holes" only relevant to those experiencing it, but for us all, and to redefine them as meaningful to understand our existence throughout the life course. As the spatiality of age relations is socially and culturally constructed, the way we narrate and interpret old age is always determined by our own position as readers. We have to interpret texts with the narrative power they have, but also make conscious the ambivalences we as readers have regarding age and aging.

Information on the author

Assoz. Prof. Mag. Dr. phil Ulla Kriebernegg, Chair of the European Network in Aging Studies (ENAS), Center for Inter-American Studies, Karl-Franzens-Universität Graz, Merangasse 18, 8010 Graz, Österreich, E-Mail: ulla.kriebernegg@uni-graz.at, Homepage: www.ullakriebernegg.net