

Book Review

**Review of: *Forgotten: Narratives of Age-Related Dementia and Alzheimer's Disease in Canada*. By Marlene Goldman. McGill-Queen's Press, 2017**

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With *Forgotten*, Marlene Goldman contributes the first book-length study of dementia in Canadian fiction and about dementia care from a historical perspective. Goldman, a Professor of English at the University of Toronto, has penned previous books on apocalyptic discourses in Canadian fiction (*Paths of Desire*, University of Toronto Press, 1997; *Rewriting Apocalypse*, McGill-Queen's Press, 2005). In *Forgotten*, she integrates this expertise with her skill in literary analysis from an Age Studies perspective, which began with her engagement with Alzheimer's discourses when writing *DisPossession: Haunting in Canadian Fiction* (McGill-Queen's Press, 2012). In this new monograph, Goldman draws on sources including asylum records, historical accounts of medicine and psychiatry, articles in the national newspapers, and literary works such as dramas, short stories and novels. She eloquently employs rhetorical and literary analysis of these fictional



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and non-fictional sources, and interweaves complex theory, to offer an age studies' analysis of Canadian biomedical, media, and literary depictions of age-related dementia and Alzheimer's disease.

*Forgotten* centres on "The idea that fiction, more than medicine, is responsible for shaping our concepts of disease" (Goldman 3). Goldman pays particular attention to metaphors, rhetorical techniques, and generic conventions that shape popular and scientific models of aging and disease. She establishes the key role that fictional and nonfictional narratives play in shaping Canadian social imaginaries about age-related dementia through the scientific, cultural, and aesthetic narratives they produce. The book's detailed Introduction clearly defines key concepts, specifies the book's goals, justifies the research approach, details Goldman's criteria for selecting the works she analyzes, and outlines the book's structure. In the following nine chapters, Goldman analyzes dementia narratives beginning with writings from the late 19<sup>th</sup> century and progressing to contemporary literature.

Rather than attempting an exhaustive review of sources, Goldman includes representative works that she notes "highlight the tensions between religious [or spiritual] and scientific approaches to dementia" (20). A key question guiding her analysis is "why have narratives featuring epidemics and apocalyptic disasters enveloped discussions of what was once termed 'senility'?" (5). Goldman argues that "the meaning of aging and senile dementia in Canada was shaped by a range of cultural narratives that altered radically over time" (39). Specifically, Goldman posits that narratives of age-related dementia and Alzheimer's disease in Canada have shifted from elegiac modes of storytelling, which offer consolation and were common throughout most of the 19<sup>th</sup> century, to narratives that, starting in the late 19<sup>th</sup> century, increasingly represented dementia (and particularly Alzheimer's Disease) as Gothic horror in which monstrous Otherness is hidden behind the natural surface (or hidden within). As opposed to offering solace like elegiac narratives, these apocalyptic narratives inspire dread through positioning illness as evil, morally wrong, and horrifying, rather than a natural, possible consequence of aging. Goldman describes examples of such apocalyptic narratives as those that "prophecy the end of the world, feature terrifying plagues, and install divisions between the elect and the non-elect" (4). In addition to identifying genealogies of dementia narratives in Canada, Goldman also asks what narratives about dementia and Alzheimer's have been forgotten. Through paying particular attention to language and genre, she astutely highlights a range of social and political forces that have led to shifts in representation (e.g. industrialization, the developing cultural role of newspapers, the popularization of various theories of aging, the emergence and growth of scientific and biomedical models, the creation of purpose built asylums, world wars, sterilization campaigns, deinstitutionalization, the rise of "neuro culture" as defined by Stephen Katz etc.)

The geographic origins of this study are centered in Europe, where Goldman traces the rise of the disease concept in late-19<sup>th</sup> century Germany where its meanings in biomedical and literary accounts are intertwined with the rise of hysteria. This historical analysis recalls how Alois Alzheimer, himself, disagreed with the classification of Alzheimer's as separate from a process of normal aging, and resisted the eponymous naming of the disease. The research then translocates to Upper Canada (now known as Ontario) as *Forgotten* considers *fin de siècle* constructions of dementia in relation to purpose-built asylums and debates amongst asylum superintendents, politicians, and families about the most appropriate care for persons with dementia. From there, the chapters expand geographically outwards considering Canadian national newspapers and

other media, and fictional works linked to various locations throughout the country, while maintaining a strong focus on Eastern Canada. Temporally, the study covers the time period from the late-19<sup>th</sup> century to present. Throughout the ten chapters, Goldman's comparative analysis reveals a wide variety of approaches to dementia and aims to identify "the distinct and sometimes contradictory paradigms by which the disease has been understood" (48). Goldman mobilizes multiple frames of reference such as Victorian theories of waste and repair, stress models, and biomedical approaches to geriatric psychiatry (such as David Rothchild's and Dr. Vojtech Adalbert Kral's theories), to illustrate how discourses of dementia arise and are animated, reiterated, and metamorphized over time.

Chapters One through Six examine narratives created and reproduced through various facets of biomedicine's efforts to name and find a cure for Alzheimer's disease. For example, Chapter Three examines, in part, how the rhetoric of asylum superintendents supported the concept of "the menace of the feeble-minded, aging population" (Goldman 41). Literary authors examined in these chapters, all of whom adopt a negative view of dementia as both inevitable and dreadful, but also, according to Goldman, promote a compassionate response to the condition, include Stephen Leacock (*Sunshine Sketches of a Small Town*), Mordecai Richler ("The Summer my Grandmother was Supposed to Die"), Alice Munro ("The Peace of Utrecht," and "Powers"), and Margaret Laurence (*The Stone Angel*).

Chapters Seven to Nine consider various literary works that "highlight the limitations of Gothic tropes and the biblical narrative of apocalypse, with its promise of revelation and the destruction of absolute evil" (Goldman 45-6); such works thereby reveal the humanity of individuals living with dementia and challenge the dominance of the biomedical model. For example, Goldman argues that Alice Munro's short stories offer an ironic view of dementia as having an array of potential biological origins and multiple, unknowable meanings. In addition to Munro, representative authors include Michael Ignatieff (*Scar Tissue*), Caroline Adderson (*The History of Forgetting*), and Jane Rule (*Memory Board*). With respect to the Canadian fiction considered, Goldman argues "Rather than join the war against Alzheimer's disease, Canadian fiction explores the fate of the combatants and their families, fleshing out the broader, historical interpersonal and intergenerational relationships often obscured by reified portrayals of this 'master illness' as a Gothic monster that supposedly can be located and vanquished on the molecular level" (46). While employing war metaphors in her argument here, Goldman also exposes and challenges the use of such tropes that are major constructive elements of the biomedical model. In sum, *Forgotten* demonstrates that historical and literary accounts cannot be divorced from their historical context.

Before lauding the substantial contributions of this study, I will address its few limitations. Goldman herself identifies that the sources and texts studied in *Forgotten* approach dementia and Alzheimer's disease from a predominantly white perspective, with the exception of David Chariandy's novel, *Soucouyant*. According to Goldman, this echoes how "mainstream media and fictional treatments of Alzheimer's in the global north continue to reflect the erroneous belief that Alzheimer's victims are white," and the result in the disproportionate and problematic emphasis on white people's experience of the condition (21). One might add that the dominant perspective is also of an industrial Western milieu. A follow-up study focusing on culturally and socio-economically diverse narratives of dementia would make a strong contribution to the field. In addition, while Goldman's research is impressively extensive, in a few instances, quotations of

historical sources seem to be taken from other analyses of the sources rather than the original documents (presumably the originals are extremely difficult or impossible to locate). Further, some of the original historical accounts from 19<sup>th</sup> century Germany appear to be analyses of translations of the original documents in which rhetorical subtleties could be altered. In terms of the breadth of her study, Goldman specifies that she has “chosen fiction rather than poetry, drama, or film because, with a few exceptions, fiction best illustrates the metamorphosis from the elegy to the Gothic” (20). Given this is the focus of the majority of the chapters in *Forgotten*, it comes as somewhat of a surprise that the final chapter turns to a discussion of Brecht’s epic theatre and analyses of plays, performances, and performative therapeutic interventions that redress Gothic dementia narratives. These include John Mighton’s play, *Half Life*, Aynsley Moorehouse’s soundscapes of dementia, and the practice of elder clowning in dementia care. Although this chapter does not feel perfectly harmonious with the rest of the book, and calls for elaboration, it does offer useful examples of ways to disrupt negative discourses through performance. Not only is this a fruitful offering to drama, theatre and performance studies scholars who study and/or create performative representations of aging and illness, it is also a practical contribution to health care professionals who integrate dementia-related performances as a means of therapeutic activity or education.

Whereas other similar studies consider how narratives of dementia have shifted over time in Europe and the United States, *Forgotten* analyzes when, how, and why age-related dementia has been articulated in Canada, through narrative, since the late-19<sup>th</sup> Century to present. That being said, this monograph is pertinent to scholars, practitioners and dementia advocates beyond the Canadian context as a brilliant model for tracing the origins, perpetuation, and transformation of a disease concept over time through biomedical, media, and literary sources. It highlights the social discourses surrounding patients and often embedded in health care. Goldman’s writing style is elegant and extremely readable. No matter how complex her ideas, we never stumble over her prose. Her frequent use of phrases such as “put another way,” in which she reformulates the argument from a different angle, facilitates the reader’s clear grasp of the point and renders complex ideas accessible to non-literary scholars. This book would be of great interest to humanities-based and cultural gerontology-focussed age studies scholars, especially those who concentrate on dementia. It would be appropriate for a graduate course on cultural aging, or selections from it would be fitting for an upper year Age Studies honours seminar, or course on rhetoric in health and medicine. Beyond the humanities, *Forgotten* would also be beneficial to health care students, researchers, and practitioners who focus on dementia. The light it sheds on how socially constructed stories (ranging from those in medical charts, patient and professional literature, to popular media and fiction) work to create particular understandings of disease, and how storytelling practices can be used to shift perceptions, is invaluable in expanding the ways we think about dementia and humanizing those who experience it.



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