



INTRODUCTION

Reflections on the “New Dementia”

Annette Leibing and Silke Schicktanz

Over himself, over his own body and mind, the individual is sovereign.

—John Stuart Mill, *On Liberty* (1837)

IN 2017, BASED ON A *Lancet* report (Livingston et al. 2017), a widely mediatised statement appeared in many newspapers around the world: one out of three dementia cases could be prevented if nine risk factors were better managed. The most astonishing part was neither the concreteness of the proportion (1:3), nor the large number of cases that could potentially be avoided in the case of a syndrome that for a long time was discussed using apocalyptic numbers and as pretty hopeless in terms of concrete prevention—it was the *kind* of risk factors mentioned that were challenging longstanding ideas about Alzheimer’s disease (AD). In a more recent report, authors claim that even 40 percent of cases can be avoided (Livingston et al. 2020).

The Lancet Commission on Dementia Prevention, Intervention, and Care (Livingston et al. 2017) mentions the following nine modifiable risk factors that are related to three life stages: early life education; midlife hypertension, obesity, and hearing loss; and later life smoking, depression, physical inactivity, social isolation, and diabetes—as well as other possible contributing factors, such as poor sleep, pollution, and poor diet. All of a sudden, prevention was no longer restricted to rather uncertain ideas around “brain training” (learning languages etc.). Dementia is now understood in more concrete terms and less simply as “destiny,” and this through well-known pathways: most of the risk factors mentioned are seen as easily treatable or modifiable, apparently (see below). The *Lancet* report can be read as a sign of a major change in scientific dementia narratives along with an accumulation of more or less consistent results from various epidemiological and intervention studies over the last years, many of them stemming from serious and independent research groups (e.g., Norton et

al. 2014). But several other possible factors and explanatory pathways are not part of the *Lancet* report, with its “big nine risk factors,” but which have nevertheless been debated in the last few years. Dental hygiene (and other inflammation processes in the body), prions (an especially scary scenario of possible contamination), and the role of viruses and bacteria, among others, have all been examined as involved in dementia pathologies. This shows the complexity and uncertainty of current dementia models that seem to pervade the history of dementia since Alois Alzheimer’s first description of the “peculiar” condition in 1906 during the 37th Meeting of South-West German Psychiatrists in Tübingen, Germany. However, that preventive action has positive effects seems to be a widely accepted notion among scientists, even though two-thirds of “preventing people” are not affected, if the *Lancet* ratio is right (for people living in richer nations).

Preventive action is a possibility, and the nine big risk factors are not causes; they are at best health-related factors whose effects accumulate over time and are not dementia specific. For this reason, the recent preventive turn should—but doesn’t always—help us conceive of (late-onset) dementia as overlapping with a number of health conditions and aging generally. And although a number of discursive limits can be identified—many can be found in this edited volume—the preventive turn can also serve as a chance for rethinking and softening lines between the complex categories of dementia and the human (and maybe animal) life course.

The *Lancet* report received some critique from within the medical field: for instance, according to Kivimäki and Singh-Manoux (2018: 1574), the impact of the management of risk factors on lowering dementia rates was conceived as too optimistic. Furthermore, the causal relationship between these risk factors and their impact on rates of dementia are not well established, and, according to Kivimäki and Singh-Manoux, more evidence-based studies are needed. They further argue that the lowering of dementia rates in some contexts might be the result of other concomitant and confounding factors and bias (e.g., good education is often also linked to better income, health care, housing conditions, and health choices). Finally, they argue that several other equally serious studies do not show the high correlations presented in the *Lancet* report. Others, however, argue that there is enough evidence from an accumulation of observational and other kinds of studies. Friedland and Nandi (2013), for instance, argue against skeptics like Kivimäki and Singh-Manoux, maintaining that the “gold standard,” an evidence-based, randomized controlled study design, is too narrow and becomes a fallacy because important studies not falling into such a strict framework get ignored. In fact, social scientists have for a long time made this kind of critical claim against overrating the so-called gold standard (e.g., Timmermans and Berg 2003; Hardon and Pool 2016).

This book will not resolve the debate about measuring risk, causality, and impact; it is first of all concerned with epistemic and social questions around what we call the “new dementia” and its impact on aging in societies at a moment when scientific dementia narratives are apparently becoming more concrete, while at the same time still relying on many unresolved and sometimes contradictory theories and models. As a result, what we call here the “new dementia” is this uncertain and contested—though apparently concrete—phenomenon of understanding dementia prevention with its epistemic focus on risk factors, risk prediction, prevention claims, and a close brain-body-interaction.

The *in-reality-not-so-new* risk factors (see below) now link the brain to the body and to the social environment in a different way than older Alzheimer’s models. Of course, in medical systems in which brain and body are not conceived as separate, as is the case in most of Western medicine,¹ astonishment about the “new dementia” might be less pronounced, or would more likely find problematic the insistence on looking exclusively at the brain for such a long time. In modern Western thinking, the brain is the central—and somehow distinct—organ of the body and the Western image of the human being is therefore often classified as neurocentric. As Jessica Wright (2019) recently showed, this idea can be linked to scientific models from early Christianity. However, as Don Bates (2000) reminded us in his now classic article about alternative medicine, different kinds of medical systems have always coexisted in all parts of the world. An example of this appears in Leibing’s early research in Brazil, in which family caregivers, but also health professionals, who in the late 1990s were confronted with genetic explanations for dementia, often juxtaposed genetic models with their own ideas: most of the interviewees elaborated on etiologies that resembled in a striking way mid-twentieth century US biomedical theories of dementia as embedded in personality and life’s stress and strain (see Leibing 2002). In the present moment, earlier models of brain-centeredness, and newer models in which cognitive decline is explained as linked to the nine big risk factors (and other factors, depending on the author), can be conceived as coexisting in scientific discourse and media output internationally, though embedded in local contexts. Little is known, however, about how individuals perceive and translate these newer insights into everyday life, although we believe that much of what is recommended as preventive merges with recommendations made for active or successful aging.² More ethnographic studies in different environments are needed in order to situate multiple translations and incorporations of the “preventive turn” in different contexts. It is possible, for example, as Leibing (2018) observed, that North Americans receive a different message with respect to preventing dementia than Europeans, the

former getting more pharma-related prescriptions, the latter more lifestyle recommendations (see also Schicktanz, this volume, on German dementia discourses).

At first glance, the turn toward prevention and its translations into practice merge with several concerns studied intensively in the social sciences in recent years: studies on risk, expectations, hope, and social capital, for instance, as well as critiques concerning neoliberal models of self-care can all be invoked with regard to the “new dementia.”

Although this book builds on these discernments made by critical studies, the contributors to this book provide new insights to the wider field of the social sciences of health, as well as the health sciences more broadly. Major changes to long-established ways of thinking are exciting to study, and, with regard to the “new dementia,” the impact on medical practices, disease models, new moralities, materialities, embodiment,³ health policies, and people’s everyday lives is significant. But what we found especially valuable and enlightening when compiling the chapters collected here is that the contributions provide very original points of view, in which commonplace narratives about dementia—including common critical narratives—are seen in a different light. Furthermore, this volume addresses what we describe as a major change regarding a phenomenon that is rarely studied, at least in Western biomedicine: the way the brain is “becoming body” (see Leibing 2015, 2019; Gardner 2017; Lende and Downey 2012). Arguments around cardiovascular risk factors (hypertension, obesity, diabetes), social factors (loneliness, hearing loss as isolation), and other brain-centered conditions (depression, stroke) impacting cognitive impairment-as-dementia has in the past often been framed as holistic or alternative thinking (or separated from AD as vascular dementia; see Leibing, this volume). In this sense, the concept of the “new dementia” is challenging the pessimistic view of many social scientists regarding neuro-reductionism, or what Fernando Vidal, in his fascinating study (2009; see also Ortega 2009) calls “brainhood”—the brain as the “location of the modern self” and central explanatory model of the vital body (Vidal 2009: 5). The “new dementia” diverges from such thinking in its critique of brain-centeredness, and moves the “encultured brain” (see Lende and Downey 2012) and the brain-as-body from “alternative” to mainstream biomedicine, although, as the chapters in this volume show, this move is not without its dangers and pitfalls.

This brain-as-body in context—the brain as entangled with conditions like diabetes and hypertension, but also with environmental and social conditions such as pollution and loneliness—conditions that in the past were often not perceived as brain-related—is a discourse alerting us to the no-

tion of environmental factors as involved in and influencing people's aging process. Awareness of such factors can provide chances for healthier old age (e.g., Maloney and Lahiri 2016) or can be framed as reductionism (e.g., Lock 2013 on epigenetics). We argue that both are possible, depending on how insights are being translated into practice and enacted in different environments. We further argue that genetics has lost much of its absolute explanatory power as compared to its status at the end of the last century and the beginning of this one, and that models involving the plasticity of the brain—neuroplasticity—based on environmental and metabolic factors acting on brain structure and functionality provide a stronger model than genetics framing the “new dementia.” In fact, the way the “new dementia” is often articulated as partly preventable reinforces notions of genetic models as *nonplastic* and as immutable, when compared to older epigenetic models, although there is no single argumentative pathway. As an example, the *Lancet* report explicitly states that “of course, not everyone will be able to make changes [regarding risk factors] . . . some risks of dementia are genetic and not currently modifiable” (Livingston et al. 2017: 2674). It is as if genetic explanations have faded away in the last years even though, as Milne (2019) argues, many current clinical trials still target genes as the underlying cause of dementia. We think that most of the idea of heredity has been relegated to early-onset dementia, which already for a long time has been conceived as more “genetic” when compared to the more common late-onset form of dementia. It is the latter that is conceived as plastic—as influenced by environmental factors—regarding brain functionality. Some researchers argue that although particular genes play a role in late-onset dementia, they are not a direct cause; they are seen as “susceptibility genes” (Schick Tanz and Kogel 2014): “While early onset AD is almost certainly genetically based, there are no specific gene mutations that are associated with inheritance of the disease in LOAD [late-onset AD],” argues Isik (2010: 307; see also Strobel n.d.).

The *Lancet* report, obviously, did not appear out of the blue, nor were the “new” risk factors understood as having been totally unrelated to the wider phenomenon of dementia in the past. These points are important in order to understand not only the historical context, but also the opportunity this new understanding *might* provide for rethinking aging. The following points consider dementia-specific clinical, sociocultural, and bioethical aspects, without advancing too far into the arguments made in the chapters of this volume. We aim only to provide some information that should orient the reader in order to understand the (in our opinion) fascinating and, at the same time, controversial developments in more recent dementia research.

Situating the Reader

The following points are mostly unresolved or partially resolved questions that, all together, show the complexity of the “dementia puzzle.” First, Alois Alzheimer’s (1907) initial question, whether the early onset form was “peculiar”—whether it was distinct from late onset dementia—can now be affirmed, at least in most cases. Increasingly, researchers are becoming aware that, as Molin and Rockwood (2016: 70) put it, “biomarkers’ ability to distinguish normal subjects from AD patients lessens with age. The typical pattern of AD-related . . . brain changes seen in the young old . . . appears to be less salient in very old patients . . . despite similar levels of cognitive impairment.” Richards and Brayne (2005: 865) make a similar observation; they argue that “in older age groups, AD seems to be a diffuse clinical syndrome representing the gradual accumulation of multiple pathologies, arising from multiple interlocking risk factors over the life course. The term Alzheimer’s syndrome seems more appropriate.”⁴ Conceiving late onset Alzheimer’s disease—or Alzheimer’s syndrome—as an accumulation of several pathologies makes preventive initiatives imaginable by addressing contributing factors that are well known as treatable, such as diabetes and hypertension, conditions that have a long history of pharmacological and lifestyle interventions. A more effective control of these conditions might explain decreasing numbers of dementia cases in some (privileged) groups.

Second, following the *Lancet* report, prevention has come to be thought of principally as *primary* prevention—controlling “modifiable risk factors to avert the occurrence of disease,” although secondary prevention—“the early detection of disease before it manifests clinical symptoms”—also plays a role (Institute of Medicine 2010). However, much of what is considered early signs—several biomarkers, mild cognitive impairment—is contested by some researchers and not reliable as clear indicators of future disease, so maybe preventive measures need to be evaluated not only regarding their effects, but also regarding how they weigh on people’s everyday lives. Furthermore, preventive measures need to be understood in terms of their impact on society, and this is especially the case when they become population-based interventions, as has been observed in the cases of several chronic diseases in which the pharmaceutical industry is also strongly involved in promoting certain disease models (see Greene 2008).

Primary prevention might make more sense if it were called risk reduction and not prevention, and it would be even better framed more generally as simply healthier aging. Several studies have shown that primary prevention in some contexts has actually reduced dementia cases, but only

given the right infrastructure, such as well-functioning health-care and education systems (see Leibing, this volume). Along these lines, a radical suggestion would be to frame prevention differently: targeting a single risk factor or a combination of several makes sense only if a “good life,” defined as covering basic needs, is guaranteed. But there is more at stake than structural and political-economic factors linked to health and social care. In rethinking prevention of dementia, increasing evidence shows that the focus on the nine risk factors can become fallacious when other—for instance environmental—factors are ignored or subsumed under a category that hides important concomitant factors. And although pollution, for example, is mentioned in the *Lancet* report, it is considered a “weak” factor, one not based on enough evidence, as the authors argue, when compared to other factors that are more common (and easier to handle) in a traditional biomedical framework. Since then, a new *Lancet* Report (Livingston et al. 2020) has included air pollution, but also excessive alcohol consumption and traumatic brain injury, as one of now twelve major modifiable risk factors for dementia prevention.

What about tertiary prevention, “the control of existing diseases to prevent more serious complications” (Institute of Medicine 2010)? Current drug interventions could be thought of as tertiary prevention, although they have been criticized for a long time as mostly ineffective and as a product of pharma-marketing. Controlling the nine above-mentioned risk factors when dementia has been already diagnosed is feasible, especially while targeting vascular health and social integration, which would, if not slow down the progress of the disease, nevertheless lead to a better quality of life with dementia. A small number of studies show that disease progression can be positively affected by targeting multiple factors: for instance, in the MEND study (Bredesen et al. 2016) the control of blood sugar levels, stress, sleep issues, and physical exercise among other factors resulted in long-term improvement for all enrolled patients, although results were received with skepticism by some researchers (see Heerema 2019 for a short overview).

Third, for clinical researchers and other health professionals, but also for social scientists, it is important to distinguish between individual, community, and population-based settings for prevention (or risk reduction), a distinction that often is not clarified in prevention studies (Orrell and Brayne 2015). And, obviously, a preventive optimism needs to be tempered by the fact that people cannot or do not want to always follow what seems likely to be best for their health. Distinguishing between different levels of prevention and the direct but less visible impact of different kinds of preventive practices—not only moral prescriptions in health campaigns and government responsibilities for resources, but also processes like biomed-

icalization and pharmacologization—need to be considered in order to make clear what is at stake regarding this “new dementia” (for a more detailed analysis of these points, see Leanza and others in this volume).

Fourth, as mentioned above, the “new” risk factors are in reality not so new: they have in the past generally been associated with vascular dementia, but also been linked to AD. However, previously not much importance was attributed to AD risk factors, except perhaps for education, tightly linked to the notion of the brain considered as analogous to a muscle—“use it or lose it” (see Keuck, this volume).

Finally, a number of ethical issues emerged with the turn toward prevention: first, it raises the important ethical question of responsabilization and who is charged with taking preventive action: the individual, the health-care system, the state, or all three? General concerns, often fueled by socioeconomic, neoliberal developments such as cutting back public health care or state investments in education, can result in an unjustified and ineffective focus on individual responsibility (see Foth, this volume; Schweda and Pfaller, this volume). However, the concept of responsabilization also needs to be situated—its meaning differs between sociocultural contexts, for example regarding the extent to which state and medical expertise are accessible and provided (see Leanza and Schicktzanz, this volume, for more details).

Another important question, one that differs from traditional “dementia ethics,” is the question of what the normative foundations and values for the underlying “prevention ethics” are. Common frameworks in bioethics focus mainly on the ethics of an inter-individual doctor-patient relationship and—in one way or another—consider primary norms, such as respect of autonomy (or just respecting the other), care and wellbeing, avoiding harm, equal rights, and access to treatment. Prevention ethics, however, cannot be easily captured within these normative assumptions. Instead, what is needed is a political-ethical framework that justifies individuals’ rights and duties toward themselves and others, including abstract institutions such as the state or future generations. Such a framework also needs to encompass epistemic uncertainties and missing causalities often prevailing in preventive claims when it comes to normative conclusions regarding concrete actions. The “if” and long-term perspective of action need to be embedded in individual as well as social consideration of what constitutes a “good life” (see Schicktzanz, this volume; Schweda and Pfaller, this volume). The increasing interest in prevention shows the urgent need to develop new prevention-ethics frameworks. Existing public health ethics still relies—in a problematic way—on too simplistic (neo)liberal or communitarian assumptions of what the individual and society “are” and what they (do not) owe each other. The dominance of utilitarian frameworks in public health, intermingled with strong assumptions about individual

sovereignty—as the quote from John Stuart Mill in the beginning of this introduction indicates—is for this purpose problematic and must be reconsidered. Normative ethics also neglect social ideas of what a good life should be and how the life course impacts our decisions and actions.

The Chapters: A Short Overview

The book⁵ begins with a section on *discursive and social practices of dementia prevention*. The chapter by Lara Keuck provides a fascinating argument: the author shows how “windows to act”—opportunities to intervene into the pathological process—became a narrative continuous in the history of dementia sciences since the category was coined in 1910, although core questions and models have changed over time. Concentrating on three key historical turning points, Keuck shows that Alzheimer’s disease—a “working title,” as she calls it—has always stood on shaky, uncertain grounds, where signs and symptoms of dementia were “performed” as a medical problem. She warns against deconstructing dementia narratives, as several social scientists working on dementia do, and invites the reader to look instead at “overarching assumptions” and to study how “they are put to work within concrete early intervention versus prevention programs.”

Annette Leibing, in the next chapter, focuses on the more recent history—the turn toward prevention—and introduces three “mini” epistemic changes (“mini” when compared to Keuck’s discussion of larger changes in the history of dementia)—changes that are part of, and support, the current preventive logic, such as the “vascularization” of the category AD. Using ethnographic data on geriatric care in Brazil, she further shows how the (not so) new risk factors—factors that previously were either marginalized with regard to AD or subsumed under the category “vascular dementia”—can easily lead to blame and exclusion. However, relying on the older metaphor, common in dementia narratives (e.g., by Alzheimer’s societies), of AD as a “democratic disease,” she shows that conceiving of dementia as undemocratic would be one way of framing prevention as a chance, but not a certainty, for a better old age.

As in Leibing’s chapter, Silke Schicktanz’s text, by examining the local “new dementia and prevention” discourse in Germany, shows the importance of situating dementia narratives. Former studies have shown that the German discourse on aging and dementia differs from US discourse: in Germany, trust in the public health-care system is strong, and positive images of persons with dementia are often invoked. Regarding health budgets, patient advocacy groups prioritize care rather than research on AD. In her analysis, Schicktanz explores in detail how dementia prevention is discussed within different areas of public discourse: the German medical professions, the media, and patient advocacy. These different spheres are

not separated but rather interlinked by various communication channels, such as popular science, clinical communication to patients, information provided by patient organizations, and, more generally, internet forums. She also identifies a tendency in the German media to simplify prevention measures and to overrate single risk information. Finally, her analysis concludes with related ethical reflections by focusing on ethical considerations that distinguish between medical-clinical and public health ethics.

In the following chapter, Matthias Leanza looks at prevention of dementia through the lens of the Foucauldian concept of governmentality. As opposed to traditional governmentality studies, however, Leanza, inspired by Niklas Luhmann and Bruno Latour, shows the *improbability* of preventing dementia through lifestyle changes. He convincingly destabilizes common narratives adopted by social scientists by suggesting that more nuanced arguments need to be found regarding the often-repeated and rarely unquestioned critique of neoliberalism.

In his chapter, Alessandro Blasimme makes the intriguing argument that the idea of dementia as more manageable through prevention is “trying to conceptualize the normal and the pathological along the same vital continuum.” He links recent clinical narratives about dementia as modifiable to geriatric frailty and (anti-aging) geroprotectors—concepts that equally conceive the aging body as modifiable. Blasimme suggests using the term “ground-state prevention,” which he defines as a more general and unspecific biological enhancement and strengthening of people’s resilience, a conceptualization of prevention that transcends the normal and pathological, as well as nosological, boundaries.

The next section is about the *early detection of dementia*, exploring an interval in which, theoretically, primary and secondary prevention might start, depending on whether mild cognitive impairment (MCI)—the topic of the two chapters of this section—is defined as *not yet or already* part of a process called dementia. MCI—the first signs of cognitive decline that might or might not develop into a dementia syndrome—are generally defined as an in-between category, as neither normal nor pathological, although it has become thought of as more pathological in recent years. The two chapters of this section elaborate on MCI as a critical issue situated between prediction and prevention. The first text, by Tiago Moreira, describes the changes (or “drift”) between conceptions of MCI in 2001 and 2018. He explains that, once considered a major risk for developing a dementia, MCI has become over the years a much looser category with little predictive value. And although the continued use of MCI is based on the need to capture the subjective memory complaints of worried people, now that “the link between MCI diagnostic work and AD technological expectations appears to be weakened, the trade-off between current patients and future therapies has lost most of its leverage.” Moreira argues that most people

with MCI will feel the burden of a diagnostic label and will live a liminal life under a category that has lost a lot of its earlier certitude and meaning.

The second paper of this section, written by Stephen Katz, Kevin Peters, and Peri Ballantyne, is divided into three parts: first, based on interviews with researchers and practitioners in the dementia field, “diagnostic inconsistencies, biomarker uncertainty, and pharmaceutical capitalization” are highlighted. The second part sheds light on the commercialization of a growing neuro-memory market, in which memory products such as foods and memory exercises mean lucrative business and, at the same time, provide hope for individuals searching for an optimization of their cognitive health. Part three is based on focus groups with people affected with MCI and shows how their rhetoric gives meaning to disruption and apprehension. Together, the juxtaposition of these three sections lets the authors show how “MCI, early detection technologies, and dementia campaigns are redrawing the health politics of aging.” They further conclude that early detection and the idea of prevention result in current landscapes of aging in a “post-diagnostic ethical fallout of personal support.”

The third section of this edited volume problematizes the central issue of the preventive turn, *prevention itself*, including lifestyle. Kirsten Bell calls lifestyle *the* core problem in current public health questions. Bell compares the recent turn toward dementia prevention with a similar, though in many aspects contrasting, process in cancer and lifestyle discourses, and situates prevention close to the notion of chronic illness, a discourse of hope and greater predictability. In her lucid discussion of the notion of chronic disease and prevention, Bell observes that “more surprising than the idea that dementia might be prevented via lifestyle modifications is that it happened so recently.” Possible answers she gives to these questions are that, unlike cancer, dementia is located between physical and mental classifications, while pathological changes are not clearly defined and often contested, and that lifestyle as prevention might also mean that “something is being done about conditions where science reaches the limits of its knowledge.”

With the rise of the prevention paradigm in contemporary society, later life is becoming a screen onto which individual and social prognoses, plans, and future scenarios are projected, as Mark Schweda and Larissa Pfaller argue intriguingly in their chapter. In consequence, the circumstances of old age are no longer seen as a matter of simple fate or luck but rather as aspects of a life phase that can be actively shaped and prudently modeled by means of preventative measures. In their more conceptual article, they discuss in detail how the critique of the “responsibilization of aging” and “successful aging” in the era of neoliberal governmentality is justified or not—and how a differentiated analysis and discussion of responsibility claims can help to substantiate the current interdisciplinary discussions at the intersection of social sciences, ethics, and moral economy.

Finally, Thomas Foth provides an important historical-genealogical analysis of the most relevant idea of “lifestyle” and therefore of the increasingly common idea of the subject’s responsibility for her health and death. Most interestingly, this idea was brought to life by a Canada-founded commission in the mid-1970s (the Lalonde report) and now dominates most international health promotion and prevention programs, including those of the World Health Organization (WHO). Foth’s genealogy dissects the underlying biopolitical and socioeconomical assumptions associated with this report and furthermore critically analyzes how the dispositive of “lifestyle” was not only strategically used to reshape public health-care systems in many socio-liberal Western societies but has even radically changed the way we think about our behavior around health-related issues.

The afterword, written by Peter Whitehouse and Danny George, is a call for more critical dementia research. The two authors see the preventive turn as a chance to focus less on the narrow paradigm of cure, and more on structural factors influencing dementia rates, such as pollution and unemployment.

Subtitle and Intentions

This book’s aims are articulated in its subtitle *Critical Perspectives on a New Paradigm of Preparing for Old Age*. Our intention is to pay attention to multiple perspectives that capture both the promises as well as the pitfalls of current preventive insights regarding dementia and, more generally, old age. “Critical,” then, does not necessarily mean deconstruction—it means acknowledging multiple ways of thinking about lowering the incidence of dementia.

The volume’s subtitle further suggests that prevention is preparation. This could suggest a naive intention to somehow avoid aging, but realistically it means that old age cannot be separated from the rest of the life course; it means that actions, alliances, biologies, stress and strain—the whole habitat of early life—cannot be clearly separated from how we age and who we are later in life. Individual actions like physical activities and good food are only details in that broader picture of a good life. And if we imagine individual preventive action as “only details” among many other factors, prevention might lose its moralizing and sometimes stigmatizing sense with respect to the individual. This is where this volume aims to contribute to future discussions: at the intersections of social sciences, public health, and ethics. Ultimately, if we think about prevention as linked to achieving a good life, ideally for all, discussions about dementia prevention become discussions about social justice, living conditions, and responsibilities—for ourselves and others.

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Annette Leibing is a medical anthropologist (PhD University of Hamburg) and had her first academic position in the department of psychiatry at the Federal University of Rio de Janeiro. There she founded and directed the CDA, a multidisciplinary center for mental health and aging, with a special focus on dementia. After a postdoctoral fellowship at McGill University, she is now full professor on the nursing faculty at the Université de Montréal. Her research focuses mostly on issues related to aging, by studying—as an anthropologist—Alzheimer’s and Parkinson’s in different contexts, aging and psychiatry, pharmaceuticals, elder care, and stem cells for the body in decline, among others.

Silke Schicktanz is professor of cultural and ethical studies of biomedicine at the Institute of Medical Ethics and History of Medicine, University Medical Center Göttingen. She publishes internationally—together with various colleagues from Israel, Sweden, the United Kingdom, North America, India, and Germany—on issues such as aging, dementia and dying, gender issues, transplantation, genetic research, reproductive medicine, democratizing science, and empirically informed ethics. Her latest book is on comparative empirical bioethics, with Israeli sociologist Aviad Raz (Springer, 2016). She also coedited *Planning Later Life: Bioethics and Public Health in Ageing Societies* (Routledge, 2017) and *Cross-Cultural Comparisons on Surrogacy and Egg Donation: Interdisciplinary Perspectives from India, Germany and Israel* (Palgrave Macmillan, 2018).

Notes

1. We are aware that “Western” and “the West” are problematic notions (e.g., Appiah 2016), although the more recent concept of the “global north/south” is equally homogenizing and inaccurate (e.g., Kloß 2017), as is “industrialized countries,” and other notions of agglomerating countries in which modern, university-taught medicine is the predominant system of healing. We therefore stick to “Western,” aware of its shortcomings and blind spots (see Tani and Sakai 2019).
2. The multidimensional translation and dissemination of the “new dementia” in different social and national contexts is an ongoing research project, coordinated by Annette Leibing and Silke Schicktanz and funded by the Social Sciences and Humanities Research Council (SSHRC; Canada) and Deutsche Forschungsgemeinschaft (DFG; Germany).
3. The embodiment of the “new dementia” can be conceptualized as attitude—“the preventive self,” for example—but also as affecting the body itself, as altered and situated biology (Niewöhner et al. 2011; Wolf and Hall 2018).
4. In 1996—a period in which genetic explanations were predominant in dementia models—Shua-Haim and Gross had already suggested changing the term from AD to Alzheimer’s syndrome, arguing that there are numerous pathways that lead to severe cognitive decline, especially shown by the involvement of different genes found at the origin of Alzheimer’s.
5. This edited volume is the result of two workshops that took place in 2018: in July in Göttingen, Germany, and in September in Montreal, Canada. Although there was a limited budget, we are very grateful that we were able to gather an interdisciplinary and international group of researchers who all provided new, original, and intriguing insights into the study of the wider phenomenon of dementia prevention. Several additional authors and coauthors—Peri Ballantyne, Danny George, Kevin Hall, Tiago Moreira, Kevin Peters, Larissa Pfaller and Peter Whitehouse—were not part of the workshops, and kindly accepted our invitation to contribute to this book.

References

- Appiah, Kwame A. 2016. “There is No Such Thing as Western Civilization.” *The Guardian*, 9 November 2016, online issue. Accessed 18 May 2018, <https://www.theguardian.com/world/2016/nov/09/western-civilisation-appiah-reith-lecture>.
- Bates, Don G. 2000. “Why Not Call Modern Medicine ‘Alternative’?” *Perspectives in Biology and Medicine* 43 (4): 502–518.
- Bell, Kirsten, Darlene McNaughton, and Amy Salmon, eds. 2011. *Alcohol, Tobacco and Obesity: Morality, Mortality and the New Public Health*. London: Routledge.
- Bredesen, Dale E., Edwin C. Amos, Jonathan Canick, Mary Ackerley, Cyrus Raji, Milan Fiala, and Jamila Ahdidan. 2016. “Reversal of Cognitive Decline in Alzheimer’s Disease.” *Aging* 8 (6): 1250–1258.
- Gardner, John. 2017. “Patient-Centred Medicine and the Broad Clinical Gaze: Measuring Outcomes in Paediatric Deep Brain Stimulation.” *BioSocieties* 12 (2): 239–256.

- Greene, Jeremy A. 2008. *Prescribing by Numbers: Drugs and the Definition of Disease*. Baltimore: Johns Hopkins University Press.
- Hardon, Anita, and Robert Pool. 2016. "Anthropologists in Global Health Experiments." *Medical Anthropology* 35 (5): 447–451.
- Heerema, Esther. 2019. "Study Highlights the MEND Approach to Reversing Alzheimer's Disease." *VeryWell Health*, online publication, accessed 1 December 2010, <https://www.verywellhealth.com/mend-approach-to-reversing-alzheimer-s-4074147>.
- Kivimäki, Mika, and Archana Singh-Manoux. 2018. "Prevention of Dementia by Targeting Risk Factors." *Lancet* 391 (10130): 1574–1575.
- Kloß, Sina T. 2017. "The Global South as Subversive Practice: Challenges and Potentials of a Heuristic Concept." *Global South* 11 (2): 1–17.
- Leibing, Annette. 2002. "Flexible Hips? On Alzheimer's Disease and Aging in Brazil." *Journal of Cross-Cultural Gerontology* 17 (3): 213–232.
- . 2015. "Dementia in the Making: Early Detection and the Body/Brain in Alzheimer's Disease." In *Popularizing Dementia, Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda, 275–294. Bielefeld: Transkript.
- . 2018. "Situated Prevention: Framing the 'New Dementia.'" *Journal of Law, Medicine & Ethics* 46 (3): 704–716.
- . 2019. "The Turn towards Prevention: Moral Narratives and the Vascularization of Alzheimer's Disease." *New Genetics & Society: Critical Studies of Contemporary Biosciences* 39 (1): 31–51. Online first publication, accessed 15 November 2019, <https://doi.org/10.1080/14636778.2019.1637722>.
- Lende, Daniel H., and Greg Downey, eds. 2012. *The Encultured Brain: Introduction to Neuroanthropology*. Cambridge, MA: MIT Press.
- Livingston, Gill, Andrew Sommerlad, Vasiliki Orgeta, Sergi G. Costafreda, Jonathan Huntley, David Ames, Clives Ballard, et al. 2017. "Dementia Prevention, Intervention, and Care." *Lancet* 390 (10113): 2673–2734.
- Livingston, Gill, Jonathan Huntley, Andrew Sommerlad, David Ames, Cive Ballard, Sube Banerjee, et al. 2020. "Dementia Prevention, Intervention, and Care: 2020 Report of The Lancet Commission." *Lancet* 396 (10248): 413–446. doi:10.1016/S0140-6736(20)30367-6.
- Lock, Margaret. 2013. "The Epigenome and Nature/Nurture Reunification: A Challenge for Anthropology." *Medical Anthropology* 32 (4): 291–308.
- Maloney, Bryan, and Debomoy K. Lahiri. 2016. "Epigenetics of Dementia: Understanding the Disease as a Transformation Rather Than a State." *Lancet Neurology* 15 (7): 760–774.
- Milne, Richard. 2019. "The Rare and the Common: Scale and the Genetic Imaginary in Alzheimer's Disease Drug Development." *New Genetics and Society* 39 (1): 101–126. First published online. DOI: 10.1080/14636778.2019.1637718.
- Niewöhner, Jörg, Martin Döring, Michalis Kontopodis, Jeannette Madarász, and Christoph Heintze. 2011. "Cardiovascular Disease and Obesity Prevention in Germany: An Investigation into a Heterogeneous Engineering Project." *Science, Technology & Human Values* 36 (5): 723–751.
- Institute of Medicine. 2010. *The Healthcare Imperative: Lowering Costs and Improving Outcomes; Workshop Series Summary*. Washington, DC: National Academies Press. <https://doi.org/10.17226/12750>.

- Norton, Sam, Fiona E. Matthews, Deborah E. Barnes, Kristine Yaffe, and Carol Brayne. 2014. "Potential for Primary Prevention of Alzheimer's Disease: An Analysis of Population-Based Data." *Lancet Neurology* 13 (8): 788–794.
- Orrell, Martin, and Carol Brayne. 2015. "Dementia Prevention: Call to Action." *Lancet* 386 (10004): 1625.
- Ortega, Francisco. 2009. "The Cerebral Subject and the Challenge of Neurodiversity." *BioSocieties* 4 (4): 425–445.
- Schick Tanz, Silke, and Friederike Kogel. 2013. "Genetic Responsibility Revisited: Moral and Cultural Implications of Genetic Prediction of Alzheimer's Disease." In *Genetics as Social Practice*, edited by B. Prainsack, S. Schick Tanz, and G. Werner-Felmeyer, 199–218. London: Routledge.
- Strobel, Gabrielle. n.d. "What is Early Onset Familial Alzheimer Disease (eFAD)?" *Alzforum*, online issue. Accessed 14 May 2019, <https://www.alzforum.org/early-onset-familial-ad/overview/what-early-onset-familial-alzheimer-disease-efad>.
- Tani, Kenichi, and Kosuke Sakai. 2019. "Realizing the Existence of Blind Spots in the 'West': A Systems-Theoretical Perspective." *Anthropological Theory*, online first publication, accessed 10 November 2019, <https://doi.org/10.1177/1463499619859107>.
- Timmermans, Stefan, and Mark Berg. 2003. *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care*. Philadelphia: Temple University Press.
- Vidal, Fernando. 2009. "Brainhood: Anthropological Figure of Modernity." *History of the Human Sciences* 22 (1): 5–36.
- Wolf, Meike, and Kevin Hall. 2018. "Cyborg Preparedness: Incorporating Knowing and Caring Bodies into Emergency Infrastructures." *Medical Anthropology* 37 (6): 486–498.
- Wright, Jessica. 2019. "Are We Our Brains? How Early Christianity Shaped Western Ideas about Power, Morality and Personhood." In *Embodied Difference: Divergent Bodies in Public Discourse*, edited by J. A. Thomas and C. Jackson, 37–58. Lanham: Lexington.