Preventing Dementia?

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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 mediatized 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 neuroreductionism, 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 *non*plastic 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" (Schicktanz 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 responsibilization and who is charged with taking preventive action: the individual, the healthcare 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 responsibilization 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 Schicktanz, 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 Schicktanz, 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 book[5] 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 healthcare 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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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.

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PART I

The Discursive and Social Practices of Dementia Prevention

1 A WINDOW TO ACT?

Revisiting the Conceptual Foundations of Alzheimer's Disease in Dementia Prevention

Lara Keuck

Introduction

Throughout the twentieth century and up till the present, Alzheimer's disease has served as a working title. This chapter offers a historical and epistemological perspective that allows us to locate and evaluate the promises of dementia prevention that allude to Alzheimer's disease as a much feared medical condition and simultaneously capitalize on the idea of a window to act (before it is too late).[1] The current popular scientific understanding of Alzheimer's disease presents the long inconspicuous trajectory of a pathology that ultimately results in devastating symptoms of dementia, such as severe mental decline and the loss of the capacity to lead one's life autonomously.[2] Accordingly, the notion of a window to act refers to a biologically defined time frame—namely, before an irreparable pathological process has caused perceivable cognitive and functional deficits. This chapter argues that this picture is based on shaky grounds, and that it represents a collage of different ways in which the disease has been conceptualized within the last century. Alzheimer's disease has acted as an ambiguous term for the diagnosis of a very severe mental disorder with dramatic effects for affected patients, their families, and care givers, as well as for the underlying, yet-to-be-fully-characterized biological process that presumably starts many years, even decades, before the manifestation of symptoms. This chapter shows that the conceptual foundations of the medical category of Alzheimer's disease rest on a history of shifting question marks concerning the relation between the pathological process, clinical symptoms, and nosological category. The window to act might serve as a sound scientific hypothesis; however, it can transform into a questionable justification for assigning a broad range of people the responsibility to

take action and adopt preventive or early intervention strategies against developing dementia. If the proposed actions come with potential negative side effects (like taking a drug after an early—uncertain—diagnosis), this is even more problematic. To give an example, the mobilization of concerned potential patients was marketed in an online advertisement campaign of the pharmaceutical companies Pfizer (who closed its Alzheimer's disease research and development program in 2018) and Eisai, which presented a middle-aged, healthy, and determined-looking man vis-à-vis a teeth-baring tiger and the slogan "face the fear of Alzheimer's disease," along with these lines: "the earlier you diagnose Alzheimer's disease, the sooner you can do something about it / fighting Alzheimer's disease right from the start / Aricept® donepezil hydrochloride (click here for healthcare professional information on prescribing and adverse event reporting)." This advertisement, which went online in 2009, evokes a picture of a clearly identified enemy. However, medical experts have redrawn the composite sketch of this enemy several times from the first description of Alzheimer's disease to the most recent formulation of a research framework.

This chapter successively presents and discusses three of the most influential sketches of Alzheimer's disease: those found within the proposals of Emil Kraepelin and Alois Alzheimer around 1910; of Bob Katzman around 1976; and of the recently published NIH-AA work group for a new research framework on a biological definition of Alzheimer's disease (Jack et al. 2018). It shows that the key questions framed by the respective research programs differed significantly from each other, yet none of them could so far be answered conclusively: the relationship between Alzheimer's disease and senile dementia, the identification of the pathological process, the biological definition of the disease—all of the enquiries remain open. However, every agenda replaced unresolved questions with working assumptions in order to probe new avenues for solving the ongoing problem of determining a diagnosis of Alzheimer's disease, and finding a way to manage, cure, or prevent it.

I have selected the mentioned positionings of Alzheimer's disease for this analysis because the respective approaches and actors already figure prominently within the existing historiography of Alzheimer's disease and have been assigned argumentative roles especially in the context of discussing the origins of, and possible measures against, the frustrating futility of research on effective treatments against Alzheimer's disease and other dementias.[3] Drawing on my own historical and philosophical research, I suggest a different understanding of the reconceptualizations of Alzheimer's disease that focuses more on the shifting epistemological roles that have been assigned to this purported medical entity. Against this background, I have considered how the acclaimed new paradigm of dementia

prevention differs from past and present conventional dementia research. I will conclude that this question must be answered case by case, but that many dementia prevention strategies draw on the above depicted "window to act"—an epistemology that also motivates the current research framework toward a biological definition of Alzheimer's disease, even if the aims and means to act may differ largely in the case of general recommendations for healthy aging versus biomarker profile–specific interventions.

The main conceptual shifts between the three research frameworks and a fourth framework that some proponents of prevention seem to embrace and that questions the coherence of the past century's approach to classifying diseases altogether will be illustrated in simple figures in the four succeeding sections of this chapter. Like all simplifications, they must be handled with care. The reality is always more complex, and the influence that the discussed proposals and their antecedent or succeeding variants have had can only be explained by looking more closely into the contexts, conditions, and incentives of using and propagating these programs. All of the discussed proposals have been controversially discussed within their times by psychiatrists and medical scientists from various institutions. This chapter restricts itself to providing a comparative representation of the conceptual foundations in which Alzheimer's disease has figured within the selected frameworks. The aim is to visualize what has remained and what has changed between them. The concluding section details why the medical category of Alzheimer's disease can be best conceptualized as a working title, and exemplifies how this perspective helps us to raise meaningful questions for evaluating present promises of dementia prevention.

In Search of a Nosological Position: Alzheimer's Disease around 1910

This section reassesses the introduction of Alzheimer's disease more than a century ago to highlight how this category was used as a working title to encourage research in histopathology and clinical psychiatry with the aim of better classifying mental disorders. Against this background, the remaining part of this chapter discusses the continuities and changes in the premises and promises of succeeding programmatic approaches to dementia research.

In 1910, Alzheimer's disease was first presented within the senile dementia section of the eighth edition of one of the most influential textbook classifications of the time, authored by German psychiatrist Emil Kraepelin (1856–1926) (Kraepelin 1910: 624–629).[4] Four years earlier, Alois Alzheimer (1864–1915), who worked in Kraepelin's psychiatric university

clinic in Munich and headed the institution's microscopic laboratory, had discussed the clinically and histopathologically "peculiar case" of a female patient who had died in her fifties of a severe form of dementia. The woman, Auguste D[eter] (1850–1906), later became known as the first case of the disease that Alzheimer "discovered" and that Kraepelin "baptized" (Alzheimer 1907).[5]

Within their time, however, Alzheimer and Kraepelin remained cautious about claiming a new disease entity. For sure, they marked their stakes: their publications feature detailed descriptions of both the clinical picture of an accelerated, progressive, ultimately fatal mental deterioration and the histopathological autopsy of plaques, tangles, and degenerated cortex tissue. Alzheimer's disease was regarded as an organic brain disease that gave rise to severe symptoms of dementia and that left its pathological traces in the anatomical substrate of a patient's brain. Similar to the characterization of infectious diseases such as syphilis and rabies that could give rise to madness, the pathological anatomy of organic brain diseases—for instance, arteriosclerosis in brain vessels—was regarded as proof of principle that psychiatry could become increasingly scientific and thereby legitimate itself as a medical university discipline. While the theoretical potential of the classification of Alzheimer's disease was ambitious, its actual realization remained underdetermined. In none of their publications did Alzheimer and Kraepelin take a definitive stance on whether the small group of "peculiar cases" should be regarded as atypical variants of senile dementia or as a distinct entity. Rather, they presented this question of how to relate Alzheimer's disease to senile dementia and other organic brain diseases within a clinical theory of diseases—the nosology—as a task for further research.

The patient records of the Munich clinic provide further evidence for the use of Alzheimer's disease as a clinical diagnosis, which did not serve to settle a medical issue but to mark interesting cases and recommend, if possible, examination of the patients' brains postmortem: not only was the diagnosis regularly accompanied with question marks and corrections, but also the parameter that most historians of psychiatry considered to be a clear defining feature of Alzheimer's disease—namely, the presenility or comparably young age of the patients (in their forties or fifties) at the onset of dementia—was not a criterion of exclusion for an Alzheimer's diagnosis. In general, the category was rarely applied: the clinic records from 1909 to 1912 list more than eight thousand patients, out of which seven received a clinical diagnosis of Alzheimer's disease. Within this small group were patients that were in their late sixties, and in the case of a 63-year-old female patient, the diagnosis was even named "senile Alzheimersche Krankheit" (see Keuck 2018a).

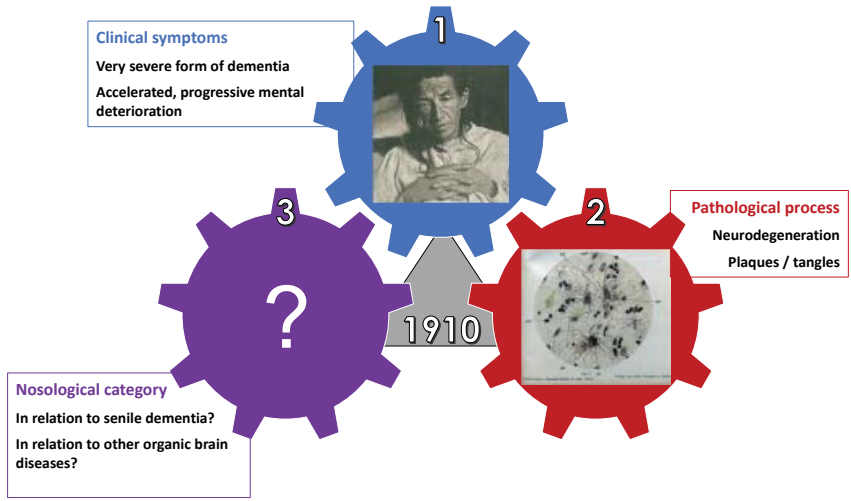

FIGURE 1.1. Schematic representation of the nosological puzzle that Alzheimer's disease presented in 1910. Picture referring to clinical symptoms: "Auguste Deter aus Frankfurt am Main," unknown photographer, 1902 (public domain, Wikimedia Commons, https://commons.wikimedia.org/wiki/File:Auguste_D_aus_Marktbreit.jpg); picture referring to the pathological process: Alois Alzheimer, 1911, "Über eigenartige Krankheitsfälle des späteren Alters," *Zeitschrift für die Gesamte Neurologie und Psychiatrie* 4: 356–385, plate IV, figure 2.

Figure 1.1 schematically represents my reconstruction of the conceptualization of Alzheimer's disease at the time of its incorporation in Kraepelin's textbook. Two aspects are salient: first, the triadic structure constituting this psychiatric category, which connects clinical symptoms with a pathological process and a nosological category; and, second, the unsettledness of the very place of this category vis-à-vis the umbrella classes of senile dementia and organic brain disorders. As mentioned above, Kraepelin (and Alzheimer, who provided all the microphotographs for Kraepelin's book) discussed the "peculiar cases" alongside a handful of other organic brain diseases as exemplars for the general potential of using pathological anatomy (alongside other service sciences that had already been incorporated into Kraepelin's vision of clinical psychiatry) to scientifically found psychiatric nosology and guide clinical differential diagnosis: when postmortem examinations showed distinctions within a clinically lumped group of patients, these should guide the clinician to search for matching differences in the symptomatology of living patients.

From the point of view of Kraepelin's clinical psychiatry and Alzheimer's cortex pathology, most of the mental disease categories were considered provisional.[6] The use of these categories served nonetheless important purposes for compiling statistics to call for more funding, for managing and overseeing the flow of in-patients from the clinics to cheaper asylums for long-term stays, and for establishing psychiatry as a sound medical discipline that strives for systematic knowledge. The latter was based on an equally systematic recording and archiving of diagnostic procedures and evaluations during the initial anamnesis at admission, the psychiatrists' visitations during the clinic stay, the epicrisis (i.e., the final medical judgment of the case after the patient was released or had died), and the review and reassessment of this empirical material in light of new theories within the qualification works (habilitation theses) of aspiring professors of psychiatry.[7]

Alzheimer's disease was presented as a nosological puzzle and used as an exploratory category in a specific way: it was left open whether the closer examination of related "peculiar cases" would give more insights into the pathological process responsible for the development of dementia symptoms in general, or whether these cases only superficially resembled forms of senile dementia and rather constituted a pathologically distinct entity. In other words, the solution to this nosological puzzle would either contribute to a refined histopathological description of senile dementia or to the characterization of Alzheimer's disease as an etiopathologically and prognostically differentiable classification. Kraepelin and Alzheimer did not take preconfigured sides on this issue; rather, they discussed potential in-between nosological positions that Alzheimer's cases could represent—for instance, as atypical forms of senile dementia. Operating with provisional categories opened up room for speculation while remaining circumspect about present conclusions: Kraepelin mused that the occasional early onset could either indicate that the symptoms associated with senile dementia were actually independent from senility or that these patients aged too early. Evidence of a "senium praecox" would strengthen the conceptual connection between the pathological process of dementia and its association with aging.

The psychiatrists could operate the triadic structure between clinical symptoms, pathological process, and nosological category as an epistemic machine: if we imagine the three aspects as cogs, in which the teeth of each cog—the specific symptoms, pathological aberrations, categorical descriptions—are worked on, are filed and oiled, we can look at how the movement of each cog changes when one of them is altered. Awkward clinical symptoms (cog 1) directed the clinician-histopathologist to look

into deceased patients' brains, where plaques and tangles were identified (cog 2). If such alterations appeared exclusively in a subgroup of patients, clinicians should look for matching differential diagnostic symptoms in living patients (moving cog 1) and revise their provisional taxonomy accordingly (moving cog 3). New categories—like that of Alzheimer's disease—were then used to label patients in the clinics, which again provided the empirical basis for testing and refining the specificity and questioned relations between a putative pathological process and the presentation of significant symptoms (so that ideally cog 1, 2, and 3 would ceaselessly bite into each other).

Throughout the twentieth century, this epistemic machine was used to set up speculative questions and research hypotheses for characterizing the nature of Alzheimer's disease. In Kraepelin and Alzheimer's texts, the main aim was to probe a new nosology. They raised questions about the specificity of the clinical symptoms and the pathological process, but these were always connected to the nosological puzzle. In the following, I analyze two further programmatic approaches to conceptualizing Alzheimer's disease that were issued to propagate research and direct it in certain directions. I argue that while these successive frameworks kept the triadic structure of Kraepelin's nosological research program, they moved the main question mark from the nosological category onto a different cog (first the pathological process, and then the clinical symptoms). This was not because the previous questions had been answered successfully; quite the contrary. The argumentative point of departure for both of the succeeding research frameworks was that the relation between clinical symptoms, pathological process, and the specificity of Alzheimer's disease as a distinct entity had remained an unresolved biomedical issue, not least because earlier attempts had put the big question mark on the wrong cog. Such negative views were not only motivated by the failure to resolve the muddle of defining Alzheimer's disease and dementia, but also mirrored a reconfiguration of the object of concern in light of the status and tasks of patients, physicians, and researchers within different sociopolitical landscapes.

In Search of a Common Pathological Process: Alzheimer's Disease around 1976

The sociopolitical landscape of postwar capitalist America, in which dementia, in particular of the Alzheimer's type, amounted to a major public health problem of the aging society, as well as a promising target for the booming pharmaceutical companies and public research funding scheme,

has been described in detail by historian Jesse Ballenger (2006a, b, for example). In this section, I zoom in on one formulation of a research program that encapsulates the main reconfigurations of conceptualizing Alzheimer's disease and that has guided much of dementia research in the last quarter of the twentieth century—not least because it was intentionally coupled to large-scale research funding.

I refer here to the canonical editorial to a 1976 special section on Alzheimer's disease in the *Archives of Neurology* by US neurologist Robert Katzman (1925–2008), who later became known as a dedicated lobbyist of research on Alzheimer's in American funding bodies and cofounder of the Alzheimer's Disease and Related Disorders Association (ADRDA; today, Alzheimer's Association).[8] The editorial gave weight to a standpoint that had been discussed since about 1960, namely that Alzheimer's disease might refer to a common pathological process responsible for most cases of "senile dementia." Katzman stressed the importance of this reconfiguration: "senility" or "senile dementia" were at the time of his writing not causes of death, but considered as effects of aging, and therefore a very common medical issue lacked recognition as a disease that in principle could be prevented and treated. He estimated that this disease would be the fourth or fifth most common cause of death. President Nixon's "war on cancer" and the $100 million founding of the National Institute of Cancer, which framed the funding of cancer research as a political act, had been issued and signed in the form of the National Cancer Act just five years earlier in 1971.[9] Katzman's hint at cancer ("malignant neoplasms") reveals a call for similar medical and political awareness for dementia research:

> The death certificates of patients with senile dementia bear witness to the bronchopneumonia, myocardial infarct, pulmonary embolus, cerebrovascular accident, or other acute event occurring at death. But such events also may mercifully end the life of patients with malignant neoplasms. Yet, the latter diagnosis enters the death certificate as the first cause of death while we officially ignore the existence of senile dementia. (Katzman 2008 [1976]: 379)

Katzman is but one contributor to the "politicization of Alzheimer Disease" in the last third of the twentieth century (Lock 2013: 38). While the consequences of this politicization, especially the dramatic extension of the patient group who would receive a diagnosis of Alzheimer's disease, received a lot of attention, the conceptual differences of Katzman's conception to earlier accounts of Alzheimer's disease have often been reduced to the broadening of the category from a diagnosis restricted to presenile dementia to including many of the much more common cases of senile dementia.

I briefly wish to point to one analysis that shows some similarities to, but also important differences from, mine. In his insightful essay "Alzheimer Disease: Epistemological Lessons from History?," clinician and philosopher Rob Dillmann describes Katzman's conceptualization of senile dementia as being potentially retractable to the disease entity of Alzheimer's disease as a neo-Kraepelinian move (Dillmann 2000). I have argued that Kraepelin's ideals of nosology should not be conflated with the actual use of diagnostic categories, which demonstrate in the case of Alzheimer's disease the provisional character of an exploratory category to guide further research and potentially settle the nosological puzzle that the "peculiar cases" presented. Some have stressed that the claiming of a new disease and the naming of it served strategic uses, such as the consolidation of Alois Alzheimer's career as clinical psychiatrist (e.g., Weber 1997; Berrios n.d.). Without doubt, the presentation of medical categories has always had a political dimension. It is, however, also without doubt that the reconfiguration of Alzheimer's disease illustrated in Katzman's 1976 editorial brought about a hitherto unknown dynamic into dementia-related research. This was a key aim, as Katzman and Katherine Bick (2000: xi) recount in their retrospective account on the founding of the ADRDA:

> We had two goals [in 1979]. The first was to reach consensus that Alzheimer disease (AD) was not just a relatively rare neurodegenerative disorder of the presenium, but was the major cause of dementia in the elderly in developed countries. The second quite different goal was to bring together investigators who had already made important contributions to the field and others whom we sought to recruit to the field in order to help "jump-start" research in AD.

The identification of the pathological process of the proposed new disease entity was framed as a political agenda—that is, a socially relevant medical problem that required substantial funding—and marked important differences from the 1910 presentation of Alzheimer's disease (see figure 1.2): while the setup remained "Kraepelinian" in its triadic structure of connecting nosology, clinical diagnosis, and pathological examination with each other, both the starting assumptions and the positioning of the main question mark moved.

Instead of presenting Alzheimer's disease as a nosological puzzle, they "reached consensus" that it should include most cases of "dementia in the elderly" (Katzman and Bick 2000: xi). The elucidation of the pathological process, on the other side, was not restricted any longer to histopathology, but should include genetics, epidemiology, and many more biomedical subdisciplines. The characterization of a pathological process specific to Alzheimer's disease was no longer primarily a means for bringing order

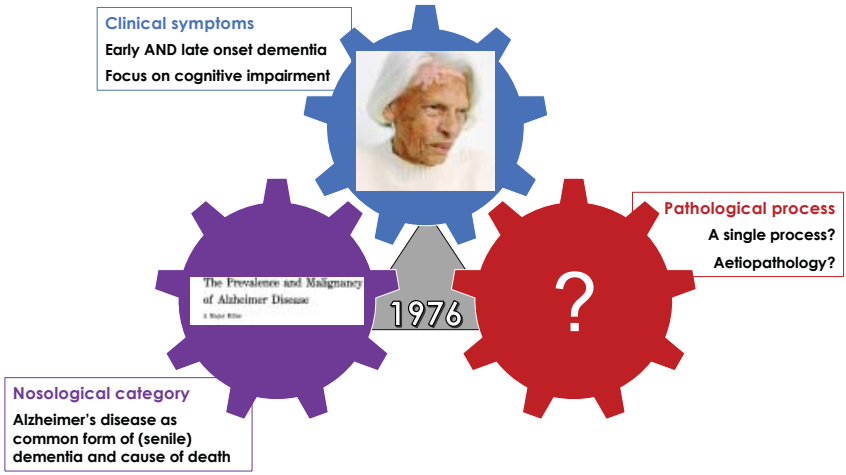

FIGURE 1.2. Schematic representation of the reconfiguration of the assumptions and the research agenda concerning Alzheimer's disease in 1976. Picture referring to the nosological category: Robert Katzman, "The Prevalence and Malignancy of Alzheimer Disease: A Major Killer," *Archives of Neurology* 33, no. 4 (1976): 217–218; picture referring to clinical symptoms: photographed by Peter Granser, reprinted from his book *Alzheimer* (Kehrer Verlag, 2005) with permission from Peter Granser/laif.

into psychiatric classification; it became an aim and object of inquiry in itself. Katzman reflected in his editorial not least on the provisional nature of the scientific evidence on which he suggested the nosological "consensus." This might again remind us of Kraepelin. However, contrary to Dillmann, I think his characterization as "neo-Kraepelinian" overshadows the re-addressing of an unresolved nosological query as a grand biomedical research program.

If we follow the Alzheimer's research field to the turn of the millennium, we can see again how the cogs were rotating—that is, how researchers refined questions and assumptions, as evidenced, for instance, through the introduction of staging and subtyping of dementia and possible precursors such as mild cognitive impairment. While the starting hypothesis and the positioning of the main question mark undoubtedly served to organize and fund research and collect a lot of data, they also increasingly gave rise to fundamental doubts, especially in the light of the failure to develop new therapeutics or vaccines despite massive private and public research efforts in the past fifteen years.

In Search of Clinical Consequences: Alzheimer's Disease around 2018

This and the following concluding section discuss two alternative frameworks that have been presented as responses to the futility of past research, in particular with respect to the development of effective drugs. They can be seen as existing in opposition to each other; however, dementia prevention strategies might be associated with both suggested reconceptualizations of Alzheimer's disease: the first, visualized in figure 1.3, is the continuation of the above-described rotating cogs with respect to early detection, subtyping and staging until the point where the main question mark shifts from the question of identifying an etiology to defining the disease via biomarker profiles and turning the successive occurrence of clinical symptoms into an empirical question. Already in the context of the revision process of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, the *DSM*-5, and in the updating of the diagnostic criteria issued by the National Institute of Aging (NIA) and the Alzheimer's Association in 2012, the controversy regarding the status of mild cognitive impairment as a diagnosis with unclear clinical relevance has received a lot of attention—not only within Alzheimer's research but also within the social sciences of medicine (see Moreira, this volume; Katz, Peters, and Ballantyne, this volume; as well as, e.g., Hughes 2006; Moreira et al. 2009): the inclusion of potential early mild forms of Alzheimer's disease has crystallized the current state of clinical research that aims for ever earlier diagnosis, thereby contributing itself to the creation of both uncertainty and new medical demands. In 2018, an expert group at the forefront of early diagnosis approaches to dementia research commissioned by the NIA went a step further when they finally published a new framework for research purposes. I will compare their conceptualization of Alzheimer's disease to the above-discussed earlier frameworks, as well as to the other currently discussed approach, visualized in figure 1.4, which follows from the futility of past research that the whole biomedical disease entity–based approach should be reconsidered in favor of public health and community-based approaches that increase the quality of life and decrease the social segregation of aging people, be they demented or not.

The comparison between the 1976 and 2018 schemes is somewhat different from their comparison to Kraepelin and Alzheimer's presentation in 1910 because there are many more direct personal, organizational, and political connections and continuities between the two more recent research programs. Indeed, as mentioned above, the definition of stages and "placeholder" categories (this is how the new *DSM*-5 category of "Minor Neuro-

cognitive Disorder" was introduced by the revision work group) could be described in terms of wheeling cogs and as a refinement of Katzman's program, in which the hypothesis of one disease entity is successively replaced with more sophisticated (potential) subtypes. However, I want to argue that the consortium surrounding Clifford Jack that proposed a new "biological definition of Alzheimer's disease," which shall not least be applied within grant proposals to the National Institute of Aging, signifies a larger conceptual reconfiguration because it alters the role of the assumed pathological features from being objects of query to acting as defining features in a nosological setup that moves the main question mark to the onset of clinical symptoms. I share both of my evaluations with critical observers from epidemiology and social work: the first being that this new framework involves experts, epistemic and economic interests, technologies (mainly neuroimaging devices) and hypotheses from the mild cognitive impairment research community; and the second being that the way in which this position is presented and powered by the National Institute of Aging provides a rather dramatic shift compared with the research criteria of the 1980s, in which the clinical diagnosis was a primary activity for selecting patient groups and not a secondary outcome of research.[10]

The NIA consortium proposed to harmonize terminology by introducing a new category, "Alzheimer continuum," which incorporated four subsets of "biomarker profiles." These profiles are determined by the abundance or lack of deposits of beta-amyloid, pathologic tau, and neurodegeneration (abbreviated as A, T, and N in the framework) as evidenced through neuroimaging in living persons. This serves to fulfill the seemingly paradoxical double task of offering a coherent biological definition of the disease to enlarge the comparability of research designs, and of presenting a conceptual and practical toolkit to put the question of what pathogenesis actually characterizes this disease itself under scrutiny. The price for this biomarker approach to defining Alzheimer's disease (AD) is the bracketing of the clinical syndrome as the primary reference point: "a syndrome is not an etiology but rather a clinical consequence of one or more diseases. A biological rather than a syndromal definition of AD is a logical step toward greater understanding of the mechanisms underlying its clinical expression," the framework's authors state (Jack et al. 2018).[11] This research framework is so much based on the epistemology of the window to act—that is, the possibility to detect and possibly intervene into biological alterations before clinical symptoms occur—that it systematically excludes approaches to identifying dementia via symptoms if they are not accompanied by an assessment of the proposed biomarkers. As a consequence, the "biological construct" is no longer the searched-for explanation of the clinical syn-

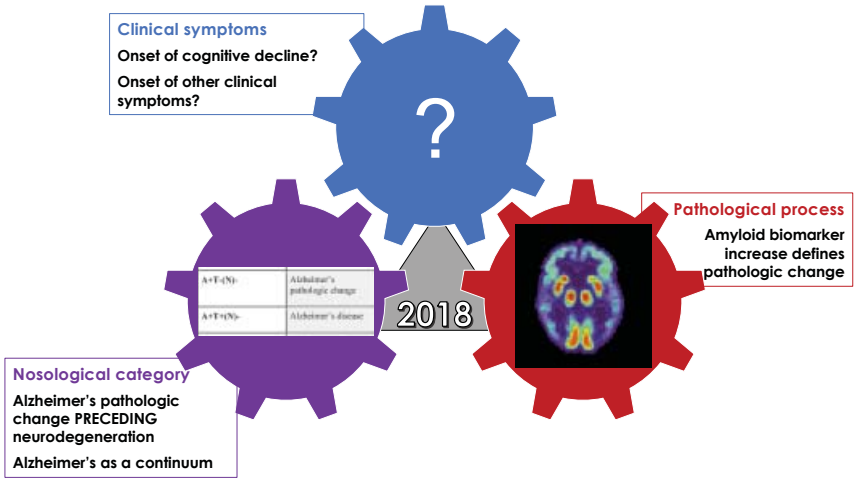

FIGURE 1.3. Schematic representation of the reconfiguration of the assumptions and the research agenda concerning Alzheimer's disease in 2018. Picture referring to the nosological category is a cutout from table 2 in Jack et al. 2018; picture referring to the pathological process: US National Institute on Aging, "PET Scan of a Human Brain with Alzheimer's Disease" (Wikimedia Commons, public domain, https://upload.wikimedia.org/wikipedia/commons/4/49/PET_Alzheimer.jpg).

drome, but becomes itself something that requires an explanation irrespective of its connection to the occurrence of clinical symptoms:

> We emphasize though that **A and T proteinopathies define AD as a unique disease** among the many that can lead to dementia. As a consequence, **disease models where A and T are not in the primary causal pathway must provide a mechanistic explanation for the development of both of these diagnostic proteinopathies**, as well as neurodegeneration and clinical symptoms. (Jack et al. 2018, their highlights)

Jack et al.'s (2018) framing of Alzheimer's disease does not undermine the triadic structure that they inherited from the early days of psychiatric nosology. However, it is utilized in a very different way, as illustrated in figure 1.3.

Time will tell how the cogs will turn this time, but two points shall be noted, which I will summarize in the conclusion with respect to the topic of dementia prevention: first, none of the three presented frameworks has so far resulted in the conclusive answering of the problems that they charted. Neither the clinical symptoms nor the pathological process have been suf-

ficiently characterized to serve as specific differential diagnostic features. The unresolved questions are carried on: Jack and colleagues motivate their new framework with both the lack of a clear taxonomic positioning of Alzheimer's disease and the past failure to identify the etiology of the disease. However, and this is the second point, given the significant conceptual reconfigurations, it is not clear how the results of the research that adheres to the new framework will relate to the questions set by earlier accounts. This does not mean that it cannot be relevant, but that extra work needs to be done to show this relevance.

The conceptualization of a window to act is a contemporary and consumerist interpretation of capitalizing on the time between the potential identification of suspicious biomarkers and the manifest experience of illness. This is the common point of conjuncture of early diagnosis and primary prevention, in which the latter shifts the timing (and often the means) of intervening even more outside of the traditional confines of medicine: early diagnosis precedes the experience of illness; prevention precedes (and ideally hinders) the onset of pathology. While some proponents of dementia prevention regard a biomarker-based early diagnosis as important to develop effective interventions, others take a seemingly contradictory step and advertise general preventive strategies, which leave open which pathological process these strategies are actually intervening in. Irrespective of the concrete operationalization of dementia, with each step ahead of time, the group of people that ought to do something—take a drug, undergo a test, eat healthy—gets bigger: from people with severe symptoms to people with mild problems or "at-risk" to everyone. What is more, both approaches legitimate themselves by alluding to the public image of devastating symptoms of dementia and the fear associated with the label of Alzheimer's disease. These legitimations build on an understanding of prevention that keeps the object of concern—what shall be prevented—relatively stable.

Conclusion: Alzheimer's Disease as a Working Title

I have argued in this chapter that the rather rigid understanding of medical entities as representing distinct pathological processes that result in specific clinical symptoms has throughout the history of the category of Alzheimer's disease served as a guiding ideal but was never accomplished. While directed toward this ideal—or, to use George Engel's polemical dictum, dogma—of a biomedical model of mental illness, the existing categories have served as working titles, thereby structuring the ways in which dementia was performed as a medical problem (see Engel 1977).[12] It follows that the question of what would be prevented when a given strategy

of "dementia prevention" is successful is not at all self-evident. If we want a sound assessment of the potential of preventive and other interventionist strategies to change disease trajectories, we need to pay attention to how the target "dementia" will be reshaped through the means that (are at) work.

The notion of a working title picks up the idea of a placeholder label that we briefly encountered in the previous section. These terms unveil an aspect of uncertainty, or undecidedness, and stress that the reference to Alzheimer's disease does not tell us much. This does not mean that possible pathological alterations or suffering from clinical symptoms associated with Alzheimer's disease are not real. It just means to acknowledge the heterogeneity of signs and symptoms and the preliminary nature of their associations to each other, and to evaluate every preventive promise against this background. Serious prevention programs that aim at Alzheimer's disease should be able to give an answer on how they handle the definitory muddle: how exactly could the success of prevention, the nonappearance of Alzheimer's, or, in the case of tertiary prevention, the deceleration of its aggravation be assessed?

Besides the preliminary nature of conceptualizing Alzheimer's disease, there is a second aspect to the notion of the working title, and this is the performative one: the work that labels do. Although, as we have seen, the big questions of defining Alzheimer's disease have not been settled, the introduction of this category, and its incorporation into research programs and the public debate, have undoubtedly had considerable effects—ranging from the structuring of self-help groups and nonprofit organizations around this diagnosis to the possibility of making an academic career as an Alzheimer's expert. Taking this performative force to the forefront—as representatives of critical gerontology have done—we can ask: how could the advertisement and pursuit of a given prevention program change the social representation of Alzheimer's disease? Does it have the potential to alter—for better or for worse—how people conceive of and treat patients with a diagnosis of Alzheimer's disease? Or, does it perhaps even contribute to an understanding of mental health and disease that transcends categorical thinking? This latter option has been propagated within the social sciences of medicine, for instance by Margaret Lock (2013). In light of the lack of success of biomedical research into Alzheimer's disease, she has suggested focusing more on public health measures to enhance the physical and social environment for old people with and without dementia-related symptoms. The prominent scientist-turned-critic Peter Whitehouse suggested even replacing "Alzheimer's disease" with "brain aging": this would enable patients and their relatives to employ less stigmatizing narratives and motivate more community-oriented interventions such as the development of

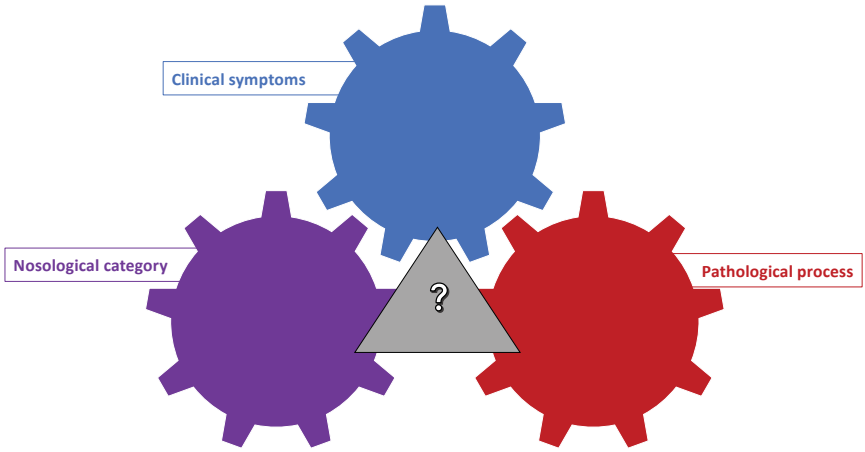

FIGURE 1.4. Schematic representation of the questioning of the medical categorical imperative.

intergenerational living environments, in which, for instance, the burden of losing capacities to live autonomously wouldn't weigh so heavy (Whitehouse and George 2008). Within the scheme of shifting question marks that I presented in this chapter, the move of questioning the integrity and utility of a specific disease entity altogether is visualized in figure 1.4:

The complete deconstruction of the disease entity–based approach and its replacement with a focus on general enhancement of the quality of life does, however, also come at a cost: it is even more difficult to evaluate the success and performative effects of prevention programs that are targeted at brain aging. Furthermore, Whitehouse and Lock might have good intentions, but the danger is that the old normative distinction between health and disease is replaced by new ones—for instance, regarding whether you properly cope with your aging body and brain.

The normative dimensions of disease descriptions do not disappear with the classification; they move to other items. As indicated in the above reference to critical gerontology, they can be derived from different disciplinary angles. I have taken here a historical perspective to highlight the shifting of priorities, assumptions, and question marks in the conceptualization of Alzheimer's disease. How the clinical diagnosis of Alzheimer's was used a century ago might not be directly relevant to recent developments in dementia prevention, but the awareness of the ways in which this category has been positioned and reconfigured helps us scrutinize—case by case—two promises of the preventive turn: the newness of its approach, and the relevance of its target of concern. With respect to the latter, I think this per-

spective can help us to think comparatively, to think through alternatives and to question what the most adequate characterization of the target of prevention—in a particular case and context—should be. My conclusion regarding the purported new paradigm of dementia prevention is equally relativist: instead of arguing for or against newness, I hope to have shown that it might be more fruitful to look for the development of overarching assumptions—such as that of a window to act—and study how they are put to work within concrete early intervention versus prevention programs. No doubt the outcome of present research enterprises will shape whether—and, if so, how—the conceptual foundations of understanding and dealing with dementia will move in the future.

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Notes

1. The British social psychologist and gerontologist Tom Kitwood (1997) coined the polemical slogan of the "Alzheimerization of dementia" to point at the dominant role that biomedical models of Alzheimer's disease (rather than person-centered care) played within the understanding of dementia in the last decades of the twentieth century. In this chapter, I do not intend to argue about whether this dominance is still pertinent. I use Alzheimer's disease as a case study and look into the

history of this medical category. My conclusions will be most informative for approaches to dementia prevention that allude to Alzheimer's disease, but I will use them to present more general questions regarding the legitimacy of the respective scope of dementia prevention.

2. "Alzheimer's worsens over time. Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. Alzheimer's is the sixth leading cause of death in the United States. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as twenty years, depending on other factors. . . . Alzheimer's has no current cure, but treatments for symptoms are available and research continues. Although current Alzheimer's treatments cannot stop Alzheimer's from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for those with Alzheimer's and their caregivers. Today, there is a worldwide effort under way to find better ways to treat the disease, delay its onset, and prevent it from developing." (Alzheimer's Association, n.d.).
3. For examples on how the establishment of Alzheimer's disease around 1910 and the popularization of the disease in the 1970s figure within analyses of the crisis of Alzheimer's research in the 2000s, see Dillmann 2000; Ballenger 2006a; Whitehouse and George 2008; and Lock 2013. For a critical discussion of the new NIA-AA research framework of a biological definition of Alzheimer's disease with respect to the shifting and closing of unresolved research questions from the point of view of epidemiology, see Glymour et al. 2018.
4. The section about Alzheimer's disease around 1910 is based on my reconstruction of Alois Alzheimer's epistemology of cortex pathology within Kraepelin's clinical psychiatry and my analysis of patient records of the Munich clinic archive; see Keuck 2017, 2018a. The latter also discusses the existing historiography of the "discovery" of Alzheimer's disease (e.g., Berrios 1990; Weber 1997; Ballenger 2006b; Maurer 2006; Gzil 2007; Borri 2012).
5. For a critical discussion on the making of the historical fact of the first case of Alzheimer's disease, and its employment within the recent biomedical discourse on the nature of this disease, see Keuck 2018b.
6. See, for instance, the introduction of Kraepelin's textbook and the programmatic opening paper of a journal that Alzheimer cofounded (Kraepelin 1910; Alzheimer 1910).
7. For a discussion of the uses of Kraepelin's categories for different purposes, see Engstrom 2005. To my knowledge, the first habilitation thesis on Alzheimer's disease was conducted by Ernst Grünthal, who handed in this work in 1925 and published it in 1926 (Grünthal 1926). He argues that Alzheimer's disease should be used as a category distinct from senile dementia, and also introduces an early age of onset as a diagnostic criterion.
8. Alzheimer's disease became such a big research issue that several new journals dedicated to this and related disorders were founded in the past two decades. One of them, *Alzheimer's and Dementia*, reprinted in 2008, the year of Katzman's death, his "landmark 1976 editorial" (Katzman 2008 [1976], quote from the editor's note, footnoted on 378).

9. For historical accounts of the development and impacts of Richard Nixon's National Cancer Act, see, e.g., Rettig 1977; Proctor 1995.
10. See Glymour et al. 2018; and, very polemical and critical, Garrett 2018. The following two paragraphs are slightly amended versions from my analysis of different positions within the biomarker debate and the roles attributed to theories of the normal and the pathological (Keuck and Freeborn, forthcoming).
11. The quoted emphasis style and page number refer to the authors' open access PMC document, available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5958625/pdf/nihms960157.pdf, accessed 15 March 2019.
12. For the performative role of medical classification in general, see, e.g., Bowker and Star 2000; Hacking 2007; Conrad 2007.

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2 THE VASCULARIZATION OF ALZHEIMER'S DISEASE

Prevention in "Glocal" Geriatric Care

Annette Leibing

Introduction

THE AIM OF THIS CHAPTER is twofold: first, I want to introduce three epistemic aspects—recent changes in the conceptualization of dementia that are part of, and sustain the current turn toward, prevention. Two of the three aspects are rarely discussed in the social sciences. And although I will focus here on only one aspect, all three are important in order to understand the way the life course and aging are rethought through the "new dementia." Second, I want to think about the impact of the recent turn: among multiple possible effects, stigma and exclusion are two that are likely to happen—a point I make relying on ethnographic data from Brazil. However, I also consider the idea of dementia prevention as a chance for a better old age, depending on how "prevention" is framed and enacted. Ultimately, I argue, prevention needs to be situated at different levels in order to make a difference.

The importance of situating the "new dementia" on a national level can be recognized when considering the accumulation of data showing that in several (high-income) countries (with the exception of Japan), dementia incidence and prevalence rates are actually stagnating or even diminishing (e.g., Manon, Gu, and Ukraintseva 2005; Schrijvers et al. 2012; Matthews et al. 2013; Qiu et al. 2013; Wu et al. 2017; Roehr et al. 2018). This observation seems to indicate that in some environments risk factors are better managed than in others. However, when looking at clinical trials that concretely tried to lower dementia rates by controlling one or several of the preventive risk factors involved in Alzheimer's disease (AD),[1] the results are not that clear-cut (e.g., Baumgart et al. 2015). As an example, the Dutch PreDiva study, which looked at efforts aiming to reduce cardiovascular risk factors in or-

der to lower dementia rates, made no significant findings. Researchers think that this is due to the fact that in Holland people already receive good health care with respect to most important dementia risk factors, and suspect that a major impact might have been noticeable in the context of a country with a less efficient health care system (Fagan 2016; see also Leibing 2018).

And if the prevalence of these risk factors (e.g., diabetes and obesity) is very high and even increasing, as, for example, in a great part of the United States (in addition to lack of access to good health care for all), the decline in US dementia rates—as has been shown in a study by Manon, Gu, and Ukraintseva (2005)—is likely linked to a privileged subpopulation within the country. This shows the importance of turning the focus of prevention studies away from individual behavior—a longstanding claim by critical public health scholars—and putting more emphasis on sociopolitical factors (Strighini et al. 2017; Bell, McNaughton, and Salmon 2011). It further shows that national studies say very little about a country's whole population, especially in nations with heterogeneous life conditions. This is also in line with a recent *Lancet* report that showed that—different from the original *Lancet* study (Livingston et al. 2017), in which the claim is that one in three cases of dementia could be prevented—in low-income countries, including Latin America, it could be a ratio of one in two because of the higher prevalence of risk factors when compared with richer nations (Mukadam et al. 2019). The ratio for richer nations has been recently revised to 40 percent of avoidable dementia cases (Livingston et al. 2020).

Adding to the complexity of recent insights into the idea of preventing dementia,[2] several authors also question the likeliness of a direct link between single risk factors and dementia, and observe that an oversimplification in the translation of such complex mechanisms into straightforward public health recommendations is taking place ("diabetes is linked to dementia") (e.g., Anstey and Peters 2018; Larson 2018; Humpel 2011). It is exactly this kind of fragmentation of otherwise interlinked biological, social, ecological, and politico-economic factors that I have called elsewhere an argumentative shortcut (Leibing 2016).

Another point regarding the situatedness of dementia prevention can be made regarding the two principal preventive measures (suggested separately or in combination) in current discussions: lifestyle changes and pharmacological interventions. Translations of such recommendations into practice and health policies are not the same internationally—local factors such as health and social politics, Pharma lobbying, epistemic cultures, and models of aging well, among other things, are responsible for differences and reveal the need for situating preventive measures in local contexts. For instance, when comparing clinical trials targeting prevention and dementia, the US trials are much more medication-focused than the

European ones; the latter privilege and more often test lifestyle changes (Leibing 2018).

So how could the idea of prevention become so successful and why did that happen only now? Although this chapter cannot answer these questions in their totality, I will mention in the next section three more recent epistemic changes that are part of the wider phenomenon and, as I will argue, are essential for understanding the recent preventive turn.

Recent Epistemic Changes Linked to Dementia Prevention: BPSD, MCI, and the Vascularization of Alzheimer's Disease

"The history of AD prevention is relatively short," remark Hsu and Marshall (2017) dryly. And knowing that a 2010 National Institutes of Health (NIH) "*State of the Science"* conference found insufficient evidence, on a clinical level, to support the association of any modifiable risk factors and AD (Baumgart et al. 2015), the current strong agreement among researchers and other stakeholders regarding the validity of the idea of dementia prevention needs some explications. After Hsu and Marshall (2015), especially the US National Alzheimer's Project Act (NAPA) initiative, launched by the Obama administration in 2011, resulted in several prevention initiatives. The novelty of the idea of dementia prevention can be also shown by the fact that as recently as 2015, a group linked to the US American Alzheimer's Association declared that

> the evidence has now reached a point that it can no longer remain simply an exercise in academic discussion. The public should know what the science concludes: certain healthy behaviors known to be effective for diabetes, cardiovascular disease, and cancer are also good for brain health and for reducing the risk of cognitive decline. For our part, the Alzheimer's Association is launching a new brain health education program, *Healthy Habits for a Healthier You*. It is designed to provide consumers with the latest research and practical information on ways they can take care of their bodies and brains to age as well as possible. (Baumgart et al. 2015: 723)

Remarkable here is the recent date of the declaration, but also that brain health is treated as part of bodily health, different from earlier brain-centeredness in dementia concepts and models. In fact, this kind of more holistic thinking became possible in recent years, because in the late 1990s a new subcategory emerged that challenged the "cognitive paradigm" that, after historian German Berrios, had prevailed in dementia research for a long time: the idea that dementia is an exclusively cognitive disease, to the detriment of the idea that any noncognitive symptom could be part of the

main definition of the dementia syndrome (Weber, Berrios, and Engstrom 2012; Berrios 1990). Support for the idea of this new category, BPSD (behavioral and psychological symptoms of dementia), was widely promoted, especially by the IPA (International Psychogeriatric Association) and generously funded by the pharmaceutical industry,[3] the latter desperately seeking new approaches to dementia because doctors until then had been prescribing medications with very limited effects on cognition. Finkel, one of the main organizers of the 1996 consensus conference on the topic, remarked that finally the first steps had been taken in recognizing that BPSD symptoms "are core symptoms of dementia and that it is as essential to study and treat any other aspects of dementing disorders" (Finkel 1996: 215).[4] Although BPSD has lost much of its initial importance as a category for assembling all those different psychological and behavioral symptoms, it was an important mechanism for a general opening up of the prevailing and narrow "cognitive paradigm." This opening up can be seen, for instance, when looking at how medications, originally developed and marketed only for cognitive decline, were relabeled for a much larger target, here activities of daily living (for a more detailed analysis of BPSD, see Leibing 2009a): "Data published . . . suggest that treatment with Reminyl® . . . may help to maintain the ability of patients with mild to moderate Alzheimer's disease to perform certain activities of daily living (ADLs), such as grooming, walking and being aware of current events" (Janssen 2004).

Thinking about prevention is also linked to a second change— a major emphasis on early detection: mild cognitive impairment (MCI)—before only loosely linked to dementia as an indicator of a possible future dementia—has now become more strongly associated with the central dementia syndrome, although more commonly in North America than Europe (Peter Whitehouse, personal communication; see Leibing 2018; but see Moreira, this volume). Further, what Metzler (2010) has called a "biomarkerization" of health and illness—the contested search for reliable early biomarkers even earlier than MCI—is linked to the general argument in dementia research (similar to other syndromes like Parkinson's disease and schizophrenia) that current interventions happen only when the pathology is already too far advanced to make much difference ("a window to act," as Keuck [this volume] calls it). It was only in 2011 that the workgroup responsible for the redefinition of clinical and research criteria, organized by the National Institutes of Aging and the Alzheimer's Association (NIA-AA), mentioned in their report the importance of biomarkers for distinguishing groups at risk at a presymptomatic level (Hsu and Marshall 2017).

A number of more critical social scientists have written about MCI (e.g., Moreira et al. 2009 and this volume; Lock 2013; Fox et al. 2013; Beard 2016; Schicktanz et al. 2016; Whitehouse 2017; Milne et al. 2018a and b;

Katz et al., this volume), and I will here just mention the authors' main arguments. The idea of early detection blurs previously existing boundaries between health and illness, and, as a result, asymptomatic or "mild" individuals can easily become "mild" patients, without the certainty that current predictive tests and biomarkers will do more than reveal a possibility of future illness. Some social scientists, such as Baker (2005), further argue that the increasing intensity of the search for biomarkers is directly linked to the desire for more cost-effective and quicker drug development. Further, preventive medications taken from midlife through old age would obviously mean major business for any Pharma enterprise, some argue, likely diverting funding that otherwise might go to improving environments of care (an either-or logic made by critical scholars that might be questioned or at least more nuanced).

A third aspect of the "new dementia" (and, like BPSD, rarely considered in social science research) is the one I am focusing on in this chapter: the growing importance of vascular or mixed dementias that in some contexts are almost merging with the previously separate category of "Alzheimer's disease."

Vascular Dementia: The New Alzheimer's?

During much of the twentieth century and especially after the Alvarez paper from 1946 on "Cerebral arteriosclerosis" (see Katzman and Bick 2000: 6–7), the focus on cognition (and forgetfulness) was paired with the idea that "senile dementia" was predominantly the consequence of arteriosclerotic changes in the blood vessels, while Alzheimer's disease was the rare early-onset form of illness that Alois Alzheimer had called "peculiar" (Alzheimer 1907; Holstein 1997; Katzman and Bick 2000). This idea began to be challenged in the late 1960s, especially after the famous Newcastle study (Blessed, Tomlinson, and Roth 1968; see also Wilson 2014). Results of this study showed a quantitative correlation of amyloid plaques and neurofibrillary tangles in the brains of deceased individuals with dementia, although the idea of a straightforward link has since then been relativized. The Newcastle researchers found these changes in presenile *and* senile forms of dementia and therefore argued that both forms of dementia were based on the same pathobiology. Since 1974, when Robert Butler and Robert Katzman made Alzheimer's disease the flagship disease of the newly founded US-American NIA (National Institute on Aging), Alzheimer's disease, now including also the late onset form, was linked to pathological changes in the brain (the famous plaques and tangles), and this became for many years the main focus of pharmacological research and interventions (Ballenger 2006; Holstein 2000). Because of the build-up of plaques

and tangles as the accepted main etiology of Alzheimer's disease, atherosclerosis lost its diagnostic strength and became an outdated category. As Hachinski, Lassen, and Marshall wrote in 1974 in the *Lancet*, "The use of the term 'cerebral atherosclerosis' to describe mental deterioration in the elderly is probably the most common medical misdiagnosis" (quoted in Reisberg 1981: 15).

At that time, vascular dementia (VaD)—always described as secondary to and unimportant in terms of number of cases relative to the major diagnostic category Alzheimer's disease—was clearly distinguished from AD by its etiology of mostly mini-strokes in the brain. And although VaD could be conceived as a continuation of the older concept of atherosclerosis with its cardiovascular origins—risk that could be lowered by certain interventions—no preventive public health recommendation resulted from insights into VaD, probably because importance given to that category was so small. Equally, although the risk factors typically linked to VaD (e.g., stroke, high blood pressure, obesity, etc.) became increasingly part of public health campaigns, these were not linked to VaD as a target of preventive measures. The National Stroke Association published the first stroke guidelines in the *Journal of the American Medical Association* in 1999, but findings—almost identical to findings in current dementia prevention studies—were not linked to AD as they are now (Hsu and Marshall 2017).

Robert Friedland, a neurologist at the University of Louisville, who suggested long before the *Lancet* report that lifestyle factors were involved in the development of certain dementias, told me in an interview about the resistance of other researchers to lifestyle suggestions:

> Sometime in the late '90s or early 2000s I presented a paper on the relationship between lifestyle factors and dementia risk. . . . At the press conference I spoke about our work and my suggestion that the available literature suggested that it was wise for people to avoid smoking, manage their blood pressure and diabetes, avoid obesity, live a life with high levels of physical and mental activity, avoid a high-fat diet and avoid head injuries. When I finished [someone from the Alzheimer's Association] got up and raised his hands out wide to the right and left for emphasis and said "Wait!, Dr. Friedland's suggestions have not yet been verified by a double-blind placebo-controlled randomized trial!" I explained that what I had recommended was already known to be good for people anyway. There was nothing I proposed that could possibly be harmful! I think the problem is that many people cannot see the forest for the trees in their search for scientific rigor. They forget that "absence of evidence is not evidence of absence."

Mixed dementia, a category meaning that AD and VaD co-occur, was considered of equally little importance when compared to Alzheimer's disease, the predominant diagnostic category claiming most funding and re-

search at the time (Ramón 2004). My argument here is not only that the boundary between AD and VaD has significantly changed—definitions for both now relying on almost the same risk factors—but also that the new turn toward prevention (and early detection) cannot be understood without taking into consideration this redefinition of AD.

In fact, the link between cardiovascular risk factors and Alzheimer's disease has been noted before: the APOE (apolipoprotein E) gene, and especially its allele ϵ4 (e.g., Slooter et al. 1997), which is understood to elevate the risk of developing the dementia syndrome, is also involved in heart disease; APOE is responsible for the transportation of fat in the body. This causal relationship was initially identified in the 1980s (e.g., Yamamura et al. 1984); however, it was widely ignored until 1993, when neurologist Allen Roses (2006) made a significant discovery that linked APOE to the "sporadic" form of Alzheimer's disease (the most common form, where heredity plays less of a role than in the rare "familial" one). One possible reason for the scientific community's delayed emphasis on cardiovascular risk factors can be attributed to the fact that when Roses established the link, hopes were focused on directly targeting the dysfunctional brain chemistry with the new cholinesterase inhibitors targeting molecular mechanisms. In 1993, Tacrine arrived on the market, although from the beginning—as was the case for its successor drugs—some critical voices argued that the target of this kind of intervention was too narrow for a complex syndrome like Alzheimer's disease (e.g., Levy 1990). Historically this is astonishing because a cardiovascular logic was becoming increasingly dominant in biomedicine starting in the 1950s, and around 2000 became the underlying condition explaining and interlinking a number of previously separated disease categories, transcending the more traditional division between mental and physical health reinforced in most biomedical realms (see Leibing and Kampf 2013 for a more detailed analysis of a "cardiovascular logic").

The merging of the categories AD and VaD has been observed by several authors. As early as 2000, Breiteler was writing about the common etiology of VaD and AD: "Evidence is increasing that the two [AD and VaD] may be more closely linked than just by chance. Epidemiological studies have suggested that the risk factors for vascular disease and stroke are associated with cognitive impairment and Alzheimer's disease" (43). But it is only recently that this merging of categories based on common risk factors has become more mainstream (see, e.g., Kolata 2019 in the *New York Times*), although translated into different kinds of recommendations depending on the context (Leibing 2018). Kling et al. (2013: 76), in their article about the "paradigm shift" regarding the role vascular disease plays in the etiology of Alzheimer's disease, write that "VaD is often said to be the

second most common form of dementia after AD; some authors have even suggested it is the most common form." So what does this rethinking of dementia mean in terms of concrete preventive practices?

New Pathways for Dementia Prevention

The changing landscape of prevention is tightly linked to etiological reasoning. These new models can be well illustrated by looking at the common metaphor used in older texts about AD as a "mysterious disease" versus newer definitions in which AD and VaD are increasingly merging (although they are still used separately by clinicians) and, therefore, are now losing their mysterious character. The metaphor of "mysteriousness" was and is still being applied in order to highlight the difficulty of explaining the etiology of AD. The use of mysteriousness causes risk factors to appear less relevant—it presents AD as rather free-floating and immutable category, devoid of context. In fact, Alois Alzheimer used the word "peculiar" when describing his first case, Frau Auguste Deters, because he did not know whether her early onset symptomatology had the same origin as senile dementia of older patients. And although earlier accounts of Alzheimer's disease also found a correlation between less education (education often merging with and indistinguishable from poverty and its manifold factors that impact on health), depression and nutrition, and a higher incidence of dementia (e.g., Friedland 1993 for the US; Aprahamian et al. 2008 for Brazil), until recently the idea of the disease as fundamentally mysterious was never really challenged. Those earlier studies that showed a link between dementia rates and some of what are now considered "new" risk factors had no wider impact on the conceptualization of dementia because the link between the brain and factors like nutrition and education was mostly subsumed under the—previously unimportant—category of VaD. Risk factors were also only peripherally linked to AD because of the great hope that came with the first dementia-specific medications (the first drug, Tacrine, arrived on the market in 1993). These medications were developed based on the idea—commonly called the "amyloid hypothesis"— that they would prevent the breakdown of acetylcholine (or, in the case of a drug called Namenda, regulate glutamate in the brain)—an idea that found an enormous market worldwide (e.g., Ramsey 2017).

An example of current usage of the word "mystery" as not knowing with respect to AD etiologies can be found in attempts to treat dementia based on the amyloid hypothesis and similar brain-based mechanisms. In this quote, Gandy (2019), a neuroscientist, summarizes dementia research this way: "So, doctors gradually began to recognize the disease, but the truth is, doctors aren't certain that these plaques cause Alzheimer's dis-

ease, and doctors don't know what usually causes those plaques. In some ways, Alzheimer's disease is still a mystery, much as it was 100 years ago." This continuing concern with the disease as basically inexplicable or mysterious is also expressed by Pharma reps in Brazil responsible for selling a current dementia drug based on the traditional model of intervening on the ß-amyloid production in the brain. However, in explaining the mechanism of this AD drug, this pharma rep makes it clear that the older focus on cognition has been replaced by the "softer" target, quality of life, and activities of daily living, a change that has become possible after adoption of the BPSD category (see above):

> The indication for this medication for Alzheimer's is to improve the patient's quality of life, to improve activities of daily living and behavior. There it works. The mechanism of how it really works is kind of complicated (*meio complicadinho*), so to speak. . . . What we studied with the MDs is that there is the acetylcholine and people with AD have such a deficit, *né*? The drug improves this activity . . . . So it works more or less like that, the question of behavior, activities of daily living, less of a decline. (pharmaceuticals sales representative in Brazil)

An example of the hope of finding a silver bullet-drug based on prevention, which equally demonstrates the transformation of "mysteriousness" into knowledge as grounded in a plausible model, is the recent failure of the much-anticipated AD drug aducanumab, which, starting in 2015, had already reached phase 3 of the clinical trial. The underlying logic here, as already mentioned above, is that treatment needs to start at a very early stage. In the end, as Biogen/Eisai announced in March 2019, patients treated with this experimental drug, a monoclonal antibody that was tested on people with mild or moderate AD, showed no cognitive improvement after eighteen months. The hype around aducanumab, which got a "fast track designation" from the FDA that only very promising drugs receive in order to reach the market more quickly, was based on earlier studies that seemed to show that the compound could switch off the production of beta-amyloid (Aß) in the brain.

The reactions to the failure of the phase 3 EMERGE and ENGAGE studies (PRIME is the name of the European equivalent study), which involved more than 3,200 patients, neatly mirror the different epistemic models currently at work in the scientific dementia research community. Comments by researchers on this event can be separated into the following (nonexclusively used) arguments: (A) those who believe that the antibody tested was not the right one, but that a similar antibody will be a solution, and that the current Aß model (or tau) is not yet dead; (B) those who think that still

earlier stages of AD need to be considered and that the current target of either Aß or tau or both is still valid; (C) prevention is seen at the moment as the only possible pathway—as one blog for researchers describes it, "All eyes are now trained on prevention trials" (Alzforum 2019)—a radical rethinking of dementia models. The following comments illustrate some of these different points of view:

> (for B): "Even though this trial was in the early symptomatic phase of AD, it is still in the phase when Aβ is no longer likely to be the driving process but where tau and inflammation probably are," noted David Holtzman, Washington University, St. Louis. "I think Aβ is still a good target for the primary and maybe secondary prevention trials of AD, before tau and inflammation have started driving the disease," he added. (Alzforum 2019)

Several, though by far not all, dementia researchers, however, question the focus on Aß, as many others did already before the trial. Stefano Sensi, an Italian researcher (CeSI-MeT), for example, writes,

> (C): The failure of the Phase 3 aducanumab trial is another warning that the field must take a different approach. Some authors have already called for a rejection of the amyloid hypothesis . . . . AD is a multifactorial condition in which, along with Aβ accumulation, the convergence of many genetic, environmental, vascular, metabolic, and inflammatory factors promotes the neurodegenerative process. . . . we need to remind ourselves that a third of AD cases are strongly dependent on the concerted activity of modifiable factors like low education, midlife hypertension, midlife obesity, diabetes, physical inactivity, smoking, and depression. . . . It is time to take up the challenge of complexity. (Alzforum 2019)

Further, Kasper Kepp from the Technical University of Denmark writes (it might be no coincidence that the more critical voices come from Europe [see Leibing 2018]):

> (C): It has been known for many years that the amyloid hypothesis cannot be correct; the reason it survives is because it is appealingly simple and offers a one-sided treatment strategy that pharma can pursue easily by antibodies and inhibitors. . . . Unfortunately, these people include, because of the paradigm's previous popularity, major opinion-leaders and big pharma with a responsibility for listening to only some key opinion makers of the dominating paradigm in the time of its sunset. (Alzforum 2019)

What is striking here is the fact that the traditional approach to dementia—only targeting Aß in the brain—and the concomitant call for recognizing

more complex approaches after the failed trial—by examining multiple preventive pathways—is transferring the inconclusive, "mysterious" concept of AD into a more grounded, manageable, and concrete concept of intervention. While this new pathway can mean (lifestyle) changes like exercise, nutrition, good education, and good access to health care, the same kind of reasoning is also opening up further possibilities for pharmacological interventions. On the US Alzheimer's Association (2016) website, hope is expressed that in the future, drugs will be developed that address the complexity of the dementia syndrome: "Many of the new drugs in development aim to modify the disease process itself, by impacting one or more of the many wide-ranging brain changes that Alzheimer's causes. . . . Many researchers believe successful treatment will eventually involve *a 'cocktail' of medications aimed at several targets, similar to current state-of-the-art treatments for many cancers and AIDS*" (emphasis added).

The vascularization of Alzheimer's disease has not only changed how dementia is being studied, diagnosed (now less clear-cut as the presence of cardiovascular risk factors used to be understood as a distinctive sign of VaD), and potentially prevented, but has also had an impact on moral citizenship or social sorting: the (re)categorization of people as morally good and bad, as in the following case study in Brazil. What I am calling the vascularization of AD is being debated internationally; however, local ways of integrating current claims and its translation into concrete practices needs to be seen as situated, as "glocal"—tightly intertwined with international theories and recommendations while confronting diverging realities in which knowledge gets adapted (Fernandez 2009).

The Vascularization of Alzheimer's Disease and Moral Citizenship: Data from Brazil

This section is based on an ethnography undertaken between 2015 and 2017 in a geriatric outpatient clinic in Brasília, Brazil's capital. Observations of the clinic's routine practices and interviews with health practitioners, family caregivers, and (a few) patients were combined with interviews and observations in other aging-related milieus (the Ministry of Health, public health posts, the Alzheimer's Society, etc.) on the meaning of prevention in this particular context. For this chapter, I will focus mainly on the interviews with the clinic's health practitioners and some researchers studying dementia-related issues (n=21), in order to flesh out the way aging individuals are described, classified, and evaluated as doing the right thing.

Brazil and Common Risk Factors for Dementia

Brazil has the sixth largest population of elderly people in the world and has experienced a very rapid demographic transition (Ministry of Health n.d.; Camarano 2006, 2008). Since the main risk factor for dementia is aging, the epidemiology of dementia has also shown a dramatic increase in recent years: after Burlá et al. (2013: 2949), this increase "varies strongly between regions and seems to be especially elevated among illiterate people," with a national mean prevalence of 7.6 percent. The reasoning adopted by Burlá et al. is striking—earlier epidemiological studies in Brazil produced results with a similar prevalence as studies from abroad, something stated regularly (and, in my opinion, proudly) in the conclusions of those publications (Leibing 2019).[5] Now, however, it has become an accepted truth that Brazil is special and that dementia rates are higher there than in the richer nations because of the many people in Brazil who receive little or no education, evoking a double penalty from the lack of education in this population: the missing cognitive reserve related to more education, and also a presumed lack of understanding regarding self-care correlated with the presence of several risk factors (e.g., alcohol, diabetes, hypertension).[6]

The newer modifiable dementia risk factors are very high in Brazil (e.g., Seibt 2017). However, better education and better access to health care—though with regional differences— occurred under the governments of Lula (2003–2011) and his successor, Dilma Rousseff (2011–2016), and hypertension and heart disease has slightly improved also among low-income groups (Massuda et al. 2018; Beltran-Sanchez and Andrade 2016; Marteleto, Marschner, and Carvalhaes 2016). One study showed that between 2000 and 2010, life expectancy without depression in São Paulo had increased (Andrade et al. 2016), possibly reflecting better living conditions in one of Brazil's richer states. Improved social conditions under these two presidents were probably too short-lived to have a measurable impact on dementia rates; the government that subsequently came to power under the conservative president Michel Temer was notable for severe austerity measures introduced in many areas (Souza 2017), while the future of health care and education under ultra-right president Jair Bolsonaro (starting in 2019) has yet to be seen, although it looks like an announced catastrophe (see e.g., *Lancet* 2020).

Interviews with Researchers and Health Professionals

In general, interviewees—mostly geriatricians—were aware of the newer factors associated with increased risk of dementia, even though few talked

spontaneously about this. When asked, most of them told me that this topic was not so important for their practice, mainly for three reasons:

1. Some geriatricians told me that they were managing these risk factors anyway, that they had always done this when treating aging individuals, and that only now was this called dementia prevention.

2. Others argued that in the public setting, most new patients were already at an advanced age, while most preventive measures take place during middle age, although in their private practices they were seeing younger adults who might still change lifestyle and medications.

3. Generally, however, interviewees answered with a deep sigh and explained that, in Brazil, prevention does not work. The lack of self-care among less educated people and a lack of government investment in health care and educational programs were perceived as insurmountable obstacles in adhering to preventive measures and, especially, vascular factors (those leading to stroke and other vascular accidents):

> We here in Brazil, we are sinning a lot by not helping people to have the chance to prevent what is preventable. . . . *Our level of education is very low, to the point that the average Brazilian does not understand* that those [dementia-related chronic] diseases need constant control, not just a brief intervention. . . . But treating diabetes and hypertension does not change much if people are not constantly stimulated, educated. . . . Neurons only degenerate if they are not constantly stimulated. (university researcher, emphasis added)

The double problem of both a need for education for its cognitively stimulating effects (brain reserve) and the lack of education regarding responsible self-care revealed in this quote is for this researcher a national shame: although this researcher accuses the government of not providing the right conditions, it is the individual's "level of education" that is the core problem, meaning that ultimately, the government's responsibility is seen as educating people into doing self-care and not as generating better social conditions in which a healthier life is possible. These politics of blame (Ladd-Taylor and Lomansky 1998) apparently name and, at the same time, reduce state responsibilities and the awareness regarding contexts of risk. Another interviewee, a professor of pharmacology, also referred to the lack of adequate education and explained, "In my opinion, Brazil has a serious problem with education. And this impacts someone's self-care. Many diseases [like diabetes and hypertension] are silent, so people say, I have no pain, so I don't have anything."

Although interviewees acknowledged with a lot of compassion social contexts and lives difficult enough that self-care can become impossible—when, for instance, food intake is driven by what Bourdieu (1984) calls "tastes of necessity," or when medications are too expensive—the blaming of poor people for their poor health occurred in more or less explicit ways. This explains, at least partly, that in this context the explicit separation of VaD and AD is maintained in clinical work, distinguishing between VaD as a category of culpability, while AD maintains connotations of a more "mysterious disease", without explanation (as it has been called for a long time in Brazil and abroad).[7] So even if the vascularization of AD was acknowledged by the interviewees, it stayed in the context of science theories; in everyday, clinical life, AD and VaD are separate entities, and the moral weight of the modifiability of risk stays within the category VaD, at least when talking about poorer patients. In the following example, mostly vascular risk factors—here clearly assigned to vascular dementia, but mirroring the newer discourse on preventing dementia—are described in order to mark people's behavior as disease-inducing.

A young resident told me about her second job at a public health center in a very poor neighborhood where she does mostly home visits. Most older people in that neighborhood have dementia, she explained, but have not received a diagnosis. They all had, in her opinion, vascular dementia and not Alzheimer's disease. "Even younger people often had already had strokes," she continued. This is in line with health statistics showing that, as in many other countries, stroke is currently the second greatest cause of mortality throughout Brazil, after cardiac conditions, and more prevalent in the country's poorer states (França et al. 2017).

She, like several other interviewees, used the expression "this is cultural" in order to explain the impossibility of intervening and changing unhealthy habits. The resident, who in general had an especially kind and sensitive way of treating her patients, told me,

> There is the cultural question, that people think they only have to go to the doctor when they are very ill. And do not do anything before getting sick. So they do not exercise, do not stop smoking, do not stop drinking. All that. And then, when they need help, the access to health care is very difficult, because there are many people out there, and the public health system cannot take care of all of them.

What is striking in this quote is that the resident described a deficient health system, unable to help all Brazilians, but this fact appeared of secondary importance compared to the sick person's bad health habits. Another informant told me bluntly that one of the risk factors, hypertension, is a disease of poor people who refuse to behave in a responsible way:

> [Hypertension] medications are distributed for free . . . in the population I studied; older people have good access to certain medications [there], but they do not control their blood pressure the way they should. . . . They don't take these medications—[because they think:] "hypertension is so common, why take this medication?" Because it makes people ordinary! . . . Hypertension is a disease of poor people. "I want to have a disease of rich people," they say. (geriatrician "A")

"We should not have this problem [of dementia]," says an interviewee at the Brazilian Ministry of Health, referring to the new risk factors as modifiable. "Diabetes and hypertension medications are distributed for free here, but people have crazy lives; we see an improvement, but not as much as we wished for."

One can see that there are different kinds of translations of risk at work: first, there are three risk factors—diabetes, hypertension, and poor education—the interviewees focus on. The first two are based on an easy-to-communicate logic of a measurable disease in combination with compliance to prescriptions for medications. The apparent simplicity of such a logic makes dementia rates of supposedly noncompliant people even more irrational. Levels of education, however, is understood in two ways: (1) as a risk factor for dementia, but also (2) as part of an attitude toward responsible self-care—in other words, as ignorance—involving all other risk factors that are not being taken care of. In fact, the mechanism found in several interviews regarding education is the merging of the risk factor (1) with the idea of education as ignorance (2), as in the following quote:

> Maybe in more developed countries, . . . the politics of controlling diabetes and hypertension meet a population that is already prepared to benefit from it; they already have an educational level that allows them to benefit from such a control of diabetes and hypertension. In Brazil there is an unprepared population, an old person or an adult who doesn't have a good educational level in order to do a constant cognitive stimulation, so that even when he controls hypertension and diabetes, this only has a minor impact. (researcher)

This kind of thinking is also prevalent when the state is explicitly mentioned as not providing the right conditions for better health. In the following quote, the association of VaD with poor people is striking—an association that could also become true for AD once the vascularization of AD becomes more widely accepted in Brazil and abroad.

> Vascular dementia in Brazil, *ave Maria*! I am sure it is worse than in any other country. In the first world, diabetes and hypertension are well controlled. We

> will never get there. That is very sad. And especially in the public system, that's a mess. . . . It is difficult to have access to medications, difficult to change lifestyle, difficult to change the diet and all that. . . . The access to health care is difficult—because of all this patients have more ischemic events, micro-angiopathies . . . . And so rates of mixed dementia and the vascular one are very high. In Ceilândia [very poor area], people are unable to buy certain medications. And if I decide to prescribe one they get for free, it will likely be an old medication, with heavy side effects. It is heartbreaking. Sometimes families can buy one medication, but not another. (geriatrician "B")

The sense of resignation regarding less educated people is paired with a resignation regarding the state. Two residents told me that poorer people only get medications that are the cheapest option, often not the latest generation of drugs, and that are less effective than those prescribed to richer people. They stated that corruption exists throughout the entire medication business. Several scandals about politicians and administrators who embezzled money from the health system contribute to the general feeling that good care also means fighting deeply entrenched immorality, contributing to the general feeling of impotence regarding the possibility of preventing dementia (and other health issues). However, others reported that although poorer people get medications that are less effective, in the end—through longer and more complicated therapeutic pathways—the results are the same when compared with people taking last-generation meds.

Conclusion: Vascularization as a Chance for Rethinking Old Age (as Undemocratic)

The vascularization of AD has been shown to be morally charged when it results in sorting out mostly economically disadvantaged people as irresponsible without taking into consideration that most risk factors need to be addressed through better health care and education—through better living conditions for all. However, this reading of recent changes should not be used in order to debunk dementia prevention, but rather as a question of framing and nuance—and even a chance for better health. I want to make this last argument by using another metaphor often found in texts explaining dementia to a wider public:

For many years—and still sometimes today—Alzheimer's Associations and other organizations, self-help books, and media releases promote the mobilizing idea that Alzheimer's disease is a "democratic disease." By adopting this equalizing notion, promoters of this idea want to make the case that everybody is at risk of getting the syndrome (and so every-

body should be concerned), independent of race, education, and socioeconomic background (e.g., Alzheimer Europe 2015).[8] This "democracy" can only make sense if AD is conceived of as mysterious—as relatively unchanging in relation to risk factors—but this idea no longer holds up. Instead of looking primarily at the accumulation of plaques and tangles, the recent vascularization of Alzheimer's disease anchors the brain, so to speak, in the body (e.g., in a cardiovascular logic), and the individual in his or her social context (e.g., in loneliness or level of education as risk factors). In terms of the increasingly popular idea of (neuro)plasticity, the new dementia has become "plastic"—modifiable by different kinds of risk (cf. Meloni 2019)—while AD conceived of as mysterious would be relatively immune to external factors. However, as Meloni (2019: 10) writes in his recent "archeology of plasticity," "not all bodies are considered equally permeable." In the Brazilian example above, poorer people's bodies were considered more plastic or vulnerable to risk factors. This kind of thinking can be understood as blaming; however, depending on the framing, the "new dementia" can also become a real chance to understand the complexity of what is at stake in arguments regarding aging in better health. By conceiving dementia as profoundly undemocratic—by inverting the relatively common metaphor of "democratic dementia"—we can no longer talk about effects on everybody, not even in terms of different kinds of effects on whole groups (as for example, in the older "ethnic" studies that compared "the" Asians with "the" Americans). The "new dementia" is a move toward thinking in terms of subgroups: VaD will "become the commonest form of dementia" worldwide, predicts Ramón (2004: 49). He suggests that differences will not exist between nations anymore, but instead between specific kinds of subgroups: "Variations in incidence and prevalence are found in different racial and ethnic groups, probably related to the preponderance of large-vessel atherothrombotic disease and cardiac embolism in some groups, and small-vessel disease from diabetes and hypertension in others" (Ramón 2004: 50). Ramón opens the door to "undemocratic" thinking of differences, although "racial" and "ethnic" factors do not explain a lot per se. The American Heart Association (see Havranek et al. 2015) recently published an extensive statement about the relation of cardiovascular diseases with disadvantaged groups. This opening up from the once too narrow perception of risk would also be possible for the case of dementia if the latter wasn't stuck with the remaining bits and pieces of brain-centeredness, mysteriousness, and the idea of a democratic disease, as well as interests in narrower frameworks by some groups, mostly parts of the pharmaceutical industry.

As with criticism made regarding more traditional public health studies (e.g., Bell et al. 2011), dementia studies establishing subgroups at risk can end up laying blame on the members of those groups, and the work on risk factors can be privatized and individualized, and interventions pharmacologized, instead of putting the emphasis on structural factors, such as living conditions in combination with responsible medication use and other interventions.[9] But if Alzheimer's disease is conceived as profoundly *un*democratic and effort is being made to enhance living conditions, there might be a real chance to have less dementia in the future.

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Notes

1. As mentioned in the introduction to this volume, the risk factors mentioned in the *Lancet* report (Livingston et al. 2017) are early life education; midlife hypertension, diabetes and hearing loss; and later life smoking, depression, physical inactivity, social isolation, and diabetes—as well as other possible contributing factors such as sleep, pollution, and diet. Although other factors can be found in the literature, for the moment I will focus on these nine.

2. The recent study by Bancks et al. (2019) further complicates the comprehension of preventing dementia as it puts a lot of weight on cardiovascular risk factors: the authors argue that in the United States, educational attainments, and not cardiovascular risk factor profiles, are responsible for better cognitive performances over time.
3. The first consensus conference on BPSD was financed by Janssen Pharmaceuticals with an unrestricted grant (see Leibing 2009a and b for more detailed accounts). The promotion of BPSD was tightly linked to the prescription of drugs, especially antipsychotic drugs, with serious side effects. See https://www.justice.gov/sites/default/files/opa/legacy/2013/11/04/us-complaint-pa.pdf for a civil action in the United States against Johnson & Johnson and its subsidiary enterprise Janssen.
4. The BPSD symptoms, as defined by the IPA (Int'l Psychogeriatric Associations 2012 [1998]): "*Behavioral symptoms*: Usually identified on the basis of observation of the patient, including physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing and shadowing. *Psychological symptoms*: Usually and mainly assessed on the basis of interviews with patients and relatives; these symptoms include anxiety, depressive mood, hallucinations and delusions. A psychosis of Alzheimer's disease has been accepted since the 1999 conference."
5. One example for earlier texts perceiving and measuring dementia rates as equal to international trends is Aprahamian et al.'s (2008: 2) observation from a meta-analysis that "Brazilian studies show similar prevalence and incidence to foreign studies." See also, e.g., Lopes and Bottino 2002; Herrera, Caramelli, and Nitrini 1998.
6. "The concept of reserve accounts for individual differences in susceptibility to age-related brain changes or Alzheimer's disease-related pathology. There is evidence that some people can tolerate more of these changes than others and still maintain function. Epidemiologic studies suggest that lifetime exposures including educational and occupational attainment, and leisure activities in late life, can increase this reserve" (Stern 2012: 1006).
7. Several authors, especially in the media, still use this older image of AD as mysterious (regarding its etiology), but now in order to highlight that it has become more manageable, more concretely preventable. For instance, "Alzheimer's disease has been a mysterious disease ever since . . ." begins an article on the blog *ScienceSource*, and continues by reporting the possibility of preventing AD by using anti-inflammatory drugs (see "Have We Found the True Cause of Alzheimer's?," *ScienceSource* blog, http://www.custom-images.sciencesource.com/science-source-blog/2018/11/9/have-we-found-the-true-cause-of-alzheimers).
8. "There is no conclusive evidence to suggest that any particular group of people is more or less likely to develop Alzheimer's disease. Race, profession, geographical and socio-economic situation are not determinants of the disease. However, there is mounting evidence to suggest that people with a higher level of education are at less risk than those with a lower level of education" (Alzheimer Europe 2015).
9. "Democratic" as a popular trope in mostly older Alzheimer texts makes sense when opposed to "undemocratic," here understood in the same sense as "democratic racism" that Marmol (2016) describes as lip service paid to equality in pluralistic societies in combination with blame, instead of a recognition of structural factors involved.

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3 IF DEMENTIA PREVENTION IS THE ANSWER, WHAT WAS THE QUESTION?

Observations from the German Alzheimer's Disease Debate

Silke Schicktanz

Introduction

German popular science author Michael Nehls published various books in short succession promoting a (specific) preventive lifestyle approach for Alzheimer's disease, all of which made it to German bestseller lists. In one of his earlier books (Nehls 2014), he primarily defends lifestyle changes regarding diet, social and physical activities, and mindfulness, while in another book (Nehls 2015), he explicitly promotes early or predictive diagnostics of dementia for "doing something against it." Apart from his economic success as a pop science author, he published one scientific article (Nehls 2016, cited six times by February 2019) to promote his "Unified Theory of Alzheimer's disease (UTAD)" in which he defends a theory of complex, interlinked risk factors: "If we want to win the fight against dementia, only an aggressive correction of all (!) individual risk factors (deficiencies) might, according to the UTAD, turn out to be a successful strategy." And he concludes, "Fighting AD does not mean fighting human nature. Claiming that AD is mainly and fatally caused by aging per se unjustifiably frightens the public. Furthermore, who would be willing to change his way of living if researchers belittle the effects. Therefore we should rather encourage a change to a healthy lifestyle and offer early diagnostic services in order to correct AD-causing deficiencies as early as possible" (Nehls 2016).

As I will argue in this chapter, Nehls's approach is somehow illustrative of the German discourse, even if Nehls is more or less ignored by mainstream scientists. The German dementia discourse can be characterized by

the new shift from cure to prevention and prediction in a rather short period of time. Within the German context, a concept of prevention prevails that is based on a complex, rather cybernetic and holistic understanding of disease etiology. The "cybernetic" aspect refers to the regulatory concept of a system, in which different components interact in a closed loop. This "systematic" approach leads to a favored combination of measurements including complex reduction of vascular risk, protective habits related to social activity and diet, the strengthening of one's resilience, and biomolecular therapies. I will examine how the debate on dementia prevention is culturally situated and show peculiarities that might also have particular ethical implications. The ethical assumptions refer to new individual and social responsibilities, while the underlying probabilistic causalities must be questioned.

To develop my analysis, I will start with some more general background observations on how the shift from care and cure to prevention has unfolded and which ethical questions were raised. I will then provide insights from our own discourse analysis based on a literature analysis of the professional and popular scientific debate of the last twenty years. Hereby particular discursive trends and differences in both fields—professional and popular science—should become apparent. In the last part, I will ethically reflect on these discursive trends and their implications for the moral self-conception of different groups and individuals in the health care system: the state, the medical profession, the individual, and the individual's social environment.

Background: Medical Shifts from Prediction To Prevention

Current research in dementia, especially on Alzheimer's disease (AD), records a shift from cure to prediction and prevention based on a new conceptualization of dementia as a continuum (Schicktanz et al. 2014; Schicktanz 2017). This AD continuum theory promotes three stages of a slowly progressing disease with a long, asymptomatic (for some: preclinical) first phase that starts without any symptomatic changes and only pathological molecular deviations become apparent (such as increased tau protein levels and/or beta-amyloid protein in the spinal liquor). The disease then turns into a symptomatic second stage involving mild cognitive impairment (MCI) and objective deviant physiological biomarkers (such as amyloid plaques or brain volume reduction, especially of the temporal lobe [measured by neuroimaging]). Eventually, in a third stage, it develops into a clinical syndromic disease with an already advanced pathology (Sperling

et al. 2011; Dubois et al. 2010; Hampel et al. 2014). Others have tried to describe this continuum with even more subdistinctions of stages (Jessen 2019) of which the onset of the neurobiopathological mechanisms occurs already twenty-five years before the outbreak of the disease. According to this understanding, this first asymptomatic phase converts to a second, only yet subjectively experienced, symptomatic stage for five to ten years, where the currently existing neurophysiological tests cannot confirm any deviance in cognitive functions. This stage is now labeled subjective cognitive decline (SCD), which is then, thirdly, followed by the MCI stage for about five to ten years, where tests show significant deviance of cognitive functions but still unchanged everyday life functionality. As a continuum, MCI can then convert into a fourth stage of early dementia, indicated by increased cognitive impairment and problems in executive functions, subsequently developing into stage five, moderate—or even stage six, advanced—symptoms of dementia.[1]

According to Jessen (2019), a leading German clinician and researcher on early AD, these first three stages are of particular relevance as they indicate different risk stages. Jessen asserts that those "patients" with SCD or MCI indicating pathological changes on the biomolecular level through "positive biomarkers" (also labeled as a prodromal stage of AD) also have a "higher risk" of developing clinical AD, thus finally AD dementia. Current research on the neuropathologies of AD mainly focuses on the validity of single or combinations of biomarkers[2] for such risk prediction.

A controversy recently emerged among ethicists about whether such predictive information is of clinical or personal value, whether it should be disclosed, and, if so, under which conditions (Gerritsen, Oyebode, and Gove 2016). Many proposals in clinical ethics rather call for being cautious about confronting persons tested with a "higher risk for Alzheimer's" or even equate it with AD (for an overview, see Schicktanz et al. 2014; Vanderschaeghe et al. 2018). They fear negative psychosocial consequences for the person tested and see no advantage in knowing, as currently no cure or effective medication to at least significantly moderate or slow down the course of Alzheimer's disease exists. As the patient advocacy organization Alzheimer Europe has stated, this "new dementia" also relates to a new status of *patienthood*, especially with the semantics of "diagnostics" (instead of "risk prediction") and "preclinical dementia" without mentioning the existing epistemic uncertainty of whether dementia will occur in this person (Alzheimer Europe 2016). This also resonates with earlier conceptual and epistemic concerns, stressing that SCD/MCI are still unclear and vague concepts (Katz and Peters 2008; Werner and Korzyn 2008).

Ethical Shifts from Late-Onset Genetic Testing to Predictive Dementia

One general ethical concern, now also discussed in other fields of predictive technologies (such as whole genome sequencing), focuses on the question of whether there is a right to know even if there is no clinical value, though there might be a "personal utility" (Schweda and Urban 2018). However, these concerns of "no clinical utility" have been challenged by the increased emphasis on primary or secondary prevention for dementia by various international experts (Sperling et al. 2011; Le Couteur et al. 2013; Sperling, Karlawish, and Johnson 2013; Sperling, Mormino, and Johnson 2014). Especially the latest World Health Organization recommendations in *Risk Reduction of Cognitive Decline and Dementia* (WHO 2019) have now moved this approach to a new level of health policy and public attention.

Another important ethical question is whether a "new" group of affected persons is to be considered in public health discussions (see Schicktanz, Schweda, and Franzen 2008; Schicktanz 2015 for more general considerations on "affected persons"). How should social, health-care, and lifestyle structures be altered to change the continuous "course" of the (not yet existing) disease? What kind of professional responsibilities occur when prevention is promoted? Overall, these questions are not culture-specific; but their relevance and possible answers can be situated in different cultural and political contexts.

"New dementia" should hence be discussed in a newer framework of "dementia ethics," reflecting both the uniqueness and situatedness of the illness context, as well as its overarching principles. Such a framework should therefore expand the "older" debates of dementia care and clinical-ethical issues related to dementia (e.g. Post 2000). For this newer perspective, ethical and legal discourses on other areas of "risk profiling," such as genetic testing, can be seen as enlightening in two ways (Beck and Schicktanz 2016; Schicktanz 2017). On the one hand, genetic testing of late-onset degenerative diseases (not dementia-specific) generated many ethical-consequential questions, such as which psychological and social risks may arise from such predictive knowledge. This has also lead to a restrictive, rather paternalistic approach to genetic testing for familial AD or for the APOE4 allele. These tests are considered to be susceptibility genetic testing (Schicktanz and Kogel 2014). For them, a professional recommendation not to test exists. However, numerous national regulations and international guidelines on genetic testing concluded that there is a respective professional duty to promote wellbeing and avoid harm by including both the "right to know" for those who want to be tested, as well as "the right not to know" for those who do not want to know (Council

of Europe 1997), often resulting in restrictive, complex guidelines for genetic counseling of incurable late-onset diseases. The corresponding set of rights represents the practical-ethical and legal standard for protection of the individual right to self-determination in the context of predictive medicine (Andorno 2004).[3] In this sense, the debate has tried to fix the dilemma of predicting late-onset diseases by focusing on the professional duties of proper information, high quality counseling, and well-reasoned communication. The German law on genetic testing has also adopted this view, and the report of a nation-wide stakeholder conference conducted in Germany in 2018 about dementia prediction mirrors this attitude (Diskursverfahren "Konfliktfall Demenzvorhersage" 2018). Many experts assume that what was developed for genetic testing should now also be adopted when it comes to risk profiling of dementia via nongenetic biomarker tests (Beck and Schicktanz 2016). Notably, the predictive medicine paradigm is often equated with genetic/genomic testing—however, biomarker research, especially in the case of dementia, illustrates that such a narrow focus on genetics is not always appropriate.

The current discursive shift to prevention of dementia again renders the moral picture. Raising the question of whether professionals should respect the right to know/not to know does not seem to be the only relevant question anymore. There are now questions of professional duties (whether to promote such knowledge), individual duties (to know and also to take individual responsibility for healthy behavior; Beck and Schicktanz 2016), and professional, social, and state responsibility (to provide sufficient means and support for structural change, as healthy behavior mainly depends on structural conditions).

But are we there already? As indicated by others (Leibing, this volume), there exists a considerable uncertainty or ambivalence regarding the promises of dementia prevention. The professional debate on chronic disease and the potential of prevention are also shaped by the disillusioned insights from difficulties in identifying and implementing highly effective preventive actions—for example, as identified and implemented for cancer (Bell, this volume). On the other hand, the hope and moral prospects of prevention, often regarded as cheaper, less invasive measures, make promoting well-being are very appealing. Therefore, a more detailed understanding of the existing debate around dementia prevention also provides us with a more nuanced picture of the underlying scientific and moral uncertainties.

Examining the Professional Discourse and Its Wider Perception

Discourse analysis as part of an ethical reflection on biomedicine is not self-evident. This methodological move requires a short note of explana-

tion. I here position myself in a strand of postconventional bioethics that strongly defends the idea that medical practices, as well as the bioethical debates that go with them, must be culturally contextualized and situated in the hegemonic discourse of "acknowledged" knowledge and reflect on rather marginalized positions in these debates (Raz and Schicktanz 2016; Schicktanz 2016). This analytical, reconstructive, and critical-reflective step is needed for constructing and shaping new approaches of ethically sound discourses (Schicktanz 2016). According to this approach, it is not sufficient to consider only experts' opinions about the ethical acceptance of medical practice as well as experts' knowledge of the disease. Instead, it is additionally required to consider the diverse, everyday, lived experience of those affected, and their understanding of "health," "illness," "morally acceptable," or "quality of life." For this, studies of the social experience and everyday life practice, the power and politics of science, and the cultural perception are valuable—even necessary—completions. This approach is replacing the ideal of a "point of view" as a "view from nowhere" (which Donna Haraway [1988] ironically termed the "God's eye position"), which is a stance many modern cognitivist approaches share, whether in ethics (Baier 1958) or the sciences (Popper 2005). Instead, it defends an epistemic view of "situatedness," in which hegemonic structures of public and professional debates are critically reflected (Fricker 2009; Schicktanz 2016) and everyday lived experience in its diversity is taken into account.

Therefore, a detailed understanding of the professional discourse, as well as how it is translated into the wider public debate via media representation, can contribute to an in-depth understanding of existing lines of mainstream medical practice and its normative justification, including potential underlying controversies and uncertainties.

As this professional discourse must be embedded in an understanding of the professional practice, we (Schweda et al. 2018) conducted the first nationwide survey for examining the current state of the art of prediction and early detection of late-onset dementia and AD in 2015 in 215 identified German hospitals and memory clinics (through databases provided by the German Alzheimer's Association's website and a website maintained by the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youths called "www.wegweiserdemenz.de"). This large number of institutions already indicates how the clinical practice of memory testing has proliferated in the last decades. Our objective was to survey the actual practice and the attitudes of physicians in order to explore whether there are practical insecurities and ethical concerns. Of all respondents (n=108), nearly half stated that persons with MCI and pathological CSF biomarkers were informed they had or would soon develop AD. While 81

percent acknowledged a "right not to know," 75 percent said that results were always communicated. A majority agreed that there was a benefit of prediction or later life planning—end-of-life, financial, family, housing (73–75 percent)—but also expected high psychological stress (82 percent) and self-stigmatization (70 percent) for those tested. Roughly half of the respondents (47 percent) knew of possibilities for prevention, and only 26 percent saw a benefit of certainty about one's own condition. By contrast, frequently mentioned negative aspects included self-stigmatization (70 percent), discrimination in the domains of health insurance (49 percent) or by family members (44 percent), social stigmatization—that is, negative labeling by society (39 percent)—and social discrimination, which included disadvantageous treatment by society (37 percent) as well as discrimination at work (34 percent). The current tendency of informing affected persons about test results for SCD/MCI and providing risk interpretations indicates an underlying assumption of a professional duty to tell. However, it is important to point out that such a duty is ethically and legally contested as mentioned above.

To complement this survey, I further conducted a discourse analysis to embed these findings in a broader picture of how prevention of dementia comes into play. For this, an online search was performed of literature in both the German medical professional discourse and media reports in leading newspapers and weekly journals for the period of January 2000–January 2019.[4] An in-depth search was based on a pilot search via Google in German language, and then in the next step, after identifying potentially relevant journals, each journal was searched individually.

For analyzing the medical professional discourse, I finally selected six leading professional journals, two covering various medical disciplines and four covering neurology, psychiatry, and gerontology: *Deutsches Ärzteblatt* (German Medical Journal), *Der Internist*, *Der Nervenarzt*, *Der Neurologe und Psychiater* (*DNP*), *Information Neurologie Psychiatrie*, and *Fortschritt Neurologie Psychiatrie*. We identified sixty-five articles, of which the majority (n=36) stemmed from these six sources and another twenty-nine from a broader range of professional journals.[5] These were found using a combined search in the German database BELIT and Google Scholar with the search items "Demenz," "Alzheimer," "Prävention," "Vorsorge," and "Gesundheitsvorsorge" ("dementia," "Alzheimer's disease," "prevention," "provision," "preventative health"). For analyzing the media discourse on popular scientific representations of the paradigm of dementia prevention in Germany, we selected five common daily or weekly newspapers or journals that have a section for popular science reports: *FAZ*, *Die Zeit*, *Spiegel*, *Stern*, *Bild der Wissenschaft*, and Süddeutsche Zeitung. Here, forty-four articles were identified for the respective period.

Overall, the picture of the last two decades (see figure 3.1) shows that the topic of dementia prevention was addressed rather seldom with a maximum of three to six scientific articles per year in all searched journals. An increased interest in the topic occurred from 2011 on, with a high peak in 2014, mainly with reference to the "*Lancet* studies" (Norton et al. 2014; Jack et al. 2010) about the "new" model of AD including biomarkers. The media discourse almost parallels this tendency, with similarly small numbers of articles (from one to six articles per year).[6]

The following qualitative discursive analysis of both the professional and the popular scientific media discourse has been inspired by critical discourse studies such as Van Dijk (2009) and Wodak and Meyer (2009). The discourse focuses on three different relevant epistemic themes: first, whether dementia/AD is regarded as preventable and, if yes, by which means and by which means not; second, how the addressed actors, social groups, or individuals are targeted by these preventive measures; and, third, how dementia prevention is assessed as a certain form of knowledge, a normative aim, or a research justification. The analysis reveals four main findings:

1. A substantial discursive shift in 2011 strengthened the somatic linkage between cardiovascular diseases/diabetes and dementia prediction.
2. The individual in his/her middle age is regarded as a target group for health promotion of lifestyle changes and risk communication, which also requires a shift in particular professional responsibilities.
3. In the popular scientific discourse, monofactorial strategies are presented in a simplified way and individual responsibility is continuously addressed as a strategy to escape a fatalistic view of dementia or to counter the "taboo of dementia"; and
4. Discursive counterstrategies are academic insistence on multimodal therapy versus popular scientific emphasis on one measure.

In the following, I will discuss these four findings.

Dementia Prevention as "Heart-Brain" Prevention

In the professional discourse before 2010, the few articles discussing dementia prevention mainly focused on medical treatment options for early or moderate stages of dementia. The medical measures mentioned for primary and secondary prevention mainly referred to antidementives, antihypertensives, and statins. Other therapies, such as hormone therapy,

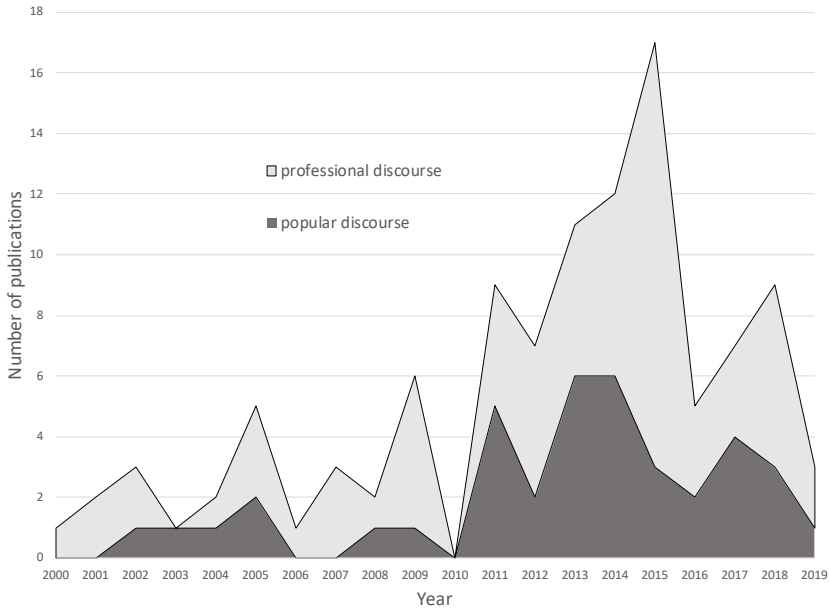

FIGURE 3.1. Results of quantitative analysis of dementia prevention discourse in German professional journals and German media for the period January 2000–January 2019.

were also mentioned as protective measures but were critically discussed because of side effects. Kornhuber (2002) already recommended cardiovascular risk prevention, as these forms of prevention seemed "cheap and show[ed] little risks," even if the evidence seemed limited for dementia prevention. From 2011 onward, articles continually reported about emerging biomarker research and a need for their systematic validation. Authors also called for further specialization of memory clinics within the field of neurology/psychiatry, as only they are able to detect target populations with higher prevalence during risk assessment (Jessen and Dodel 2014). Expensive medical treatments, also those with a higher risk for side effects, should only be provided for those high-risk populations. For the general population with a low prevalence, articles instead recommended cheap and low-risk preventive actions such as lifestyle risk reduction. While preventive effects of physical activities were reported repeatedly, many authors (e.g. Schulz and Deuschl 2015) stressed the need for multimodal therapies, expressing skepticism toward simple solutions. If risk factors were addressed, the following triumvirate was mentioned: physical inactivity, smoking, and obesity/being overweight (e.g., Luck and Riedel-Heller 2016). Further

practical guidance for general practitioners also included social activity, cognitive activity, and integration in daily activities. However, concrete studies showing the protective effects of this form of "good living" were missing at the time. The extrapolation from large epidemiological studies on changing prevalence and incidence (Wu et al. 2017) has iteratively substantiated this new "knowledge." Overall, the fact that these forms of prevention are commonly shared recommendations within the professional discourse—also for leading a "good life," including social and psychosocial aspects—can explain why these recommendations persist without contradiction. In this sense, not a purely somatic conception of dementia prevention exists, but one that also follows "holistic" tendencies of the mind-body interaction. Overall, the German professional discourse depicts dementia prevention as a multimodal, multifactorial approach consisting of diverse strategies that almost resemble a holistic idea of integrating bodily, psychological, social, and biological views. However, this multimodal treatment also includes pharmaceutical treatment, especially antihypertensives.[7] In his latest article, Jessen (2019) therefore suggest a two-way strategy for prevention: a more general lifestyle-risk prevention as a primary form of prevention, and a molecular secondary form of prevention that targets "high risk" populations in a prodromal stage (yet asymptomatic, but showing neurobiopathological biomarkers).

Alzheimer's Disease as a Disease of the Second Stage of Life

Dementia, including "Alzheimer's disease," is often characterized as an age-related illness or at least inevitably linked to the late third or even fourth age, mainly affecting people over the age of sixty-five. The new preventive discourse, however, identifies a new age group, namely, people in their forties onward, the "second stage of life." A common recommendation found in the literature today is that identified lifestyle risks and an increased health consciousness must be tackled in the population of people within the middle of their life course (e.g., Klein 2014; Schulz and Deuschl 2015; Luck and Riedel-Heller 2016). This reconfiguration appears as a logical implication of the new dementia, conceptualizing the disease as a slowly progressive neuropathological trajectory that starts two to three decades before the onset of any (obvious) symptoms. With this, AD is, at least in this line of argumentation, no longer a disease of old age; instead, it evolves into a disease whose risk population is in the "height" of one's life. Apart from recommending protective lifestyle changes, it also becomes a medical imperative to already start medical treatment of hypertension in one's mid-forties because existing preventive studies indicate low effects with a population already too old, thus, highlighting the consequences if started "too late" (Klein 2014; Pantel 2016).

Popular Scientific Claims for Individual Responsibilities and Simplifications of Monofactorial Strategies

In the popular scientific sections of the explored mass media, the discourse, however, differs. Already around 2000 until 2014, articles addressed the "individual who can do something against dementia." According to an early *FAZ* article from 2002, age-related dementia is "self-inflicted." The interviewed "dementia" expert refers to the necessity of being social and ensuring a balanced diet and sufficient physical exercise, drawing on "obvious evidence" of existing studies. In the same vein, *Die Zeit* titled an article in 2014 (Bahnsen 2014) "Everybody Can Do Something About It";[8] it referred to studies on lower incidence rates of dementia in Western countries, which are traced back to a healthier lifestyle after the second half of the twentieth century and correlate with cardiovascular risks (see also Wu et al. 2018). Apart from lifestyle changes, "protective" statins, which are cholesterol-lowering drugs, are explicitly recommended. Also *Süddeutsche Zeitung* (Collmar 2014) sent out the message "What is good for the heart, is also good for the brain." Hence, insights from these epidemiological and lifestyle studies, which are quoted by several articles, are linked to responsibilization of the individual for an "active" lifestyle. Provoking titles such as "Laziness Makes You Stupid" (Blech 2008) or, less accusing, "Routine is the Enemy of the Memory" (Neubauer 2014) stress that long and intensive employment seems to function as a protective measure against dementia. Obviously, it is the (still healthy and young) individual that is addressed here as moral subject. Apart from very few voices, such as Wewetzer (2012), who mentions doubts about any "silver bullet" to prevent dementia, recommendations of cardiovascular risk prevention now seem unavoidable in any article.

Another striking finding of the media discourse analysis is that the vast majority of identified articles focus on only *one* risk factor, indicating that not multimodal but single-factor treatment can help prevent dementia. Citing an "outstanding" study on manageable risks is a common strategy. The risk factors are often oriented toward "everyday life," including stress (Groll 2012), poor sleep, or diabetes. Hence, articles focus on reports with very concrete, individual measures, such as dancing, gymnastics (Niejahr 2011; Batzer 2018), or just being physically active every day (Blech 2008), drinking green tea (Spiegel online 2005), consuming more cacao (Bild der Wissenschaft 2014), or playing video games (Dickentmann 2017). Apart from this hegemonic discourse of a responsible lifestyle, only a few articles raise doubts or provide "critical" news. One report used genetic factors such as APOE or BDNF mutations as an explanation why the lifestyle "fight" against dementia might not work (Stollorz 2011). Another article

(Müller-Jung 2014) reported on the failing of the Alzheimer's disease vaccine studies, which might undermine the promise of dementia research.

In 2017, various media (*Die Zeit*, *Der Stern*, *Der Spiegel*, *FAZ*) reported on the *Lancet* study by Livingstone et al. (2017) and stressed that "many" risk factors exist and further stressed how they can be tackled by a healthier lifestyle. Only the journal *Der Spiegel*, politically rather close to social-liberal positions, referred to the "protective" factor of good education and stated that there would be an immediate reduction in the risk of dementia worldwide if children had access to education of a high standard.

Counterstrategies between the Academic and the Popular Scientific Discourse

Although the existing voices in the German professional discourse reiterate epistemic vagueness regarding prevention claims—by emphasizing that the effects of existing prevention lifestyle studies are rather low or by pointing out that study conceptions are not designed appropriately ("too short, too small samples") for making solid claims—overall, an acceptance of integrating the new dementia into the prevention paradigm shines through, and vice versa. This also seems to be triggered by a kind of desperateness as no effective medical treatment yet exists to "heal" dementia and many clinical studies of new pharmaceuticals have failed. As biomarker and basic research of the neuropathological, molecular mechanisms of AD and other forms of dementia necessitates public money and is in continuous search for justification (especially as it competes with public attention and resources for better care of late stages of dementia), the promise of prevention now functions as a perfect justification for new biomarker research. And even if the evidence is partly missing or critically discussed, the underlying moral assumption is that recommending health or healthier lifestyle is nothing that harms, even if it would be ineffective. In this sense, the recommendations for protective measures in an almost holistic attempt—as they also embed recommendations for social and psychological integration—seems to be unproblematic for many. However, doubts regarding the effectivity of physical activity interventions are supported by the latest systematic review study (Brasure et al. 2018: 30), which concludes, "Evidence that short-term, single-component physical activity interventions promote cognitive function and prevent cognitive decline or dementia in older adults is largely insufficient. A multidomain intervention showed a delay in cognitive decline (low-strength evidence)." However, following a "better than nothing" logic, the latest WHO (2019) recommendations "strongly" endorse lifestyle changes regarding smoking, diet, and alcohol consumption, even if the scientific evidence is "low." Here, similarly, the

justification for this low-evidence-based medicine is that the harms are low, but the general benefit could be high.

It becomes apparent that strong moral claims regarding individual responsibility are rather prevalent in the popular scientific discourse, in which journalists overstress single actions and frame their news in a sometimes very provocative or even accusatory language. Especially the fact that preventive options are immediately framed as individual responsibility is a striking finding. Furthermore, it is also worth reflecting on which factors are omitted in the media discourse. For example, Livingstone et al.'s (2017) reasonable findings claiming that education is a crucial protective factor for dementia were rarely mentioned, except by the article in *Der Spiegel*. This observation points to a common problem—namely, that the medical and educational system in Germany are economically, organizationally, and politically strictly separated systems. Public health education as part of public school education is almost nonexistent, and, on the macro level of allocation, public resources for education and those for health rather compete. Overall, Germans tend to believe that their education system is sufficient or even good (Killus and Tillmann 2017). And while the relation between health and social gaps in education are commonly discussed in public health, they are rarely taken up in other areas, such as dementia research.

Other scientific findings—ones that might contravene common expectations, such as studies indicating that moderate alcohol consumption might even be beneficial (Kornhuber 2002) or that being underweight has also been identified as a risk factor (Schulz and Deuschl 2015)—were not taken up by the media.

A Patient Advocacy Group's Perspective as a Third Angle in the Debate

In contrast to the professional and media dementia discourse, another sector was identified as very relevant—namely, the public voices of patient advocacy. However, it is important to note that the German patient advocacy organization Deutsche Alzheimer Gesellschaft (DAlzG) is rather cautious in promoting preventive measures. We could identify only very few reports or short commentaries regarding the prevention of dementia.[9] In 2006, a commentary briefly summarizes four common protective factors: physical activity, brain training, diet, and hypertension control. The authors of the commentary argue that prospective studies allowing for the conclusion of more profound insights only exist for the last factor, hypertension control. They criticize all other existing studies as retrospective correlation studies that do not provide sufficient evidence. In another statement paper ten years later, in the year 2016, the DAlzG discussed critically so-called

"half-truths" and problematic "promises of healing." Again, concrete risk factors, especially for cardiovascular diseases (e.g., such as diabetes, being overweight, smoking, and alcohol abuse) were mentioned but framed as not sufficiently proven. It was argued that the reduction of these risk factors will causally lead to the prevention of dementia. They criticized existing studies again as often methodologically weak, with selection biases of the participants' population, and too short regarding their survey period. Another risk factor for dementia explicitly mentioned is deafness; thus hearing aids are recommended because if not intervened, this impairment could otherwise lead to an increase in depression or dementia.

Overall, the patient advocacy organization generally recommends a healthy lifestyle and physical activity but does not frame it as an individual duty or strong responsibility. This might also be understood in the broader framework of the German dementia patient advocacy groups, whose positioning toward the politics of dementia differs substantially compared to their American counterpart (Schicktanz 2017: 213ff). While the US advocacy group demands a world "free from dementia," supports all kinds of dementia research, and argues with the image of dementia as a threat and epidemic, German advocacy groups defend a dignity-oriented, protective stance; criticize research with persons with dementia; and also employ in their arguments images of dementia as a stage in which one can also be very happy or have fun.

Situating the Moral Imperatives of Dementia Prevention

The morally problematic attempt of framing dementia prevention as an individual responsibility has recently also been reported for other countries by various researchers. Elizabeth Peel (2014) has pointed out that British newspaper articles on dementia show a significant "panic-blame" framework, in which the disease is strongly dramatized on the individual and social level, and often suggest only individual responsibility of undergoing lifestyle changes to "prevent" dementia. Lawless et al. (2018) analyzed websites of eight nonprofit Alzheimer's disease associations of English-speaking countries (Australia, New Zealand, Ireland, the United Kingdom, the United States, and Canada). They also found a strong moral tendency postulating individual responsibility for dementia risk management, and further revealed how the associations' websites address the audience as being at risk and therefore as being responsible for lifestyle changes. However, it seems that according to their analysis, "brain health" still seems to be a dominant focus of these imperatives (advice to keep your brain active, often combined with detailed suggestions of what to do), while advice regarding cardiovascular health remains very general (eat healthily,

be physically active, look after your heart, be social). This finding is remarkable, because a current systematic review of eleven trials lasting at least six months showed that the effects of cognitive training on cognitive decline are rather disillusioning. Butler et al. (2018: 1) found that training in older adults with normal cognitive abilities improves cognition performance only in the domain trained. "Evidence regarding preventing or delay of cognitive decline or dementia is instead insufficient."

In comparison to this, the German debate shows two particularities: one, the professional debate stresses multimodality and multi-risk management, which do not share the simplistic messages of the "healthy life = dementia prevention" equation; and, two, the popular scientific media discourse instead focuses more strongly on "specific" habits and actions by singling out particular risk factors and preventive measures. The leading German patient advocacy organization is very reluctant to promise prevention of dementia by pointing to individual lifestyle changes. However, as part of an increasing health movement, it recommends—but in a cautious manner—a "healthy" lifestyle as something that can "never" be harmful and generally promotes one's wellbeing.

What the dementia prevention discourse in all of these fields share is, according to my understanding, an implicit new reconstruction of AD as a non-age-correlated disease. Of course, "dementia" itself, as the middle- and late-stage symptoms of AD, still remains age related. However, according to this new understanding, age is nothing more than a correlating factor for the more explicit symptoms—the outbreak. The disease as such and its underlying molecular patho-mechanisms start already during the second stage of life (so around the age of forty onwards). This observation—and this should be understood as a theoretical shift, yet not empirically proven—can imply a radical reconfiguration of dementia from a purely age-related disease that until now contributes significantly to ageism, discrimination, and stigmatization of older adults to a disease linked to all stages of the life course. As later age was repeatedly configured as the biggest risk factor for dementia (for further details see Evans et al. 2018), persons with dementia often experienced two forms of stigma, namely stigma related to later age and stigma related to dementia. But the higher risk of dementia and memory loss also contribute to general ageism, which is normally a result of the classification by others based on physical appearance. One scenario could be that this stereotype *might* change with the insight that at least the causes and even the (molecular and pathological) prefiguration of dementia are located not in later age, but already much earlier in life. As such, the discrimination of older people with dementia might increase with a dimension of blame for previous "poor" lifestyles or irresponsible behavior. However, one can also raise a counter-question—namely, whether this shift

could also reduce ageism or even dementia-related stigma, or at least lead to a more generation-egalitarian perspective of affectedness. In addition, protagonists diagnosed with dementia risk have more agency to voice their own perspective and can more actively fight exclusion and discrimination. This ethical vision, however, needs to be tested against the social reality in which the new dementia will be embedded. While it might be too soon to say something about broad social effects of such a shift, it could, however, be worthwhile to encourage social empirical research for such new forms of resistance and reform of existing discrimination and stigmatization.

Ethical Issues of Prevention as Part of Public Health Ethics?

Ayo (2012) has clearly pointed out what is at stake when health promotion and preventive imperatives are sent out—especially in a dominantly neoliberal climate. For him—as perhaps for many critical social scientists—individual responsibility is a logical result or a paramount part of the basic tenets of neoliberal health policy. This view results from minimal state governance and minimal implementation of market rules as well as a focus on choice-risk management. Hence, individual responsibility is the new norm of these systems, and inequality as a consequence of (wrong) choices is inevitable. As he argues, self-regulated, individualized practices are championed over state-regulated, social practices; thus "healthy" consuming is favored before providing socially supported education, food, or care.

However, this fundamental critique does not address convincingly what we observe in the current German discourse. First, state governance is not minimal, but rather very dominant. Second, market rules only partly work, while the power of health professions is another strong factor to be taken into account. Although an increasing focus on lifestyle changes (such as on a healthy diet) can be observed, it mainly takes part in the media reports where rather often expensive food (because of its "high" quality) is favored. This consumerist approach is not repeated by the professional and patient advocacy discourse. Here, multimodal approaches—including indirect references to physical activity in social settings such as public sports and their claim for general access to highly qualified and standardized memory clinic testing—very strongly address social and professional responsibilities.

Furthermore, it is important to reflect on the normative settings of such preventive claims. Conventional medical ethics focus on the doctor-patient relationship and the clinical setting. The attention of practical ethical reflection focuses on the special setting of institutionalized health care and the need to empower patients (and their relatives) against the (often paternalistic) habitus of medical doctors (and also the nursing profession) in an

asymmetric relationship of power (e.g., Roberts and Reich 2002). Hence, respecting patient autonomy and balancing all interventions against the benefits and the harms for the patient was and remains paramount in the German debate. However, prevention—at least when understood as primary prevention—and its normative framing do not fit very well into this medical-ethical framework. Instead, it seems necessary to move toward a public health ethics agenda. Public health practice differs significantly from medical practices because it focuses on the health of a population, while medical practice targets the illness of the individual. Promoting and protecting health in a larger group is the main aim of public health activities. This requires explicitly the consideration of rather broad social settings of health conditions (different social groups, education, and working and living conditions). Furthermore, public health ethics expands the space and time dimensions: population is thought of as a forward-facing entity, and time scales often cover a whole generation (~three decades). The professional norm of "preventing," in contrast to "curing," therefore requires diverse target groups and different underlying concepts of illness and health. Furthermore, public health ethics must reflect on the relationship between the individual and the addressed community, as well as ponder on the underlying normative assumptions of justice. Marckmann et al. (2015) have suggested a systematic framework for such a public health ethics. It integrates five main normative criteria that, according to their understanding, need to be assessed: (1) expected health benefits for the target population (here they stress the role of evidence), (2) potential harm and burden (including the comparison to alternatives), (3) impact on autonomy (respect for autonomous choices as well as protection of privacy and confidentiality), (4) impact on equity (including access to interventions and the distribution of benefits and harms across different subgroups), and (5) expected efficiency (including a cost-benefit ratio). For the authors, these five criteria sustain a normative framework to assess the normative justification of particular promoted public health preventions, independent of being primary, secondary, or even tertiary preventive interventions.

However, the classification of primary, secondary, and tertiary is based on an underlying idea of disease trajectories as well as on the biological mechanism of a disease. This was criticized by Gordon (1983), an NIH deputy, as being too unspecific or even semantically misleading toward a hierarchy of efforts ("the primary comes first"). He instead suggested using the term "prevention" only for all *universal* interventions targeting people who are not yet suffering. These measures, he argued, can be advocated confidently to the general public and in many cases even without professional advice. Examples are, according to Gordon, advice regarding general hy-

giene, diet, or using a seatbelt while driving. These measures are beneficial in general and their imposed harm is minimal. All preventive measures that target at-risk-populations and already show a particular benefit-risk ratio should instead be called *selective*, per Gordon, as individual motivation is required to follow particular imperatives. Furthermore, any measures that target people who already have a high risk for a disease or symptoms and need treatment should be termed *indicated*. Gordon's attempt at an alternative classification illustrates the normative problem of the existing ideas of prevention: where to start with what kind of measure and how a particular intervention is justified by various normative assumptions; they are often not sufficiently spelled out. Gordon's suggested classification did not resonate with the scientific community, but it has become clear that only universal and selective interventions are part of a public health agenda, while secondary or even tertiary interventions remain part of a medical-clinical treatment setting.

If we now apply the general framework put forward by Marckmann et al. (2015) to the current discourse on prevention of dementia, one could raise the following critiques. First, potential health benefits seem to be very unspecific and particularly not dementia-specific if people follow the general imperatives regarding a healthy diet, physical activity, social engagement, and hypertension control. In this sense, these universal recommendations *might* lead to general wellbeing, but would—considering the lack of evidence—not specifically prevent dementia. Regarding the second point, namely potential harms and burdens, current physical harm can be related to adverse effects of some pharmaceutical interventions (e.g., hormone therapies; see Fink et al. 2018). The WHO (2019) also refers to the risk of musculoskeletal injuries as a result of excessive sport. However, more general effects of shame and stigmatization when individuals are addressed as being "too lazy"—as predicated by some newspapers—are yet not taken into account, but should be. Another aspect is that the insistent framing of particular lifestyles (e.g., including the consumption of alcohol or "fatty" foods, smoking, or being sedentary instead of engaging in sports) as risky leads to a cultural bias of what is a "possible" choice. From a liberal point of view, this is very problematic as individual choices in lifestyle are an expression of freedom. Whether these decisions are seen as wise or rational is something else, but this again relates to the putative evidence of condemning a particular lifestyle. Thus, the media discourse's focus on single measures is very problematic, as evidence in a statistically valid sense seems to be absent, and the burden of increasing stigmatization or even costs (e.g., by buying expensive food) is unjustified.

Professional and media imperatives for preventive measures in Germany remain very general and are only partly embedded in concrete schemes

such as taxes on alcohol and smoking (but not on fat or sugar or other activities). German health insurances offer some incentives for sports activities or fighting against being overweight, but the effect on the insured population remains vague.[10] Overall, one can say that the impact on individual choices by these new trends on prevention remains rather low. Other areas such as vaccination, pre- or postnatal screening, and measures of hygiene in public spaces, to date, are much higher on the German agenda. Concerns regarding the individual responsibilization of the citizen yet rest on a cultural-climate level of vagueness and declaration, but cannot be supported by concrete health care activities compared to places where individuals are forced or manipulated to do this or that because otherwise a particular treatment would not be covered or access to a particular treatment would be denied. The social health care system in Germany still works on a rather low level of health literacy, and methods of nudging and incentives remain rather the exception than the rule (Krisam, Philipsborn, and Meder 2017). Other countries with a more privatized health care system, however, have other possibilities in place to put pressure on the individual. In general, access to important public sectors such as education, public sports, and healthy food (along the lines of the Mediterranean diet) is not equal for all classes and social income groups. Health disparities regarding class and education and therefore affecting the regional level are well documented, but still rarely addressed in the German health policy discourse (Voigtländer et al. 2010). In this sense, equal access to potential primary prevention is not guaranteed. But what would that entail? Costly diets or special types of cognition training that should be consumed or done at one's own expenses? As these consumerist activities are neither proven to be effective nor evidently beneficial, it might sound a bit cynical but within the liberal spirit to ask whether wealthy middle-class people spending their money on these extras, though it might be absurd, is actually an ethical problem. It would be if they were misled by false information, I assume.

The German professional discourse, as argued above, does not simply focus on universal, primary interventions, but is prone to "multidimensional," sometimes even apparently holistic, approaches. These approaches, however, blur the lines between medical and public health as they consist of very general rules as well as rather very specific forms of interventions, even in part pharmaceutical. In the case that some interventions turn out to be effective and beneficial in the future, an actual problem will be that access to special health care or particular preventive measures is especially difficult in rural areas in Germany. A so-called problematic concentration of general as well as specialized physicians and clinics prevails in urban areas, with a deficit of those in the countryside.

Conclusions and Brief Outlook

The discourse on "prevention of dementia" needs to be situated and differentiated along the lines of different actors (professionals, media, patient advocacy, etc.) but also along the lines of various health care cultures. One interesting change that might be heralded by the current discourse on new dementia prevention is that it deconstructs the mythology of fatefulness and its problematic effects on stigmatization and self-efficacy. Especially the idea that there is nothing a person can do can result in low self-efficacy, as some psychologists have proposed (Badura 1998). Low self-efficacy results in low self-esteem and therefore makes people more vulnerable to external stigmatization. Additionally, the observation that the new dementia and prevention discourse conceptualize dementia as a disease of the second rather than of the late age can lead to a reformist attitude toward dementia, so the optimistic approach echoes. Furthermore, the multidimensional and multi-risk debate opens a window for conversations about priorities and cultural and subjective values. In this sense, the prevention paradigm does not automatically lead to self-restriction and self-responsibilization, but it is the general health care policy and cultural climate that counts. Prevention in a non-neoliberal but social welfare climate, supported by profound study concepts, might lead to more profound insights as well as to better care for people. Having said this, the current discourse suffers from epistemic vagueness, which rather fuels the negative sides of an unspecific prevention discourse. Hence, blaming, shaming, and unjustified responsibilization of the individual cannot be ignored—these are real risks for those living with the illness. Therefore, what is needed is a detailed ethical and social analysis of these processes as well as of new concepts on how to change established discourse structures—for example, by actively initiating and restructuring public and social debates (Schicktanz et al. 2012; Nowotny et al. 2001). Here, more participatory and deliberative approaches might be promising, as they can counter existing hegemonic structures as well as an (at times) unhealthy alliance of the media, interest-oriented experts, and neoliberal proponents. Furthermore, the traditional separation between medical ethics and public health ethics should be critically questioned; in contrast, as this case illustrates, it is important to consider public health ethics, medical ethics, and political bioethics as theoretically and practically highly interwoven. However, these ethical approaches operate with different assumptions about the underlying power relations and the relevant moral actors. Here again, new concepts of interdisciplinary cooperation are needed to see the close links and overlapping areas.

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Notes

1. This new dementia includes also new terminology—or redefinitions: according to Dubois et al. 2010, *Alzheimer's disease* is a "clinical disorder that starts with the onset of the first specific clinical symptoms of the disease, and encompasses both the predementia and dementia phases." Another term is *prodromal (or predementia stage of) AD*:

   > "predementia phase of AD in which (1) clinical symptoms including episodic memory loss of the hippocampal type (characterized by a free recall deficit on testing not normalized with cueing) are present, but not suffciently severe to affect instrumental activities of daily living and do not warrant a diagnosis of dementia; and in which (2) biomarker evidence from CSF or imaging is supportive of the presence of AD pathological changes. This phase is now included in the new definition of AD. The term of prodromal AD might disappear in the future if AD is considered to encompass both the predementia and dementia stages."

   And *AD dementia* refers to the phase of AD during which cognitive symptoms are suffciently severe to interfere with social functioning and instrumental activities of daily living, a threshold that is considered to define dementia in association with changes in episodic memory and in at least one other cognitive domain. Finally, preclinical AD is, according to Dubois et al. (2010), to be distinguished into *asymptomatic at-risk state for AD*—"this state can be identified in vivo by evidence of amyloidosis in the brain (with retention of specific PET amyloid tracers) or in the CSF (with changes in amyloid β, tau, and phospho-tau concentrations)"—and *presymptomatic AD*—this state applies to individuals who will develop AD, and "this can be ascertained only in families that are affected by rare autosomal dominant monogenic AD mutations (monogenic AD)." While this new terminology is not consequently adopted by all authors involved in the debate, it indicates very nicely how the continuum theory requires the boundary work of diagnosis and conceptions.

2. While the focus in mainstream/overview publications is on the three nongenetic biomarkers mentioned above, also other tests, including neuropsychological testing and inexpensive, noninvasive blood tests, are increasingly discussed (Preische et al. 2019).
3. A paradigmatic case for this is genetic testing for Huntington's disease (HD), a late-onset, nontreatable neuroprogressive disease. Clinical ethical standards for genetic counseling in the case of HD require a time- and counseling-intensive procedure of pretest genetic and psychosocial counseling (MacLeod et al. 2013). These standards are defeated especially in cases where no efficient treatment of the disease is available. Main value of such disclosure can be seen in the relief or personal value of knowing.
4. I would like to thank Benjamin Söchtig, a student assistant in Göttingen, for special support in literature research.
5. *Aktuelle Ernährungsmedizin*, *Bewegungstherapie u. Gesundheitssport*, *Bundesgesundheitsblatt*, *CME*, *Deutsche Zeitschrift f. Sportmedizin*, *DMW*, *Gerontopsychologie u. –psychiatrie*, *Gynäkologie u. Endokrinologie*, *Klinikarzt*, *MMW*, *Orthomolekulare Medizin*, *Pharmazeutische Zeitung*, *Prävention/Gesundheitsförderung*, *Psychiatrische Praxis*, *Zeitschrift f. Gerontologie u. Geriatrie*, *zkm*.
6. A list of all articles found can be obtained from the author on personal request. A more detailed analysis will be published elsewhere. Here, I focus on the main findings.
7. A current systematic review by Fink et al. 2018 of fifty-one unique trials concluded, however, that there is no evidence to support the use of the following tested pharmacological treatments (antihypertensives, diabetes medication, nonsteroidal anti-inflammatory drugs, hormones, and lipid-lowering agents) for cognitive protection in persons with normal cognition or MCI.
8. Translations of the German newspaper article headlines are my own translations.
9. See also the archive of the Deutsche Alzheimer Gesellschaft, such as their newsletter "Alzheimer Info," accessed 17 September 2020, https://www.deutsche-alzheimer.de/unser-service/archiv-alzheimer-info.html#c3318.
10. There exist only few reports regarding such public health programs in Germany; see *Heute und Morgen* 2017. A third of German clients have at least once used such an incentive, but more than the half never. An early study of the Bertelsmann Stiftung in 2006 revealed even much less interest in such an incentive program, and effects were only reported for vaccination, screening programs during pregnancy, and first aid courses for children; see Bertelsmann Stiftung and Universität Bremen 2006.

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4 DEMENTIA PREVENTION
Another Expansion of the Preventive Horizon

Matthias Leanza

Introduction

In spring 2015, the Swiss Alzheimer's Association and the Foundation Pro Senectute launched a campaign called "Dementia Can Affect Everyone." This nationwide awareness campaign was part of the National Dementia Strategy approved by the federal government and cantons in 2013 (FOPH and CMPH 2018: 4).[1] Through posters, web banners, TV spots, and online video clips, the organizers tried to draw the public's attention. Those who wanted to learn more about it and obtain basic facts and practical information on the subject could visit the campaign's website (memo-info.ch). The campaign aimed to reduce the prejudices against patients who have dementia and raise awareness of underlying risk factors and clinical symptoms. Although aging is the most significant risk factor for developing Alzheimer's and other forms of dementia, the website explains that, according to new medical studies, people can reduce the risk of the disease through various lifestyle modifications. These include a healthy diet and regular physical exercise, social activities and mental exercise, such as learning a new language.

This campaign is not specific to the Swiss health system. In recent years, medical research on dementia has gravitated toward prevention (Leibing 2018; focusing on mild cognitive impairment, see also Moreira 2010). Based on the new evidence, mainly from longitudinal epidemiological studies, the Lancet Commission on Dementia Prevention, Intervention, and Care estimated in 2017 that modifiable risk factors cause around 35 percent of dementia cases (Livingston et al. 2017: 2678).[2] Although this "optimistic" estimation has not remained uncontested (Kivimäki and Singh-Manoux 2018), there is a growing consensus among researchers and practitioners that lifestyles, and not aging and genetic predispositions alone, play a crucial role in the complex and not yet fully understood eti-

ology of dementia or, more precisely, of the various syndromes and impairments which this umbrella term encompasses (Haeusermann 2017). Therefore, health professionals and media experts in different countries are now raising awareness of risk factors contributing to dementia and advising how to avoid or mitigate them best. There is, in other words, a current trend to include dementia in the class of preventable diseases and to institutionalize the expectation in society that people should take reasonable preventive action whenever possible.

In the social sciences, there exists a large corpus of literature interpreting the recent proliferation of disease prevention and health promotion in Western, (post)industrialized societies, of which dementia prevention can be regarded as an example, as part of an expanding neoliberal health imperative that is penetrating more and more areas of life. Drawing on Michel Foucault's (2007, 2008) concept of "governmentality," Thomas Osborne (1997: 185–186) had already asserted some twenty years ago that people are increasingly "made responsible for their own health, with all the 'victim-blaming' consequences that this implies." Regarding the World Health Organization's concept of "community participation," Alan Petersen and Deborah Lupton (1996: chap. 6) contend similarly that in our neoliberal "age of risk," there is a moral "duty to participate" in programs of disease prevention and health promotion. This is today an even more widely-held view that informs large parts of the "critical" literature on public health, medicine, and aging (e.g., see Rubinstein and de Medeiros 2015; Lawless, Augoustinos, and LeCouteur 2017; Shimoni 2018). The current trend in dementia research toward prevention can then be understood as another example of an expanding "neoliberal governmentality" based on personal responsibility.

This chapter aims at outlining a different approach. Rather than depicting dementia prevention as a powerful tool of governing people, which will, in the end, result in an erosion of the welfare state, this chapter emphasizes, first, what I call the "improbability of dementia prevention" and, second, the collective nature of promoting and implementing healthy lifestyles in society. Success in motivating people to change their daily routines and to organize their lives to mitigate the risk of developing dementia not only is unlikely; it also requires a joint effort of various actors to achieve at least partial success.

Although this argument is inspired by Niklas Luhmann's risk and communication theory in the first section and Bruno Latour's sociology of associations in the second section, it is not entirely dependent on these theories. The chapter ponders how to find an alternative perspective to the critique of neoliberalism and employs for this purpose various theoretical resources. In this way, I wish to contribute to a critical reflection on the con-

cept of neoliberalism without completely denying its analytical and political value. "Theoretical concepts such as neoliberalism," as Kirsten Bell and Judith Green (2016: 241) remind us, "clearly have their uses: they signal to readers the kind of argument a writer is making, and act as a shorthand to summarize complex configurations of economic, political and cultural change that do, arguably, have some commonalities across different contexts." But there is the risk of overstretching concepts that have once been successfully established by automatically applying them to every new phenomenon or research problem. Therefore, as Bell and Green (2016: 241) rightly argue, "there are now diminishing returns in simply documenting how technologies, policies or products 'illustrate' neoliberalism."

That such a "critique of the critique" does not have to refrain from any form of critical assessment is discussed in the third section of this chapter. Here, I distinguish three concerns connected with the prevention of dementia and other diseases. I explain why and how these concerns matter before concluding with a summary of the main points of my argument.

The Improbability of Dementia Prevention

The expansion of the preventive horizon mentioned above will have, if successful, first and foremost, the following consequence: dementia will no longer be considered as a natural component of the human aging process, a component that might also be linked to inherited predispositions, which likewise cannot be changed. Rather than being regarded as a *danger* lying beyond human control, dementia will then appear as a *risk* that, to a certain degree, arises from our decisions and actions. The sociologist Niklas Luhmann (1996: 40) explains this difference between danger and risk as follows: "One can regard it as a danger if one has to expect earthquakes, floods, or hurricanes; but also as a risk considering the possibilities of moving away from the endangered area or at least of getting insurance."[3] According to this view, risks are not objective features of the world existing independently from our perceptions and assessments, as appears to be the case for Ulrich Beck (1992). Instead, they are social phenomena relying on the assumption that human decisions and actions influence, one way or another, the likelihood, intensity, and characteristics of potential damages in the future. We face dangers, whereas people are responsible for risks.

According to Luhmann (2005: chap. 2), there is a general but by no means linear or irreversible trend in modernity to transform dangers into risks. By opening up new possibilities for preventing future harm through scientific research and technological innovation, the propensity for creating moral, political, and legal duties and obligations to make use of the now

available opportunities has enormously expanded the realm of human responsibility in the modern era.[4] Not using practically accessible opportunities to prevent potential damage will, in many cases, be regarded as irresponsible, especially when the cost is severe and countermeasures could easily have been taken (Luhmann 2005: chap. 1).

Against this backdrop, it not surprising that dementia research has gravitated toward prevention in recent years. In roughly the last two centuries, the preventive horizon has expanded repeatedly. New knowledge about disease causation and risk factors, as well as practical innovations, such as vaccines and sanitation, have widened the expanse of preventive action (Leanza 2017). However, within the general trend toward expansion, the preventive horizon has expanded unevenly, and an effective response strategy does not exist for every concern. Moreover, even when preventive countermeasures are available, there are other factors, too, determining whether they can be established in society. For example, introducing smoking bans in public spaces usually requires not only scientific evidence but also additional normative arguments specifying what restrictions are reasonable and, therefore, must be accepted (Procter-Scherdtel and Collins 2013).

The same holds for dementia prevention. New scientific evidence alone, which indicates that lifestyles play a crucial role in the etiology of diseases such as Alzheimer's, does not automatically justify holding people accountable for not modifying their daily routines and activities accordingly. Obstacles and counterforces hamper the transformation of dementia from being a fate-like danger into a risk that we are responsible, to a certain degree, to prevent.[5] To begin with, the arguments in favor of prevention in general, and dementia prevention in particular, are inherently fragile *ab initio* because they deal with an open future that remains ultimately unknown. The diseases and impairments that interventions seek to prevent, after all, have not yet occurred. And for the individual case, it cannot be known whether the risk will ever materialize and, if it does, when and with what impact. This fact that might keep people from taking preventive actions is complemented by the question regarding the effectiveness of preventive interventions. In most cases, you can only assume, but not know for sure, that someone has not (yet) fallen ill because of preventive action or whether the person would not have become sick anyway (Fuchs 2008: 364). Moreover, only a certain proportion of dementia cases, as we have seen, are considered to be caused by modifiable risk factors.

Systematically, the relevant unknowns are these:

1. You cannot know whether you will develop dementia in the future and whether prevention is, therefore, necessary at all.

If you are nonetheless inclined to take preventive action,

2. you cannot know whether this will be the reason why you stay healthy, and

3. you cannot know whether you will get sick anyhow.

Considering these unknowns from the individual's perspective, the choice to carry on as usual and not change established habits and routines is understandable. This is not to be regarded as a psychological or normative argument. It shall instead indicate that dementia prevention as a practice is inherently fragile because it is directed toward an unknown future, and it is difficult to formulate binding rules based on uncertainty.

There are external obstacles and counterforces, too. Health education campaigns, for one, require funding; otherwise, the scientifically available knowledge will not reach the general public. A change in demographics toward an aging society might serve as a persuasive argument for launching dementia prevention programs, as is the case in Switzerland's National Dementia Strategy (FOPH and CMPH 2018: 7). From the state's perspective, after all, 1.7 percent of its population, with a growing tendency, are affected by this disease, which will, in the long run, lead to a massive increase in nursing costs if countermeasures are not taken promptly (BASS 2018). However, even if funding is provided, the communication of information on how to (possibly) mitigate the personal risk of dementia does not necessarily translate into behavioral changes of recipients. Besides the unknowns discussed above, individuals might also prefer to redirect their attention to other, possibly more pleasant topics rather than pondering how to prevent a dreadful disease (Hafen 2013: 69–71). Not only money but attention and interest, too, are scarce resources.

Therefore, Luhmann (1990: 89–92), in his communication theory, distinguishes between the problems of dissemination and success. While so-called dissemination media—writing, press, broadcasting, and, nowadays, the internet—allow information to circulate in ways beyond face-to-face encounters in society, "symbolically generalized media," especially money, power, law, value commitments, and truth, increase the chances of the recipient accepting "the selective content of the communication (the information) as a premise of his own behavior." This includes both "acting by corresponding directives but also processing experiences, thoughts, and other perceptions on the assumption that a certain piece of information is correct" (Luhmann 1990: 88). But "it is particularly noteworthy in this connection," as Luhmann (1990: 93–94) points out, "that no symbolically generalized communication medium has been developed to support the manifold activities designed to bring about change in individuals, ranging

from education to therapeutic treatment and rehabilitation, although this is a functional domain totally dependent on communication."

Because of this lack of specific technologies that would allow changing individual attitudes and lifestyles with a fair degree of certainty,[6] dementia prevention relies on the more general communication media, as mentioned before (Hafen 2013: 71–73). So financial incentives, such as deductibles, no-claims discounts or rewards for physical activity, and power in the form of social and moral pressure, might be employed for this purpose. However, in liberal democracies with universal health care, as in Switzerland and Germany, the state also sets clear boundaries on such persuasive practices, of course, without completely inhibiting them. If dementia prevention were to be enforced by these means, it would run counter to society's fundamental norms and institutions, especially the entitlement of every citizen to health care and the right to choose one's way of life without being stigmatized. Similarly, law cannot be used to prescribe a modification of health-related behavior unless it takes place in public spaces and endangers others since the legal system protects citizens from these sorts of state interventions by guaranteeing civil liberties.

Health education can, then, only inform but not instruct. Therefore, the acceptance and implementation of information is dependent on the value commitments of recipients. As has often been noted (e.g., see Kickbusch 2007), health is in modern societies indeed a significant value—a value that after World War II even became a fundamental human right. Information on how to preserve one's health, when credibly communicated, is of great interest to everyone who shares a commitment to this value. However, values offer only basic orientations for societies and increase the chances that particular decisions and options for actions are preferred over others. In no way do they determine individual behavior (for a discussion of values in comparison to other communication media, see Luhmann 2012: 199–214). Nonetheless, this is the only real lever dementia prevention has. The pressing question is then this: how can dementia prevention mobilize the individual's commitment to preserving his or her health?

The Collective Dimension of Healthy Lifestyles

Rather than regarding dementia prevention as a given phenomenon with certain features, its establishment in society must be examined. At the moment, it is uncertain whether and to what extent these attempts will succeed. The approach put forward here thus starts with "an assumption of improbability" (Luhmann 1990: 86). Accordingly, the questions are whether and, if successful, how an initiative for dementia prevention will

manage to overcome this initial improbability so that it "can be expected to occur with a high degree of certainty" (Luhmann 1990: 86–87).

This approach resonates with Bruno Latour's (1988: part 2) assertion that sociology should be more concerned with explaining the emergence and stability of social phenomena rather than taking them for granted. Starting with the initial "weakness" of individuals and groups, or ideas and institutions, allows us, to trace how they are gradually gaining form, potency, and social weight by allying with other groups, allocating resources of various kinds, and establishing routines. Latour (1988: part 1) has explicated this approach, among others, in his study *The Pasteurization of France*.[7] By relocating disputes over the causes of epidemics to the terrain of the microbiological laboratory, where they were translated into testable hypotheses, Pasteur and his team succeeded not only in reforming the French hygiene movement, which earlier was more concerned with the quality of the water, light, and air than with preventing transmittable microorganisms from spreading; they also helped to sanitize the country. For the bacteriologists of the Pasteurian school, the laboratory served as a "fulcrum" (Latour 1988: 72–75); the move to the lab enabled them to resolve the controversy over the cause of epidemics and to bring about change in France's hygienic conditions.

For dementia prevention, tapping the individual's commitment to preserving his or her health, as explained above, is—under the conditions of universal health care and civil liberties, including the right to live in an unhealthy manner—the main point of leverage to initiate a change of behavior. If successful, these efforts help establish and foster a particular form of subjectivity for which a health-oriented lifestyle is a characteristic feature. An influential strand of literature on public health, medicine, and aging, depicts this form of subjectivity as being part and parcel of an expanding neoliberal health imperative. In the German-speaking discussion, this narrative of a general trend toward privatizing responsibility in the era of late liberalism is discussed under the title of the "preventive self." This concept was coined by the historians Martin Lengwiler and Jeannette Madarász, who published an edited volume on the subject in 2010 (see also Lengwiler and Beck 2008). Drawing on Nikolas Rose's (1996) assertion that in "advanced liberal democracies" citizens have increasingly been made responsible for their wellbeing, Lengwiler and Madarász (2010) see a fundamental shift that took place in public health during the second half of the twentieth century: from prevention practices based on state and civil society actors to a liberal regime of personal responsibility. This shift has led to the rise of the "*preventive self*, the rational subject who acts to minimize disease" (16), a process that already started in the interwar period but only prevailed in the decades after World War II. The prevention debate took "a

liberal turn" (22), which meant that "lifestyle recommendations were increasingly brought to the fore, at the expense of institutional, welfare-state reforms" (23).

At first glance, this appears to be a compelling argument that could not be better suited to describing and critically evaluating the lifestyle recommendations given in the currently emerging field of dementia prevention. However, a closer look reveals the problematic aspects of this position. First, is it empirically correct to describe the history of disease prevention in roughly the past seventy years—albeit only in its main tendencies—as an increasing withdrawal of state and civil society actors? In the booming sector of self-help literature, lifestyle recommendations do indeed play a crucial role. Still, health guides are not an invention of the second half of the twentieth century—they were already a popular genre in the Enlightenment (Leanza 2017: chap. 1)—and the state and other collective actors have not generally withdrawn from public health. For instance, in Germany, to which several articles of Lengwiler's and Madarász's volume refer, you will find numerous examples of public health authorities that intensified their efforts during that period (Leanza 2017: chap. 6). Besides the state adopting several legislative reforms in epidemic control, consumer protection, and pollution control, the authorities in the portfolio of the Federal Ministry of Health—in particular, the Robert Koch Institute, the Paul Ehrlich Institute, and the Federal Center for Health Education (Bundeszentrale für gesundheitliche Aufklärung), established in 1967—must be mentioned here. These institutions are responsible for monitoring the health of the population, providing data to public health services, advising political decision-makers, and educating the general public on health-related topics. Last but not least, they have to take necessary precautions for epidemics—for example, by guaranteeing that reliable and safe vaccines are available (for more information, see the website of each at www.rki.de, www.pei.de, www.bzga.de). If one considers that global public health was promoted as a policy field during the time of the establishment of the World Health Organization in 1948, UNAIDS in 1994, etc., and thereafter (Youde 2012; McInnes and Lee 2012), then, contrariwise, one might say that an increase in the number of public health actors characterized the latter half of the twentieth century.

However, even if one regards the hypothesis of an overall trend toward privatization of health-related responsibility in the second half of the twentieth century as too biased, it still could apply to campaigns that promote healthy lifestyles, as is the case in dementia prevention. But there is another and even more profound problem here regarding the conception of responsibility. Assigning new tasks to individuals and increasing their duties does not necessarily lead to a discharge of collective actors such as

state authorities, non-governmental organizations, research institutions, and other health experts. In everyday life, we often understand responsibility as a zero-sum game: if someone's responsibilities expand, other parties lose some of their responsibilities and vice versa. That is, however, only the case when goals have already been set and corresponding tasks have been established. For example, in 1930, the German government introduced a prescription charge of 50 Reichspfennig, and, with the adoption of the Law for Cost Containment in Health Insurance (Krankenversicherungs-Kostendämpfungsgesetz) in 1977, patients had from then on to pay one German mark for every prescribed medication. With the Law for the Modernization of the Statutory Health Insurance (GKV-Modernisierungsgesetz) of 2004, the deductible was eventually raised to 10 percent of the drug price but not more than 10 Euros per medication and 2 percent of the annual gross income (1 percent in case of chronic diseases) (Edalat 2017). In these cases, there is indeed a shift in responsibility from a collective actor, the statutory health insurance, to the individual policyholder.

In principle, the things people are responsible for, however, are not fixed, and in many cases, more than one actor will gain new responsibilities at the same time. Regarding campaigns such as the Swiss "Dementia Can Affect Everyone," it is certainly true that individuals are assigned a new responsibility: preventing dementia. But other actors, too, have to contribute to reducing the dementia incidence rate within the population. For the "preventive self" to emerge and subsist, scientists must provide reliable knowledge about disease mechanisms and risk factors. Professionals in health education must translate scientific findings into an "easy-to-digest message." Politicians must secure majorities for funding the required measures, and media experts must draw attention to the issue (for the variety of actors involved in Switzerland's National Dementia Strategy, see the website of the Federal Office of Public Health [Bundesamt für Gesundheit] under www.bag.admin.ch). In other words, individuals require support and cooperation from various actors to develop a healthy lifestyle.

The competences people acquire to preserve their health thus not only depend on their personal effort; they also rely on the activities and achievements of others who, in a sense, "make" them the actors they are or strive to become (on "actor-making," see Latour 2005: 204–213). Hence, going beyond the preventive self does not mean denying its existence. The preventive self does exist—but only within a collective that is defined by a distributed agency and shared responsibility. If you consider only the last link in this long chain of operations, as is often the case (e.g., see Lawless, Augoustinos, and LeCouteur 2017), you overlook a crucial point: the production of preventive subjectivity is only as durable and resilient as the preceding links in the chain (Latour 2005: 128). Therein lies the paradox

of healthy lifestyles: it takes a collective effort to create a self-responsible subject.

In the language of actor-network theory (Callon 1986; Latour 1999), the preventive self can, then, be described as the end product of a long "chain of translations" that traverses scientific research, expert debates, political arenas, and public spaces until it eventually reaches individual lifestyles. The metaphor of *translation* used here emphasizes, in contrast to the notion of *diffusion*, that information can only travel by being situated—that is, modified by the requirements of the new environment (Latour 1987: 132–142). Health education communicates contents differently from how scientists talk and write about the same issues, and it has to because it addresses a broader audience. However, the recipients also have to translate the information presented to them in generic terms by relating it to the specific features and conditions of their existence (Latour 2005: 205–206). It is, thereby, an advantage if the recommended measures themselves, and not only their intended outcomes, are attractive, which also applies, by and large, to measures in dementia prevention. Neither a Mediterranean diet nor physical, mental, and social activity is particularly unpleasant or excessively demanding. On the contrary, many people undertake them as ends in themselves. But there is no guarantee that recipients of public health campaigns translate the communicated advice into their daily lives and change established habits and routines. The chain of operations might well end here, and, indeed, it often does whenever the presented information does not create resonance within the recipient. Dementia prevention relies on mobilizing the individual's commitment to preserving their health and has thus only a weak lever.

Prevention and Its Discontents

Dementia prevention, like any other form of prevention, does not start from a position of power and strength. Efforts must be made to establish dementia prevention in society without any fair degree of certainty that it will succeed in motivating people to modify their behavior. Against the assertion of a trend toward privatization of health-related responsibility, according to which market principles are creeping into every corner of our individual and collective existence, I have, first, pointed to the fact that in countries such as Germany and Switzerland there is no general withdrawal of the state in public health. Second, individual responsibility and collective responsibility are not necessarily a zero-sum game. Consequently, individual lifestyles are not so individual as they might appear to be. The form of subjectivity that dementia prevention seeks to establish flourishes only

within a collective that encompasses various centers of activity and that is characterized by distributed tasks and responsibilities.

But that does not mean we have to refrain from critical assessment so that we are obliged to affirm every new program developed by medical scientists and implemented by politicians and professionals in health education. Despite the objections presented above, some of the concerns that drive the critical literature on disease prevention and health promotion can also be used to check whether there is a misalignment within the collective regarding (1) the power of definition, (2) the distribution of tasks and responsibilities, and (3) the importance disease prevention has in individual lives.

The first concern is most clearly articulated by what is known as "medicalization theory." The concept of medicalization refers to the processes through which either normal biological and psychological phenomena are defined as being pathological, or social problems are addressed and dealt with in medical terms. According to Peter Conrad (2007: 162), a leading proponent of this view, "Virtually any human difference is susceptible to being considered a form of pathology, a diagnosable disorder and subject to medical intervention." From this vantage point, medical and other health experts in dementia research and prevention could be regarded as powerful actors seeking, in alliance with the state, to redefine a condition inherent to the aging process as an illness linked to lifestyle decisions. Without making the link to prevention, John Bond (1992: 398) had already written about the pathologizing of age almost thirty years ago: "Since epidemiological studies have shown that age is the most important risk factor for dementia there is some indication that deterioration in cognitive function might be part of the normal aging process." He further notes, "Biomedical research points toward understanding dementia as a separate disease entity but like other medical conditions such as high blood pressure, the different types of dementia are socially constructed, the difference between normal and abnormal being quite arbitrary." According to this view, the category of dementia is used with wide inclusivity. Although it is recognized as a distinct nosological unit, in reality, it is merely a continuum of differences in cognitive abilities (on medicalization by diagnostic expansion, see also Conrad 2007: chap. 3). By this view, physicians and other health experts create an urgency to act and redefine what is normal and what is not to expand their influence over laypeople's lives.

The second concern is addressed by those scholars who see the current situation as characterized less by patronizing "medical imperialism" than by a neoliberal marketization of the social (Miller and Rose 2008). As already explained above, this position argues that today individuals are increasingly urged to optimize their health and other sorts of capital. Prevention programs that target unhealthy lifestyles and motivate individuals

to work on themselves, as in dementia prevention, can then be regarded as another example of a general trend in contemporary Western societies toward expanding the individual's responsibility to take care of their well-being (Shimoni 2018). Accordingly, to successfully age requires leading an "active" life. As Stephen Katz (2000: 135) argues regarding debates in American gerontology during the second half of the twentieth century, the discourse of "active aging" has to be understood against the backdrop of an emergent "neoliberal 'active society.'" In such a society, "activity has become a panacea for the political woes of the declining welfare state and its management of so-called risky populations" (Katz 2000: 147). In the same vein, Robert L. Rubinstein and Kate de Medeiros (2015: 1) understand current developments in gerontological theory—namely, the emergence of the Successful Aging paradigm—"as consonant with neoliberalism."

Though both kinds of critiques do not necessarily exclude each other, they are driven by different concerns. While the first type emphasizes the power of experts, in alliance with the state, over the laypeople (or expert knowledge over laypeople's experiences and attitudes), including the ability to define phenomena as pathological that are part of the normal aging process, the second focuses on the individual's increasing responsibility to manage their health and be active. Both types of critique raise important questions indeed and address concerns that are worth consideration. At the same time, there is the risk of overstretching in principle correct and essential insights by totalizing individual aspects. The expansion of the scope of preventive action, which entails increasing the experts' knowledge and the responsibility of the individuals for shaping their futures, cannot be assessed as problematic per se. There is a wide range of other factors to consider. What do the measures look like, and how do they impact people's lives? Do laypeople have a say in the decisions of politicians and medical experts "acting in their best interest"? Are there options for individuals to not participate in specific programs without suffering moral, economic, or legal sanctions? Moreover, both critiques tend to depict individuals as passive recipients of powerful expert discourses or general expectations from society and not as actors responding creatively to their environments—for example, by pondering whether to deploy a particular health regimen or not.[8] The first kind of critique is also marred by double standards. While medical experts "construct" the pathological and the normal, the social science critic knows that "in reality" this is a mere construct that only social forces can explain (for a critique of the Janus-faced character of many varieties of social constructivism and the outline of an alternative—that is, symmetric approach—see Latour 2003).

Despite these reservations, both types of critique are valuable because they evaluate the role of professionals and laypeople in defining the nor-

mal and healthy and distributing the responsibilities among various actors. The core concerns driving both forms of critique should, therefore, be kept in mind. First, there is the risk that medical experts alone, due to their professional education and organizational power, determine what must be regarded as pathological and what, by implication, is healthy and, in our context, a successful way of aging. As has often been noted (see still Canguilhem 1991: 181–201), health is a highly normative concept and can only be defined in relation to specific natural and social environments. It thus needs to be negotiated between all parties concerned. Second, the promotion of healthy lifestyles might be used as an excuse to neglect such social determinants of health as inequality and poverty. These conditions, too, contribute to the prevalence of dementia (this emphasizes Foth's contribution to this volume on a biased understanding of Lalonde's health field concept, which initially included health care organizations and the social environment). However, there are also limits to both the social explanation of health and disease and, practically, to what collective actors such as the state can do. Beyond a certain point, individuals have to take responsibility for themselves because others cannot decide for them how they organize their daily lives and conduct themselves.

So what can we regard as normal and pathological, and how are the tasks and responsibilities to be distributed? These are the questions that need to be collectively negotiated and reassessed not once but periodically. I want to add a third concern to this list, and this is the unease with becoming a preventive self. This unease is linked to what I call the preventive horizon. A horizon is a field of vision. Hence, speaking of a preventive horizon means that prevention is, first and foremost, a way of looking at the world. You can view virtually everything from the perspective of prevention—that is, from the perspective of mitigating the risk of adverse events such as violence, crimes, disasters, accidents, and, last but not least, diseases and impairments such as dementia. The preventive horizon turns, however, into a kind of blinder when it is made into an absolute. If you have to review the risks and potential benefits to your health—for example, to your cognitive abilities—before you decide to meet a friend in a bar or to engage in a sport, you might lose sight of the fact that you can enjoy these things as ends in themselves without worrying about the health-related consequences of these activities.

This point was already noticed surprisingly early in the history of disease prevention. During the Enlightenment, so-called dietetic self-help books were immensely popular in Germany and other European countries. Dietetics, which originated in ancient Greek medicine, recommended a temperate, well-balanced way of life to stay healthy, which was also equated with being rational. At the same time, however, suspicion grew among

physicians, philosophers, and others that worrying too much about one's health could itself become a pathological obsession leading to hypochondria—that is, imagined symptoms and diseases. A health-oriented lifestyle was, in consequence, no longer considered to be necessarily rational. An excessively health-oriented lifestyle could also turn into a kind of irrationality. Therefore, some self-help books recommended that their readers moderate their striving for a moderate lifestyle to stay healthy (Leanza 2017: 56–66). Translated into today's terms: health education should not only teach different health skills but also the meta-skill of knowing when to stop worrying about one's health. Therefore, the last concern is this: is the relative importance someone places on one's health and disease in one's personal life reasonable and justified or is the person running the risk of becoming obsessed with one's health?

Conclusion

This chapter pondered how to make sense of the current trend to include dementia in the class of preventable diseases. While a broad and influential strand of the literature on public health, medicine, and aging, regards the promotion of healthy lifestyles as another example of an expanding neoliberal health imperative, the argument developed in this chapter sought for an alternative approach. Drawing first on the work of Niklas Luhmann, I suggested that this trend was a transformation of the way dementia is reframed in society—not as a danger, which lies beyond human control, but as a risk that is preventable by modifiable decisions and actions. However, obstacles and counterforces exist, hampering this transformation. Unknowns exist that, when considered, raise the question about the grounds on which, for example, a general duty to change your lifestyle is based. Additionally, campaigns of dementia prevention rely on public funding, and, more importantly, they require recipients of information to pay heed to the information and take an interest in the issue. In liberal democracies with universal health care, these campaigns cannot deploy coercive means because they are mostly dependent on the listener's commitments to preserve one's health.

Thus, dementia prevention does not start from a position of power and strength. On the contrary, it has to be meticulously established in society, as was explained with recourse to Bruno Latour's sociology of associations. The form of subjectivity dementia prevention seeks to create, however, has to be related to a wider collective in which it can flourish. As I have argued above, in countries like Germany and Switzerland, the state and civil society actors have not generally withdrawn from public health. The creation

and distribution of responsibility are more complicated. Though there are examples of individual and collective responsibility relating to each other as a zero-sum game, this does not have to be the case. For dementia prevention, and for other causes for promoting healthy lifestyles too, it is not necessarily and entirely a zero-sum game. Scientists, politicians, experts in health education, and the media also contribute to the successful establishment of healthy lifestyles in society. The "preventive self" is the end product of a long chain of translations, and with every translation, there is some form of modification and the risk that the process interrupts before reaching its goal. For dementia prevention's aim to bring about a change of behavior, it is advantageous that not only the intended outcomes, but the recommended measures themselves are attractive, or at least not particularly unpleasant. Nonetheless, its success remains dependent on individual value commitments, and there is no real solution to this problem.

There are also concerns regarding programs such as dementia prevention. Without claiming to be exhaustive, this includes the following questions—who defines what is normal and what is pathological, and on what grounds? How are tasks and responsibilities distributed between various actors, ranging from individuals to state authorities? Moreover, how much room should the issues of health and disease take in people's lives, given that there are other aspects, too, that define our existence? Thus, there can be no obligation to affirm programs professionals in disease prevention and health promotion develop and propagate if these concerns are not addressed appropriately and if satisfactory answers are not provided. However, dementia will remain a matter of public interest in our aging societies for the foreseeable future. Therefore, it is highly desirable to be able to respond in a possibly balanced and constructive manner to both the public health threat itself and the measures taken against it.

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Notes

1. The National Dementia Strategy ended in 2019 and is now being transferred to a platform. The campaign promoted programs in four areas: (1) health literacy, information, and participation, (2) needs-appropriate services, (3) data and knowledge transfer, and (4) quality and professional skills. As part of the first action area,

the campaign "Dementia Can Affect Everyone" sought to "raise awareness and reduce prejudice" and "strengthen participation and comprehensive information for those affected" (FOPH and CMPH 2018: 4).

2. These are "education to a maximum age of 11–12 years, midlife hypertension, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking, and social isolation" (Livingston et al. 2017: 2678).
3. All quotations from German texts are the author's own translation.
4. There are, to be sure, opposite developments as well, such as environmental pollution and climate change. For a long time in modernity, as Luhmann (1989) argues, ecological problems have accumulated in the "blind spots" of society. They can thus be regarded as a prime example of collective irresponsibility. Only recently have our social institutions begun to learn to build more awareness of environmental issues.
5. See also Peter Fuchs (2008: 370–371) and Martin Hafen (2013: chap. 5), who also draw on Luhmann to make a similar point.
6. As Luhmann (1991) discusses elsewhere, the "child" as a pedagogical construct can, however, be regarded as such a medium. In a similar manner, also communication techniques deployed in psychotherapy and related settings seek to bring about change in individuals. But what both have in common is, ultimately, effortful and costly "personal interaction that remains the only way of convincing people of the desirability of change" without any "sure prospects of success" (Luhmann 1990: 94). Current developments in behavioral economics, especially techniques that are often referred to as "nudging" (Thaler and Sunstein 2009), are tackling this problem. However, it is one thing to prestructure consumer decisions in canteens and supermarkets by building corresponding "choice architectures," and another to bring about long-term change of attitudes and recurring behavior patterns, which are, moreover, mostly taking place in private spaces.
7. In the second part of this study, Latour presents the axioms underlying his approach in a systematic but also highly abstract and condensed form, which is not always easy to comprehend. For an instructive commentary on Latour's *Irreductions*, see Graham Harman (2009: chap. 1).
8. The complexity of individual sense-making processes in the context of dementia-screening programs based on individual biomarker testing is beautifully shown in Lock (2013: chap. 7).

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5 MIND'S FRAILTY

Elements of a "Geriatric Logic" in the Clinical Discourse about Dementia Prevention

Alessandro Blasimme

Introduction

We tend to think about the manifestation of disease as a clear-cut departure from a state of species-specific physiological normality. Dementia, in particular, is generally understood, both in clinical and in common parlance, as a disruption of high-order cognitive functions such as memory, communication, and reasoning, and it is often associated with the appearance of psychiatric symptoms and personality traits that a person has never exhibited before. In a person affected by dementia, departure from normal cognitive functioning is a radical transformation that disrupts the very biographical continuity of that person and that others frequently perceive as a loss of personal identity. Few other diseases lend themselves so easily to be understood as a qualitative shift between a normal and a pathological state. While this dichotomy intuitively make sense, French historian and philosopher of medicine Georges Canguilhem (1904–1995) famously warned against assuming that such qualitative distinctions are uncontroversial (Canguilhem 2012a). According to Canguilhem, the way in which medicine understands and tries to tackle the manifestation of pathological states is inseparable from its assumptions about what it means to be normal, or in good health. In the words of anthropologist Paul Rabinow (1996: 85)—who has been an acute reader of Canguilhem—the French philosopher demonstrated "the constant presence of evaluative notions like 'preservation,' 'regulation,' 'adaptation,' 'normality,' in both every-day and scientific approaches to life." Those assumptions are normative in nature in two ways. On the one hand, they include practical injunctions about how one should be leading one's life in order to preserve a healthy state. On the other hand, life itself is often represented as phenomenon animated by inner tendencies or forces determining an organism to acquire

certain vital states. Such vital forces manifest themselves, for instance, in development, in spontaneous recovery from illness, or in the progressive loss of an organism's capacity to cope with its environment over the course of its biological life.

Until recently, however, the clinical discourse about dementia has not paid much explicit attention to life's normativity. The clinical manifestation of dementia as an obvious and inexorable departure from a previously attained level of cognitive functioning has militated against seeing this disease along a progressive continuum of cognitive decline whose origin can be located back in a person's normal or healthy life course. But the conceptualization of dementia and of Alzheimer's disease (AD) in particular has switched between several different models (Leibing 2014) over the last few decades. In present days, the clinical discourse about dementia is showing signs of yet another epistemological and normative shift toward new ways of representing dementia and new strategies to prevent it. The main thesis of this chapter is that the vision that is taking shape in the new clinical discourse about dementia relocates cognitive decline along a broader trajectory of age-related functional decline, emphasizing dementia as a phenomenon that, while not being fully controllable, can be modulated through the course of a person's life experience. In what follows, I maintain that the new clinical discourse about dementia is trying to reconnect the pathological abnormality of this disease with the forces that shape the vitality of an organism, its capacity to cope with its environment, and to actively produce the conditions to resist degradation. In other words, the new epistemology of dementia is trying to conceptualize the normal and the pathological along the same vital continuum.

The already prominent clinical narratives about preventing dementia, I will show, are branching out in the direction of emerging paradigms in geriatrics—namely, research on frailty and research on geroprotectors, which are drugs designed to prevent or postpone the effects of aging. This encounter between the science of dementia and aging research represents a hybrid space of epistemological experimentation where specific ways of thinking about cognitive decline and intervening in it are tentatively taking shape. Emergent paradigms in geriatrics, as I will show, reinforce the idea of preventing dementia as scientifically and technically plausible. I reconstruct the early steps of such epistemological convergence, which started between 2007 and the early 2010s, based on a careful analysis of relevant scientific literature. Such literature shows the possible emergence of a new clinical discourse about dementia. I do not intend to claim that such novel understandings are bound to become mainstream. Nor, as a matter of fact, do I look at such new epistemological trajectories as more than early signs of a possible new articulation of dementia and dementia prevention. The

status of such novel discourses is still far from established, as they rather represent a still-precarious epistemology of dementia. However, it is precisely such precariousness that makes such discourses a privileged site to observe the potential emergence of new "styles of thought" (Fleck 1981; Löwy 1988) about dementia and cognitive health. From a disciplinary perspective, this paper offers an epistemological analysis of a still ongoing realignment of the normal and the pathological that makes preventing dementia conceptually possible. My focus is partly sociological, in the sense that I do trace back the realignment of the normal and the pathological to actual instances of exchange and contamination between different biomedical fields. However, I also take a more philosophical stance as I attempt to draw essentially conceptual connections between certain emerging models of aging and disease that play a role in recasting the clinical discourse about dementia both epistemologically and practically. To this aim, I take inspiration from Canguilhem's constructivist understanding of medical normality as a concept that "when considered within the human order, always remains a normative concept of properly philosophical scope" (Canguilhem 2008: 133). This stance invites one to pay close attention to the practical or, as it were, ethical demands that derive from specific ways of thinking about life, health, and illness. In particular, in attributing to the individual self the responsibility for the preservation of cognitive functioning, the new clinical discourse about dementia attempts to construct a more hopeful narrative around the disease. But, at the same time, it buys into broader currents of thought that see health as a *product* of individual care and agency.

In the coming sections, I reconstruct what in the title of this chapter I call a new "geriatric logic" about dementia prevention as a series of conceptual shifts in the understanding of cognitive decline and in the notion of prevention as applied to cognition, for which I have coined the expression "ground-state prevention."

Normal Trajectories of Functional Decline

Preventing dementia is not a new idea. Repeated failures in the development of drugs to target AD biomarkers (such as amyloid and tau proteins) have certainly influenced the quest for earlier interventions. But as Annette Leibing (2014, 2018) showed, specific epistemological changes were needed for the consolidation of the preventive narrative. First, the rediscovery in the 1990s and the further development of studies highlighting the link between dementia and atherosclerosis of brain vessels introduced what Leibing and Kampf (2013) call a "cardiovascular logic." According

to this logic, the etiopathology of dementia can be assimilated to the same modifiable risk factors that have been identified for cardiovascular diseases—that is, hypertension, diabetes, obesity, and sedentary habits (see also Leibing 2014). The second epistemological change is the interest in early—even presymptomatic—predictive biomarkers and cognitive signs of an incipient dementia. In particular, the identification of mild cognitive impairment (MCI) as a possible prodromal syndrome affecting individuals who may be on their way to develop clinical dementia has given further impetus to the cardiovascular logic, since people affected by MCI are ideal candidates for lifestyle adaptations that may slow down or delay the onset of dementia. These epistemological elements configure what Leibing (2018) calls a "new dementia."

In this section, I would like to show how the prevention narrative that characterizes the "new dementia" is enabling further epistemological reconfigurations of dementia possibly producing yet a newer interpretation of this disease. To begin with, I will focus on the emerging interest for the identification of frailty as a modifiable risk factor not only in geriatric medicine in general, but specifically in the context of cognitive disorders.

Despite its centrality for current research and clinical practice in geriatrics, there is no unique scientific definition of frailty. Frailty is generally understood as a progressive, age-related decline affecting an organism's intrinsic capacity (defined as the total physical and mental capacity an individual can rely on; WHO 2015), increasing both vulnerability to environmental stressors and the risk of disability and other adverse health outcomes. This multidimensional geriatric condition can be measured through different scales. Two of the most widely used methods are the frailty phenotype (Morley et al. 2013) and the frailty index (Rockwood et al. 2005). The frailty phenotype aims at detecting five symptoms: involuntary weight loss, exhaustion, slow gait speed, poor hand grip strength, and sedentary behavior. The absence of any of such symptoms is typical of robust individuals. The presence of three or more of those features denotes a frail person.

The frailty index is instead composed of seventy criteria describing the health deficits of an individual. This index is based on the deficit accumulation model by Mitnitski and Rockwood (Mitnitski and Rockwood 2007; Rockwood and Mitnitski 2011) and measures the capacity of an organisms to absorb the progressive accumulation of deficits (Cesari et al. 2014).

According to this model, "with aging, damage accumulates in cells and tissues, whether by random or genetic mechanisms, involving sub-cellular and organ-specific pathways" (Mitnitski and Rockwood 2007: 724). This process is controlled by mechanisms such as DNA damage response (Ou and Schumacher 2018), cell senescence (Zhu et al. 2015), protein kinase

pathways (Wei et al. 2017), and oxidative stress (Sohal and Weindruch 1996).

Evidence about an association between frailty and dementia started to emerge in the field of neurology between 2007 and 2008 through the work of Aaron Buchman and colleagues (Buchman et al. 2007, 2008). Such research was based on previous studies highlighting an association between general physical function and cognition (Stewart et al. 2005; Rosano et al. 2005; Wang et al. 2006). The idea that the best screening models for dementia should be based on multiple risk factors can be considered established by 2010 (Stephan et al. 2010). Based on such data and on this newly emerging paradigm, at the beginning of the new decade, the community of geriatrics started to produce retrospective studies further corroborating the association between frailty—a multiparametric measure of physical function—and dementia, showing that the age-related accumulation of deficits, in addition to known risk factors, is indeed a risk factor for dementia and AD (Song, Mitnitski, and Rockwood 2011). Further research is currently underway to better understand the potential role of frailty in dementia. In a 2017 observational study on people diagnosed with MCI, individuals with a higher baseline frailty index score had a significantly higher risk of converting to AD (Trebbastoni et al. 2017). In other words, this study hypothesizes that frailty may contribute to the transition from MCI to clinical AD or to weakening the capacity of people affected by MCI to revert to normality or remain stable over time. A recent meta-analysis has shown that frail older adults are at higher risk of incident cognitive disorder, in particular vascular dementia, as compared to nonfrail elders (Borges et al. 2019). The interest of these studies for the prevention of dementia lies in the fact that frailty is considered to be amenable to interventions and therefore to improvement, both through public health measures and by adopting healthier individual lifestyles in terms of nutrition and physical activity (Landi, Onder, et al. 2007; Kelaiditi, van Kan, and Cesari 2014; Bonnefoy et al. 2015; Landi, Calvani, et al. 2016).

Targeting frailty as a proxy to preventing dementia is reminiscent of the interest in the cardiovascular determinants of dementia. What may be at play here is a geriatric reconceptualization of dementia or, otherwise stated, the emergence of a "geriatric logic" in the quest for preventing dementia. This new logic pushes for the conceptual inclusion of frailty in a broader, multidimensional understanding of dementia. From a conceptual point of view, frailty is one possible way to measure the cumulative effects of an organism's overall biological and environmental determinants. Such complexification of dementia as a disorder owing to a multiplicity of factors (which frailty captures by measuring a variety of functional parameters) represents dementia in the perspective of an organism's whole life—as

opposed to a sudden, almost serendipitous disruption of higher cognitive functions. This view is reminiscent of Canguilhem's invitation to look at health from the perspective of a whole life, lived by a subject as its capacity to "cope with." As Canguilhem (2012b: 72) very clearly argues: "What is proper of an organism is to live as a whole and not to be able to live except as a whole."

The quest for conceptualizing dementia (also) in light of frailty foregrounds a more holistic idea of health that manifests itself through a person's whole experience (Blasimme 2020).[1] The geriatric logic is therefore sustained by an epistemological aspiration to recast dementia under a broader clinical perspective, reconnecting it to the normal trajectory of age-related decline that frailty tries to capture in all its complexity. The aspirational or, as it were, reformistic character of the geriatric logic in dementia comes clearly to the fore in another paper questioning the external validity of AD clinical trials that fail to control for frailty as a modulator of dementia. In this study, upon retrospective assessment, AD patients enrolled in randomized controlled trials appear to be less frail than those who are not included, as indicated by both higher frailty index scores and higher prevalence of frailty in the excluded cohort (Canevelli, Trebbastoni, et al. 2017). This is probably due to an unintended effect of inclusion criteria that privilege patients who are overall in better shape.

The convergence of dementia and frailty research is promising, but it is still in its infancy (Lim, Canevelli, and Cesari 2018). Available studies are limited in number, and evidence for establishing and explaining an association is still preliminary. What is more, a recent review has shown evidence from published observational studies that both frailty and MCI can spontaneously revert to, respectively, robustness and normal cognition (Canevelli et al. 2017). These findings and the current paucity of dedicated observational or interventional studies on the topic invite caution in embracing the geriatric logic about dementia. Still, this body of work is starting to attract attention in the scientific community as a way to systematically screen for who should be a candidate for preventive interventions. What I want to highlight here is that the geriatric logic rests on an epistemological move that aligns the pathology of dementia with the normality of age-related decline. Since frailty does not refer to a disease but to a spectrum of parameters describing a trajectory of decline, looking at frailty and dementia along the same life-course continuum operates a sort of geriatric normalization of cognitive disruption. Conceptually speaking, this normalization of dementia is a result of a pre-existing emphasis on dementia prevention, but it relies on distinctively novel epistemological elements with respect to the antecedent cardiovascular framing. What the geriatric logic shares with the cardiovascular framing is that both cast aging individuals as be-

ing "at risk" for dementia. As a consequence, normalization opens the door to a countertrajectory of pathologization of normal age-related decline. Considering dementia as the result of life-long exposure to multiple risk factors that progressively debilitate a person's resilience to age-related decline makes room for a novel interpretation of what preventing dementia ultimately means.

Preventing Cognitive Decline

The idea that health depends on an intrinsic kernel of properties that an individual employs to counteract the inner tendency toward age-related decline is also visible in the current clinical discourse about preventing cognitive decline. In particular, lifestyle-based preventive measures have focused on three domains: cognitive training, physical activity, and nutrition.

Cognitive Training

The notion of cognitive reserve (Stern 2002; Stern et al. 2018; Pettigrew and Soldan 2019; Giovacchini et al. 2019) suggests that innate cognitive abilities, education, and occupational attainments offer "a set of skills or repertoires that allow some people to cope with progressing AD pathology better than others" (Scarmeas and Stern 2003). According to this model, an intellectually and socially engaged lifestyle can delay the onset of dementia (Scarmeas and Stern 2003). While the idea of cognitive reserve, its relation to AD, and its characteristic emphasis on "cumulative life experiences" have been attracting considerable attention since the late 1980s (Cosentino and Stern 2019), evidence in support of cognitive training to prevent dementia is encouraging but still inconclusive. According to the 2017 report on preventing cognitive decline and dementia by the US National Academies of Sciences, some randomized controlled trials like the ACTIVE trial (Advanced Cognitive Training for Independent and Vital Elderly) show that cognitive training can delay or slow age-related cognitive decline, but no evidence from interventional studies supports the notion that cognitive training can prevent, delay, or slow down MCI or AD (National Academies of Sciences 2017). In particular, the ACTIVE trial showed that training can improve cognitive function in the specific domain being trained (moderate-strength evidence at two years; low-strength evidence at five and ten years), but transfer to other domains was infrequent (National Academies of Sciences 2017). Interestingly, the ACTIVE trial also showed greater maintenance of independence in instrumental activities of daily living for individuals who received cognitive training—although

with a five- to ten-year lag since the intervention. Based on these findings, it can be argued that more prospective randomized controlled trials with long follow-up are needed to produce conclusive evidence about the potential benefit of cognitive training as a way to boost cognitive reserve and possibly prevent, delay, or slow down cognitive decline and dementia (Cosentino and Stern 2019).

Physical Activity

Physical activity has been proposed and widely investigated as another strategy to improve an organism's inner capacity to cope with age-related decline. In geriatrics, numerous studies have addressed the role of physical activity on frailty components, including functional impairment and cognitive performance. One review dating back to 2010 reports that physical inactivity is an established very strong predictor of disability in elders (Landi, Abbatecola, et al. 2010). The same review suggests that while physical activity decreases the risk of early cognitive decline and poor cognition in late life, some studies undermine the association between physical activity and dementia (Landi, Abbatecola, et al. 2010). In this respect, the authors observe that in most studies, the effect of physical activity is assessed in older adult life, whereas regular levels of physical activity throughout life may be required to exert a protective function against cognitive impairment. A retrospective analysis of ilSIRENTE trial (Aging and Longevity in the Sirente geographic area, Italy) data shows that a history of high physical activity is associated with better cognitive performance in very old community dwellers (Landi, Russo, et al. 2007). Many other studies have addressed physical activity in relation to maintenance of cognitive performance throughout life (Laurin et al. 2001; Rovio et al. 2005; Ravaglia et al. 2008; Forbes et al. 2008). A 2014 systematic review and meta-analysis concludes that longitudinal observational study lend support to the notion that higher levels of physical activity reduce the risk of cognitive decline and dementia (Blondell, Hammersley-Mather, and Veerman 2014).

Nutrition

Emerging notions like "nutritional frailty" and "diet resilience" conceptualize poor nutrition as a determinant of age-related vulnerability and, by the same token, identify diet as a key area of intervention to conserve an organism's functional capacity and to protect it against age-related decline (Shlisky et al. 2017). Systematic reviews and meta-analyses of randomized controlled trials established lower risk of dementia and a positive impact on cognitive trajectories of specific nutritional patterns (Cao et al. 2016;

Canevelli et al. 2016). In particular, the so-called Mediterranean diet (rich in starchy foods, vegetables, fruits, and fish, and low in saturated fatty acids) has received specific attention. Reviews based on epidemiological evidence and data from interventional studies established that the Mediterranean diet might benefit cognition in healthy adults (Loughrey et al. 2017) and have a potential protective role against the risk of dementia (Lourida et al. 2013; Petersson and Philippou 2016; Canevelli et al. 2018). Most of the above-mentioned studies, however, highlight that available evidence is still not sufficient to support specific recommendations in the absence of long follow-up randomized controlled trials.

Geroprotectors

Geriatrics also studies the effect of fasting and reduced calorie intake on the longevity and health span in animal models. Recent studies have demonstrated that the mechanism is effective even in primates, in which it leads to longer life span and delayed onset of age-dependent diseases, including cancer, diabetes, cardiovascular diseases, and brain atrophy (Colman et al. 2009). Evidence that caloric restriction delays aging and leads to longer lives in mammalians has been available since the 1930s (Heilbronn and Ravussin 2003), and, as a matter of fact, the existence of a possible correlation between eating less and living longer has been known since antiquity (Schäfer 2005). Nevertheless, the long-term effects of calorie restriction on longevity in humans are still poorly known due to the lack of studies with sufficiently long follow-up. However, it is established that calorie restriction in humans causes the same metabolic adaptations as in rodents and primates, therefore decreasing risk for diabetes, cardiovascular disease, and cancer (Fontana and Klein 2007). Recent studies in humans have also shown that a fasting-mimicking diet for five days a month has a favorable impact on aging markers and risk factors such as weight, body fat, blood pressure, glucose levels, triglycerides, cholesterol, IGF-1 hormone, and an inflammation marker called C-reactive protein (Wei et al. 2017). But caloric restriction and fasting, like healthy, varied and balanced nutrition, may be difficult regimens to adhere to—especially for those who belong to lower socioeconomic strata (Payette and Shatenstein 2005; Darmon and Drewnowski 2008).

As a consequence, in recent years researchers have been devoting increasing attention to pharmacological compounds that could attain the same health-related outcomes of healthy nutritional regimens. Research in model organisms has led to the identification of a class of drugs, now commonly called geroprotectors (Bellantuono 2018), that can slow down aging, extend life span, and increase health span acting on the same bi-

ological mechanisms—namely, metabolic and inflammatory pathways (Mercken et al. 2013)—that are activated by caloric restriction. The list of geroprotectors is a long one and includes, among others, already approved compounds like metformin (Martin-Montalvo et al. 2013)—already in use for type II diabetes and metabolic syndrome—and rapamycin—already employed to prevent transplanted liver rejection and occlusion of cardiac stents (Ehninger, Neff, and Xie 2014). Another class of age-delaying drugs is senolytics (Xu et al. 2018), which are small molecules that cause apoptosis in senescent cells. A senescent cell is a cell that, as a defensive response to the accumulation of DNA damage (due, for instance, to UV light, ionizing radiation, smoking, or oxygen radicals), enters a state of proliferative arrest. In a senescent state, they produce pro-inflammatory factors that eventually lead to organ failure or malfunctioning (Baumann 2018). Along the course of an organism's life, the number of senescent cells increases. Senolytic drugs can reduce their number by pushing them toward apoptosis—that is, cellular death.

The current interest for the use of geroprotectors to prevent dementia is a further instantiation of the emergence of the geriatric logic I introduced above. In a commentary published in *Nature*, prominent scientists in this field argue for a reconsideration of the way we study age-related conditions such as AD (Fontana et al. 2014). Instead of addressing one disease at a time, the authors maintain, we should try to "stall incremental cellular damage and changes that eventually yield several infirmities" (Fontana et al. 2014: 405). This quotation confirms that dementia—at least as a translational research entity—may be undergoing a conceptual reconfiguration. More specifically, from an epistemic point of view, this disease is being normalized as one of the many chronic age-related conditions that can be addressed by trying to improve individual health span.

Since in animal models geroprotectors have the capacity to delay age-related conditions, including declining cognitive performance, and to boost resilience, they have recently been hypothesized to have a potential role in the delay or even reversal of frailty and thus to improve the capacity of an organism to resist or recover from adverse events (Trendelenburg et al. 2019). According to the geriatric logic, age and age-related conditions, including those affecting cognition, shall be seen along the same continuum and treated accordingly from a clinical point of view. In keeping with this vision, and drawing on initial evidence of an association between metformin use and reduced risk of cognitive impairment (Ng et al. 2014), a recent review has analyzed the evidence in favor of metformin (an inhibitor of gluconeogenesis acting through the AMP kinase pathway) as a geroprotector (Piskovatska et al. 2019). This study concludes that there are positive effects of metformin use in metabolic disorders, cardiovascu-

lar disease, inflammation, cancer, and frailty, but evidence is conflicting as to whether metformin can address age-related cognitive decline. Yet it is known that activation of certain kinase pathways, such as AMP, may have a role against aging-related conditions including AD (Salminen et al. 2011).

Research is currently underway to isolate a subclass of geroprotectors that could pass the blood-brain barrier and specifically target cognitive conditions such as AD. A paper by Schubert and colleagues labels this subclass "gero*neuro*protectors" (GNPs) and suggests a drug screening pipeline to identify suitable candidates (Schubert et al. 2018). GNPs are not expected to prevent dementia per se, but to "promote healthier brain aging and long-term neural function" (Schubert et al. 2018: 1004). Geroneuroprotectors, like geroprotectors, should thus not be understood as disease or risk-specific, but rather as targeting multiple neurodegenerative and age-related processes. Interestingly, the authors say that bona fide GNPs should intervene through the same molecular pathways that are implicated by caloric restriction, metformin, and rapamycin (Schubert et al. 2018: 1006). This condition further demonstrates the extent to which the geriatric normalization of dementia creates an epistemological line of continuity between aging itself and cognitive decline.

Ground-State Prevention

The logic that operates here is that of boosting an organism's intrinsic capacity to cope with age-related decline. I have illustrated how this logic operates in the geriatrization of cognitive health in the current clinical discourse around dementia prevention. I would like to propose that the idea of prevention at play here be called "ground-state prevention" of the degradation that occurs due to accumulated deficits along an organism's life and of the consequent deterioration of that organism's intrinsic capacity to cope with age-related decline. Ground-state prevention, as opposed to primary, secondary, and tertiary prevention, is not risk-specific (i.e., it does not target a specific risk factor), nor even disease-specific (i.e., it does not address a specific disorder). Moreover, it does not aim to provide or restore any measure of species-typical functioning or normality. Rather, ground-state prevention is a sort of biological enhancement aimed at boosting the intrinsic capacity of an organism to face its progressive functional decline and the appearance of age-related pathologies. As far as dementia is concerned, ground-state prevention is an attempt to operationalize the geriatric normalization of dementia in a more holistic perspective—that is, along the continuum of aging and age-related diseases. It will not escape the at-

tention of the reader, however, that, by the same token, ground-state prevention does not privilege one specific type of practical approach, as it can be achieved through either lifestyle-based or drug-based interventions. The aim of ground-state prevention is to boost resilience, and it does so by extending the preventive medical gaze not only to presymptomatic but also to not-yet-senior individuals. While it is too early to assess how ground-state prevention will play out in practice, in terms of public health and health promotion strategies, it has to be noticed that this approach might actually reinforce the long-debated risk of biomedicalization of old age—a problem that emerges precisely from seeing aging as a process of decline (Estes and Binney 1989).

Discussion

What I have described as the emergence of a geriatric logic in dementia prevention presents family resemblances with broader currents of thought about aging. Current medical thinking about aging is devoting considerable attention to the so-called healthy aging model, spearheaded by the World Health Organization (WHO). Healthy aging is defined as the capacity to develop and preserve levels of functionality that are conducive to wellbeing in older age (Ou and Schumacher 2018). The healthy aging model insists on the combination of intrinsic capacity and environmental factors. In this model, intrinsic capacity is the sum of three elements: a person's genetic endowment, health-related features, and socioeconomic characteristics. The environment—natural, physical, and social—interacts with a person's intrinsic capacities to determine the quality of that person's aging.

In the healthy aging model, aging is represented in terms of one's life trajectory. Throughout the aging process, a person's capacity to function in his or her own environment degrades with time. However, different people decline in different ways, as some remain sufficiently functional for longer, while others experience earlier or more rapid age-related degradation depending on their intrinsic capacities and dwelling conditions. While progressive decline in intrinsic capacity is assumed as a biological fact in the healthy aging model, intrinsic capacity is clearly represented as modifiable, that is, amenable to capacity-enhancing behaviors such as physical activity and good nutrition.

By now, the resemblance between the geriatric narrative about dementia prevention and the healthy aging model should not strike the reader as surprising. In both ambits, a realignment of the normal and pathological is at play. The metaphor that depicts life as a trajectory of age-related de-

cline operates a normalization of old age, while at the same time orienting ground-state prevention as early as possible in the course of an organism's life. It is premature to say whether and how the epistemic shifts I have illustrated in this chapter will yield clinical fruits. However, one cannot fail to notice that the inner tendency of the geriatric style of thought about dementia prevention is, so to say, the "agification" of life itself. Boosting resilience operates by projecting the management of the age-related health risks into earlier (younger) phases of life. The effects of these epistemological reconfigurations of dementia and prevention are even harder to anticipate. For this reason, future work on the broader anthropological, social, and ethical consequences of the geriatric framing shall be giving careful consideration not only to the epistemic merits of this framing, but also to its undesirable consequences. As pointed out by Stephen Katz (2020: 54) in a chapter on precarious forms of life, the very idea of resilience, while "promot[ing] a positive and democratic approach to coping with old age," still reinforces a socially exclusive model of successful aging. This bifurcation, according to Katz (2020: 54), "creates a division between being resilient and failing to cope." Resilience, Katz (2020: 54) reminds us, is and "remains . . . an individual trait." The intrinsically individualistic character of resilience, as a consequence, demands a broader imagination about how individual decline can be integrated into community care in the pursuit of collective security from the vagaries of old age.

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Note

1. Here I use the word *experience* in a philosophical way, drawing on Gadamer's (2004) elucidation of the notion of *Erlebnis*. In its philosophical meaning, *Erlebnis* indicates the immediate lived experience of a subject in its present manifestation, but also, at the same time, the sediment of a person's life, the cumulated effect of his or her immediate experiences, the memory of what occurred to a person throughout life (Gadamer 2004).

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PART II

From the Prediction and Early Detection to the Prevention of Dementia

6 REVISITING MCI
On Classificatory Drift

Tiago Moreira

In this chapter, I investigate the evolution of a diagnostic category—mild cognitive impairment (MCI)—in the last two decades. My point of departure is a comparison between two "practice parameters" or guidelines on MCI published in 2001 and 2018. Published in the journal *Neurology*, the official publication of the American Academy of Neurology, both guidelines' collection and consideration of evidence were led by Ronald C. Petersen, the Mayo Clinic neurologist who systematized the category, drawing on earlier uses, at the turn of the 2000s (e.g., Petersen 2003). Further, both guidelines were developed by a team of academics that included not only neurologists but also psychiatrists and psychologists, as well as academics with expertise in clinical epidemiology and neuropathology. Contrasting these two guidelines—taken as public statements of a wider "professional consensus" on the meaning of current scientific and clinical information—provides a window into the transformation of the social, epistemic, and technological networks that support diagnostic practices concerned with memory problems.

On the first, defining guideline on the category, the justification for focusing on MCI is clearly placed on the emerging diagnostic requirements of promising therapeutic approaches to Alzheimer's disease (AD):

> Basic research, such as the identification of secretase inhibitors and the development of an immunization model for the prevention of amyloid deposition, underscores the importance of developing techniques for early detection (of AD). Parallel with these endeavours, clinical research aimed at identifying the earliest signs of cognitive impairment has progressed. . . . Mild cognitive impairment deserves recognition and further study because, as preventive treatments for AD become available, it will become incumbent on clinicians to identify persons at risk of AD and those with the earliest signs of clinical impairment. (Petersen, Stevens, et al. 2001: 1133)

By contrast, in the 2017–2018 revision of the guideline, the explanation given for using the diagnostic category is considerably less future oriented:

> Mild cognitive impairment (MCI) is a condition in which individuals demonstrate cognitive impairment with minimal impairment of instrumental activities of daily living (IADL). Although MCI can be the first cognitive expression of Alzheimer disease (AD), it can also be secondary to other disease processes (i.e., other neurologic, neurodegenerative, systemic, or psychiatric disorders).
>
> . . . Persons with MCI are at higher risk of progressing to dementia than age-matched controls. . . . Persons diagnosed with MCI may remain stable, return to neurologically intact, or progress to dementia (. . . 14.4 percent–55.6 percent reverting to normal). (Petersen, Lopez, et al. 2018: 127–128)

It goes on to make recommendations, including the following:

> Although subjective cognitive complaints alone are insufficient to diagnose MCI, such complaints from either patients or their close contacts are core to most major MCI diagnostic criteria, as they may reflect a change in cognitive function.
>
> . . . For patients for whom the patient or a close contact voices concern about memory or impaired cognition, clinicians should assess for MCI and not assume the concerns are related to normal aging. (Petersen, Lopez, et al. 2018: 132)

Between 2001 and 2018, MCI has shifted from being defined as the major risk condition for Alzheimer's disease to being demarcated as a category loosely associated with a variety of possible etiologies, with a significant proportion of "persons diagnosed with MCI . . . reverting to normal." In addition, while clinicians' attention to MCI in 2001 was linked to wider processes of biomedical research on AD and the therapeutic possibilities attached to the amyloid hypothesis, by 2018 MCI had lost most of its connection to strategic biomedical innovation, grounding its continued existence on the importance of clinically legitimizing subjective memory complaints. At the start of the twenty-first century, MCI encapsulated the techno-economic promises of Alzheimer's disease research (Moreira 2009; Lock 2013). Two decades later, MCI is proposed to clinicians as an opportunity to discuss "diagnosis, prognosis, long-term planning, and the lack of effective medicine options" with patients (Petersen, Lopez, et al. 2018: 128)

How did this happen? How can we understand the transformation—the drift—of the MCI category? In earlier work on MCI, I have proposed that its stabilization at the turn of the century was due to its ability to work as a *politico-epistemic scaffold*, enabling the exploration of possible equivalences between biomolecular markers, neuropathology staging systems, and com-

monly used clinical dementia rating scales (Moreira, May, and Bond 2009). In this process, MCI became temporarily settled as a hybrid "risk category" at the boundary between normal and pathological aging, and the laboratory and the clinic, articulating the experience of "memory problems" with neuroscientific standards. One consequence from this analysis is that MCI's transformation from being a distinctively bioclinical category to becoming mainly defined by its clinical utility in the 2018 practice parameter requires not only an increased misalignment between research and clinical practice, but also an enduring necessity to enact and manage "memory complaints" in the clinic. In what follows, I address these two processes.

First, I explore the mechanisms leading to the increased misalignment between what Jutel (2011) labeled the "engines of diagnosis" in MCI. In particular, I focus on the evolving disconnection between existing clinical dementia classification systems, on the one hand, and dwindling expectations attached to therapeutics strategies and diagnostic technologies—biomarkers—on the other. Next, I suggest that the survival and classificatory drift of MCI can be explained by the role ascribed to "subjective memory complaints" not only in the consolidation of MCI as a category but also in bringing to bear a particular configuration of health care driven by choice and the "logic of the market" (Moreira 2012) in this domain. To do this, I draw on interviews with international biomedical and clinical scientists, originally collected in 2004–2006. My contention is that the significance of the data is not related to its "historical" interest but to how it provides insight into the reality-making, durable categorical politics invested into MCI, which have held to the present day. In the concluding third section, I consider the possible "torquing" effects (Bowker and Star 1999) of MCI's classificatory drift for people experiencing memory problems.

The Rise and Drift of MCI

One of the reasons AD has generated steadfast interest in the social studies of medicine is that it is generally seen as an exemplary case to understand the dynamics of biomedicine in the late twentieth and early twenty-first centuries. Although formulated originally by Alois Alzheimer within the scientific and institutional context that historians usually describe as "laboratory medicine" (e.g., Pickstone 2000), it was only in the turn of the 1980s that a renewed concern with the condition emerged, supported by the converging sponsorship of the US National Institute of Ageing (NIA), the National Institute of Neurological and Communicative Disorders, and the Alzheimer's Association. Through this process, AD became articulated as both a political issue—linked to demographic aging—and a medical/scientific problem.

With the establishment of the Alzheimer's disease research centers by the US NIA in 1984, the condition gained an institutional foundation from which it was possible to coordinate the relationship between research, therapeutic experimentation, and clinical practice. Such coordination is embodied in the development and publication of what came to be known as the "McKhann criteria" (McKhann et al. 1984). As a conventional standard, the McKhann criteria aimed at setting the procedures through which existing techniques and tools could be used to identify a new illness, thus enabling the transit of cases and materials such as brain tissue between laboratories and clinics. Recognizing that there was "insufficient knowledge about the disease" (McKhann et al. 1984: 939), McKhann and his colleagues proposed that diagnosis of "possible" or "probable" Alzheimer's disease required a harmonization between clinical, neuropsychological, and laboratory investigations that should be used in the clinic, and further research on the condition. This, I would suggest, can be seen as a major turning point in the establishment of Alzheimer's disease as a bioclinical entity.

Embedded in this conventional standard was a technological expectation, the promise that distinguishing between normal and pathological aging would be the best route for "finding a cure" for AD. This technological expectation was underpinned by the assumption that therapeutic development was propelled by a combination of standardized diagnostic criteria and the application of new biomolecular techniques and instruments. Importantly, this promise related not only to the personal troubles experienced by people living with dementia and their care givers, but also to the social and economic problems associated with aging populations. Crucially, the proposition was that such problems could be redefined as opportunities for innovation and the creation of economic value, affiliating AD research with what Felt and colleagues (2007) have called the regime of techno-economic promises. In this regime, research is justified by reference to the capacity to address a societal "need," arguing that this aim is best achieved by competitive market arrangements between researchers, universities, and companies, underpinned by strong intellectual property rights regulation. These arrangements, in turn, delineate strong boundaries between researchers and nonexperts, who assume the role of users or consumers of technologically enhanced health care.

One of the defining features of the field of AD research has been the cognitive and financial investment in this innovation model, helping to define its structure, and associated narratives such as "rational drug development" or "translational medicine." Its rootedness in the field is evidenced by the fact that the attachment to this innovation model persisted even after the first trials of therapies that "translated" the cholinergic hypothesis

showed modest results in the late 1990s, gaining new support as a strategy to "test" the amyloid hypothesis (Moreira 2009) within the new "preventative" approach for AD that became established in the 2000s. Thus, in ethnographic fieldwork in AD conferences in the beginning of the 2000s, I would often hear the argument that it was the understanding of the causes of the disease that needed addressing, not the innovation model. In many respects, it was as if the introduction of an alternative disease model reinforced the commitment of researchers, pharmaceutical company strategists, and policy makers to the regime of techno-economic promises.

As research groups and companies became increasingly interested in finding pharmacological agents that would target the molecular mechanisms that precede neuronal death, one of the strategies to implement this "preventative paradigm" was the creation of new risk categories that could serve as a bridge between normal aging and AD. This approach is evident in the 2001 MCI "practice parameter" extract provided in the previous section, where the proposal is to identify a population for research on the bioclinical antecedents of dementia and to test the effectiveness of preventative therapies for AD. As such, in its original formulation, MCI defined a transitional stage between normal cognitive aging and dementia (Petersen, Smith, et al. 1999), intended to work as a new "biomedical platform" (Keating and Cambrosio 2003) coordinating between different types of laboratories—molecular biology, neuropathology, neuropsychology, neuroimaging, etc.—and a new type of clinical setting, the memory clinic. In this regard, MCI could be seen as "nested"—in the sense proposed by Lampland and Leigh-Star (2009)—within the previous AD conventional diagnostic standard (the McKhann criteria), but only to extend and modify it.

During fieldwork in a memory clinic in the mid-2000s, I observed how the category of MCI was invested in by practitioners as a means to articulate "hope" and link individual diagnostic work to a wider techno-economic collective. This was possible because the clinic where I conducted the fieldwork had a strong research tradition, being associated with a major international academic program on dementia. Indeed, as the normative, population-based parameters for tests such as the Mini-Mental State Examination (MMSE) or MRI were not fully established for MCI or preclinical dementia, clinicians viewed their work as both care and science, and related to patients according to whether they thought they were a straightforward case—of depression, for example—or one that required further investigation. Persons with memory complaints became either "patients" or "research participants," and their engagement with the clinic was significantly shaped by their bioclinical identity—their data and commitment being routinely maintained. There was a sense—even among staff that did not "buy into the Mayo Clinic view of things"—that characterizing, in the

clinic, early signs of dementia was a pathway to scientific discovery and therapeutic development. They were part of a bigger picture, a wider bioclinical assemblage.

In the following years, there was a weakening of the coordinating practices between standards in this assemblage. Nowhere is this more evident that in the attempts to develop, validate, and implement biomarkers of AD. As researchers and their sponsors increasingly advocated the use of MCI mostly as a point of entry to more detailed, biomarker-based investigations (Leibing 2016; also Boenink 2016), the fragility of "circuits of translation" on which MCI relied became paradoxically more discernible and unsettling. One of the key reasons for this is that, although proposed as crucial for investigators to draw equivalences and conserve passageways to more easily available—and accepted—diagnostic standards such as dementia rating scales, reliance on biomarkers has proved challenging because these are only available in very selected clinics. This, in effect, means that it has become increasingly difficult to maintain the coherence of the AD bioclinical collective, with memory clinics working with "old" diagnostic technologies, classification systems, and categories such as MCI (Hillman and Latimer 2019), and research projects deploying complex, "innovative" biomarkers for AD.

This disjointing between the clinical category of MCI and the world of AD research has been compounded by a series of negative trials of amyloid-based therapies in the last decade (Metha et al. 2017; Garde 2018). This and the difficulties inherent in coordinating the longer large clinical trials that are required by a disease-modifying, preventative approach to AD might be behind the current withdrawal of key pharmaceutical companies from the AD market (see, e.g., "The Brain Drain" 2012). Such disinvestment is significant because it destabilizes not only the assemblage of economic and biomedical actors gathered around AD as an entity, but also the model of innovation that AD research was supposed to embody and represent. The techno-economic promises of AD research and innovation now carry less weight than a decade ago. MCI and the diagnostic practices associated with it—"informant interview," MMSE, etc.—are less easily linked to a collective investigation, and become primarily related to "personal troubles." In other words, and drawing on the conceptual model I proposed for my analysis of memory clinics (Moreira 2010), current diagnosis of preclinical dementia individualizes memory complaints without providing a horizon of "hope."

Meanwhile, interest in MCI at the turn of the century motivated a series of community-based population studies that attempted to validate the category or provide it with a more nuanced etiological understanding (Ritchie and Ritchie 2012). As is well documented in the 2018 MCI practice parameter, there was a multiplicity of criteria used to identify MCI in the com-

munity (Petersen, Lopez, et al. 2018: 135), leading to the reflourishing of the dementia-continuum controversy. This is because even those studies focusing solely on amnestic MCI have found that while there is increased risk of developing dementia compared to age-matched participants, longitudinal data also show that persons diagnosed with MCI might also remain in that condition or revert to normal. It is not only that the boundaries between dementia categories are becoming increasingly blurred, but also that the transit of person between those categories is not unidirectional. This challenges both the usefulness of the categories in determining illness trajectories, but also the relationship between MCI and the "preventative paradigm" in AD research. Furthermore, compared to accuracy envisaged by biomarkers, MCI has progressively lost the ability to identify with some degree of certainty "persons at risk of dementia." What it is doing instead, however, is not at all clear.

Research on the psychosocial consequences of being diagnosed with MCI has consistently found that the diagnosis has particular implications for the identity of persons experiencing memory problems. Corner and Bond (2006), drawing on Goffman's concept of stigma, suggested that MCI's association with dementia has led to feelings of worthlessness and increased anxiety. Beard and Neary (2013), more recently, have found that MCI diagnosis leads to a form of "courtesy stigma," where others' expectations of the evolution of the condition positioned persons experiencing cognitive impairment outside of full social membership. Others have found, however, that this loss of social membership and participation rights was balanced by the advantages of being able to "put a name" to the difficulties experienced in everyday life, and to thus devise coping and mitigating strategies (Lingler et al. 2006; also Joosten-Weyn Banningh et al. 2008). Noticeably, the 2018 MCI practice parameter excluded analysis of the literature on "the potential psychological distress of a diagnosis of MCI" (Petersen, Lopez, et al. 2018: 132), focusing instead on the provision of lifestyle advice and long-term planning (living wills, etc.).

Despite not providing clues on etiological causes, and being unable to identify treatment options or predict outcomes with some certainty, MCI continues to be proposed as a diagnostic category enabling clinical engagement with patients and care givers. This is justified, as suggested in the previous section, by the significance of "subjective memory complaints" for the person and his/her caregiver. But what is the meaning of this significance if, as argued above, the link between MCI and the disease model of dementia, and the bioclinical collective that enacts it, has been extensively weakened?

One possible answer to this question is that the expression of memory complaints is a signifier for a mode of health care organization that config-

ures persons experiencing such troubles as consumers of health care. This possibility overlaps fully with the regime of innovation that dominated the field of AD research and policy in that it positions individuals as consumers of technologically enhanced health care. However, the suggestion is that this attributed role can persist despite a fragile link to innovation practices because of how it is also attached to a regime of coordination of health care that relies on market implements and practices. In the next section, I develop and evidence this hypothesis.

Market Memories

Between 2004 and 2006–2007, within a multimethod study that aimed to understand the social, political, and biomedical mechanisms leading to the establishment of MCI as a diagnostic category, my colleagues and I conducted thirty-seven interviews with experts in dementia research, care, and policy in the United States, United Kingdom, Canada, and two continental European countries. These were qualitative semi-structured interviews on the scientific, clinical, and societal meanings of MCI and/or early diagnosis and prevention of dementia. Our analysis of this dataset indicated that participants saw the emergence of MCI not only as a consequence of changes in the biomedical and epidemiological knowledge base about dementia, but also as related to the social organization of health care, leading to differences in the use of MCI across the countries included in our study (Moreira et al. 2008). Indeed, one of the key findings was that experts saw the adoption of the MCI label as a function of how "marketized" the health care system was. For our participants, this was made evident in the way in which health care systems were responsive to "demands" expressed in the clinic.

This was a surprising result in our data analysis because while, at the time, the debate in the literature revolved around the possibility of moving MCI to the clinic, our participants seemed to suggest that the need for a category such as MCI originated partially in the clinic. This differed significantly from science-push explanations of the emergence of MCI, where scientific and technological changes would have led to the implementation of the category at the clinical level. In our interviews—confirmed by fieldwork data—the needs of patients and of their families were seen as essential to understanding the scientific relevance of MCI. For example, in an interview with a US neurologist, experiential knowledge of subjective memory complaints and the needs they entail were rendered as the source of the search for a new diagnostic category:

> Neurologist (N): My opinion, I am unusual in being so bold: those patients and even more importantly their families know something is wrong and they

don't want to wait to see if they are going to get worse before they start therapy (hmm) so yes they are interested in clinical trials, I mean does that make sense?

Tiago Moreira (TM): Yes.

N: I mean they know something has changed.

TM: So would you say . . . that the fact that people are demanding, the patients are demanding other forms of treatment is also moving the field forwards in preclinical Alzheimer's disease?

N: Yes absolutely.

In this exchange, the neurologist's suggestion was that the need of persons with memory complaints to "put a name" to their troubles and attempt to do something about it had driven the field toward a focus on preclinical AD. Interestingly, the emergence of memory troubles is seen as underpinned by a change in their daily experience, whereby "patients and even more importantly their families" are able to ascertain the appropriateness of remembering or the inappropriateness of forgetting in specific familiar situations (the location of car keys when leaving the house was an oft-mentioned example). This knowledge that "something had changed" had not only an epistemic authority but also an ontological reality that appeared obvious to interviewees.

In establishing this authority and reality, participants made reference to established ways of enacting experience and symptoms. The solidity of experience of memory complaints came from it being enacted in clinical practice but also in clinical research over a period of time. As one US geriatric psychiatrist I interviewed put it,

Erm (pauses, laughs), people know, I mean this is not news for us, so, er, all these years, twenty five years [ago, we did a study, and], I don't think it's changed, also those people always knew (laughs), er, what was going on and, y'know, and we published [research paper about that a few years ago]. In other words this is not new, the people, y'know, er, and especially today . . . the patient (laughs) patients know, they're afraid and they don't need to be convinced (laughs) at all.

So, here there are two versions of knowing that, according to the extract, reinforce each other. On the one hand, the familiar, everyday knowledge that "something has changed," and, on the other, the gathering, processing, and analysis of those different experiences as one shared experience. This transformation of dispersed experiences into an equivalent category

is crucial because it exactly relies on the use of an epistemic instrument to assign reality to a particular phenomenon (Latour and Woolgar 1979). Furthermore, the repeated use of the same instrument—the interviewee was referring to a dementia rating scale—enables the production of a stable object that was known already "twenty five years ago."

This stability refers to the diagnostic category itself—and its clinical referent—rather than how it is distributed in the population and across years. Such epidemiological characterization relies, in fact, on the permanence, the unchangeability, of the category, supporting the experts we interviewed to develop what could be conceptualized as a *members*' historical sociology of diagnosis (Garfinkel, 1984), identifying the constitutive elements that brought MCI to bear in the clinic. A common element in this historical sociology was the growth of the number of persons complaining of memory problems; one example from my interviews follows:

> Well, I'm head of the [Alzheimer's clinic] and, em, our research is aimed at early diagnosis and treatment of early Alzheimer's disease, and in that sense we are interested in MCI. We see, compared to five years ago, we see more and more patients that enter in the memory clinic actually that have only memory problems. So they will be classified as MCI.

A neurologist in an international clinical research center located in Netherlands, he perceived that there had been an increase in the number of people who "have only memory problems" in the five years before the interview. We found also that clinicians in all the five countries where we conducted interviews shared this perception. It is thus at the aggregate level that the clinic can be seen to be mediating the knowledge need articulated by patients. In this, it was perhaps decisive that all clinicians we interviewed also had research responsibilities. Thus they saw themselves as spanning the boundary between the laboratory and the clinic. The language of consumerism enabled clinician-researchers to maintain authority in the research community.

People experiencing "only memory problems" were problematic because they did not display all the other markers of AD, yet presented with a pressing problem. This change, and its moral weight, had been, according to the same interviewee, one of the main drivers of the clinic's reorientation toward MCI, responding to a demand that was not there previously. Such responsiveness was a critical element in the process of remaking clinical practices. As another US geriatric psychiatrist put it,

> I do think the views on MCI are moving here though, in that, um, people are seeing the patients, I mean people are getting referred now, and you know we're all seeing a group of people in reasonably large numbers that we didn't

> tend to see before, and I think realizing that you can't just send them away and say there's nothing wrong with you, you're normal, because they're not actually normal, and what do you call them? What do you with them? And there is increasing awareness of that.

In this participant's case, the story was that while he was at first resistant to MCI on scientific grounds, his views had moved because of the "reasonably large numbers" that were being referred to the clinic with "only memory problems." These patients were not only different from those presenting with AD but had a unique, distinctive quality to their experience. The same geriatric psychiatrist described this uniqueness thusly:

> The patients that we see in a hospital setting, or go to their GPs and come here [to the memory clinic], they're the ones . . . whose lives are being really kind of wrecked by this worry that they've got a brain tumor and they can't really get on with their life until they get that sorted out, and I think they are a completely different type of person, and you know they should be seen and dealt with and assessed.

Being a "completely different kind of person" justified a different approach to health care. For the interviewee, this worked through a typification of a set of practices of engagement with health care practitioners and institutions: these were people that experienced memory problems, however minor, and were concerned with the possible causes of such troubles; they wanted reassurance and to be able to "put a name" to it, a legitimation of the concern (Freidson 1970). Most importantly, they actively sought the diagnosis and the reassurance. That is to say, they are defined, or configured, as active agents in seeking information and help about their forgetfulness. Crucially, participants in our study described this process typically by drawing on a market vocabulary, where the concepts of "need," "demand," and "expectations" were articulated. Clinical practice as well as research in MCI was thus framed by our participants as being a response to these requirements.

This is because participants' views emphasized how users' needs were channeled by the clinic. Participants highlighted how significant the memory problems were for patients presenting at their clinics. This significance was associated with the levels of worry and fear that were attached to forgetfulness by patients and their families. While this might lead to questions about whether patients can act as consumers because these emotional and personal attachments would prevent the patient from acting according to an ideal of rationality, our interviewees viewed these emotions as motivating the act of information seeking that characterizes consumers. Not being able to offer a long-term therapeutic solution, clinicians saw their role as

providing information individually to patients. In this respect, clinicians were able to use the language of consumerism to reinforce their professional roles and identities.

Our analysis of the data suggested that it was because clinicians are dealing individually with members of what they saw as a specific social group that they are able to both reinforce their professional identities and to reinforce their authority in a research field that is becoming increasingly biomedicalized. In our ethnographic fieldwork, informants consistently characterized the social status of MCI patient as white, middle-class "baby boomers," also sometimes described as the "worried well." Social research on "baby boomers" has shown that this generation ascribes strong value to self-actualization through consumption, which is one of the key driving forces in the changing health dynamics of contemporary societies. As one of our interviewees jokingly put it,

> I mean what one worries about is the baby boom generation that's in its, in its infant narcissism (laughs) and as it gets older and starts to worry about misplacing its keys then, then, one can imagine that studies to look at misplaced keys will be very high in priority (laughs).

This typification is significant for our purposes not only because of how it accurately reflects reality but also because it enabled participants to further detail the social process underpinning the construction of MCI as a category. For example, in an interview with a female psychiatric epidemiologist, a linkage between MCI and the transformation of American society was offered:

> The US has really developed into a society with very high expectations, er, very high entitlements, um, and you know the belief that we should take enough vitamins and exercise enough, you can avoid getting any diseases at all. And you know it's sort of not realistic, but I think the medical profession and the pharmaceutical industry have, in a way, contributed to these beliefs. Um, so that nobody accepts aging as a process of, of, you know, incremental losses any more. . . . But because of this very high expectation people have and then also because we have a society where people are not living in an extended family and don't have great support systems, there is such a fear of becoming disabled and dependent and not being able to maintain autonomy. Because this is a society that really, really values autonomy. . . . Um, you know, I think that trickles down to things like whether they want to hear about every breakthrough and, you know, want it implemented immediately and at the same time we're going to turn round and sue somebody if it doesn't go well. And there's no question that that affects the way clinicians react to patients, the way the government reacts to the public, the way, what the public expects of the government.

In her view, expectations about maintenance of health and functionality across the life course, significantly shaped by the medical profession and pharmaceutical industry, had led to situation where "nobody accepts aging as a process of incremental loss." This she linked to the core American value of autonomy, whereby aging is seen as a threat to defining qualities of agentic personhood—an analysis that echoes that proposed by key sociologists of aging (e.g., Cowgill 1974). Technological innovation, the interviewee suggested, has been promoted as a way to extend health span and maintain autonomy, making persons experiencing memory problems expectant consumers of possible medical "breakthroughs." One thing distinguishes her view from most of the other experts we interviewed: that the ability and willingness to act as consumers was embedded in a cultural and technological background. Interestingly, her view was that the consumer role was enacted as part of a wider technological regime, one where investment in biomedicine is justified by possible "compression of morbidity" and a reduction in health and social care budgets (Moreira 2019).

The person with memory troubles becoming a health care consumer was a historically contingent outcome of a variety of elements: health promotion programs, fiscal and economic policies, demographic projection, technological forecasts, changes in health care provision, and a generational culture. In this regard, the sociological analysis of diagnosis offered by the interviewee adds an important layer to the one proposed in the previous section, in that it links the regime of techno-economic promises to a specific political context, and defines the outcome in terms of expression of expectations on the life course and consumer behavior. Out of this assemblage, participants produced a typical individual—an ideal type—who seeks medical help relating to forgetfulness and memory problems. This idealized person, because of his/her high standard of wealth and education, his/her ability for self-assertion and expression, requires a different form of diagnostic practice, one that, as suggested above, is centered around the provision of information tailored to specific individuals, as described in this interview extract:

> Yeah, well for me it's the amount of information that you have available to you, so you know you have it within the context of the individual past life history, so obviously the retired professor in mathematics you need to operate a slightly different standard when you see him in the office than with seeing the man who cleaned his office, and so you need to be able to [take in consideration things] like that.

It would not escape any social scientist how class markers were used by the interviewee, a US neuropsychiatrist, to explain his different approach to the diagnosis of MCI. The implication is that with a more educated patient

you are operating at a cognitively "different standard," with emphasis on explicit information and content, possibly linking advice to evidence-based protocols. Clinicians responded to this new type of expectant consumer by transforming the basis and structure of the clinical consultation on memory problems. "Responsiveness" to new demands and needs of patients was seen as crucial in maintaining professional authority in a marketized health care. In this, the value of medical diagnosis was linked not only to the legitimation it produced, but more importantly to how this legitimation led to the deployment of a form of disposal, a prognosis:

> Er yeah, that's sort of what I meant and my understanding in the seventeenth century was that your quality as a doctor was, um, boiled down to pretty much how good you were at predicting the death of your patients, and that was pretty much, you know, your role really, and in the dementia it's, we do more than that obviously, but an important part of our role is seeing people with memory and other cognitive problems talking about prognosis, what's likely to happen to them. And that's valuable to patients, it's valuable to caregivers, and it's not to be, er, dismissed as a trivial thing. It's an important thing.

In this extract, the interviewee—a UK geriatric psychiatrist—makes an interesting historical analogy between the work of seventeenth-century doctors and those providing diagnosis and prognosis for people with memory problems. Characterized by patronage and close relationship between doctor and patient, seventeenth-century medical practice valued prognosis but lacked therapeutic tools to change the course of most illnesses. In the same way, clinicians in memory clinics are able to provide a close and detailed diagnosis, excluding possible alternative diagnoses, and to provide patients with an assessment of "what's likely to happen to them." This information is, he argued, valuable to patients and caregivers, enabling them to imagine possible future selves and the arrangements they will require.

Diagnosis and prognosis of MCI enrolled patients in practices that Clarke and colleagues (2010) see as characteristic of biomedicalized conditions: new forms of bodily engagement whereby individuals are provided with information of their genetic or biomolecular makeup so as to tailor their own form of health maintenance. In this regard, the category of MCI served as a form of "standardised differentiation" (Busch 2011), where value is produced by the close alignment between specific needs of a particular group and the type of service that is provided to that group. The same UK geriatric psychiatrist further specified what constituted value in this exchange:

> TM: Yes, yes. When you say that it's nice to put someone in a category, what do you mean by that? What are the advantages of doing that?

> Psychiatrist: I guess it would allow one to say, em, right, you know, you don't have dementia, you might get dementia, but so might I. But you don't have dementia at the moment, but you're not normal, so I'm not saying the complaints of your memory are in your head and you should go away and forget that; there is something there. Um, and, you know, your risk of Alzheimer's disease has increased, you know, you could do this and that to try and prevent, you could think about this. You know you should live a bit of a healthy life, everything like that. So these are the kind of things that, em, we can say to people. If we didn't have the category, I don't know how we could try and take things forward.

The suggestion was that the MCI category enabled a form of work that went beyond usual practice in dementia clinics. Being in the category positioned the patient between the normal and pathological boundary—"you don't have dementia at the moment, but you're not normal"—a space where it was then possible to engage the patient on prevention work. In this, the role of the clinician was seen as being mostly related to the provision of information, as already suggested above, and guidance on how to tailor general health advice to one's particular situation. This information was valuable exactly because it was "personalized." It took into consideration the persons' somatic makeup and lifestyle. Indeed, the focus on health advice, as opposed to technological interventions, was seen as a signifier for this practice of "personalization." One US neurologist expressed this in the following way in response to one of my questions:

> TM: But at this point those interventions are mainly lifestyle interventions or, let's say, nonpharmacological, i.e., more exercise etc. . . .
>
> Neurologist: Those are very important yes, absolutely. But I wouldn't, and I wouldn't minimize those; I think they have tremendously important significance for all of us and, er, but it can be a diagnosis of mild cognitive impairment of one form or another could be a wake-up call for somebody who's, you know, involved in a lifestyle that has, er, that is basically going to exacerbate the rate of progression of the illness, um, and so, um, making that diagnosis can have a major impact, not only in planning [for the future], as I said earlier, but also in the rate of progression of the disease.

In this is expressed the paradox of MCI: that while the configuration of persons with memory problems as expectant consumers results from the technological expectations invested in AD research, in the clinic, the exercise of consumerism was mostly deployed through ordinary, nontechnological health advice, albeit tailored to specific persons with a specific life history. However, this paradox also offers a solution to the problem posed at the outset of this chapter: how to understand the transformation—the

drift—of the MCI category from being a key vehicle in the delivery of therapeutic solutions to AD, to being solely a way to discuss "diagnosis, prognosis, long-term planning, and the lack of effective medicine options" with patients (Petersen, Lopez, et al. 2018: 128). In the clinic, MCI was, from the outset, a form of personalizing, of tailoring, health care to particular persons. There were two related ways this was articulated.

First, clinical diagnosis of MCI could give the patient the possibility of modulating the rate of progression toward dementia. In this, the main role was attributed to lifestyle interventions. It was reflexively understood by the participants in our study that those practices are imbued with moral meanings about one's relation to one's body and others around oneself. Thus class and education typifications of the person experiencing memory problems reinforced the relevance and appropriateness of lifestyle advice. There was a degree of elective affinity between consumers and the advice provided.

Second, participants in our study argued that clinical diagnosis of MCI could provide patients the opportunity to plan better for a trajectory of probable future cognitive decline. Because of the legal implications of a diagnosis of dementia, they viewed MCI also as offering patients "time," a decision point in their trajectory to ensure that arrangements in the future will be organized according to one's wishes. What is striking about this is how it appeals to the values of autonomy, cognitive agency, and control that epitomizes the baby boomer generation, as was recognized by many of our interviewees. Participants saw their role as providing the means through which patients could retain control over their lives by giving them a temporal horizon to which they should orient themselves. Overall, participants were aware of the different character of diagnosis entailed by MCI. While they conceptualized it mainly as information giving, they were also aware of social, cultural, and moral meanings of the information given, as well as of the information-giving situation. They were aware that MCI was a market making device, in that it constituted a specific relationship between providers and users of health that was shaped by consumerism.

On Classificatory Drift and Torque

In the chapter, I have investigated the evolution of MCI as a diagnostic category in the last two decades. Originally defined as the major risk condition for AD, MCI has become a much looser category associated with a variety of possible etiologies, with a significant proportion of "persons diagnosed with MCI . . . reverting to normal." In addition, while in the beginning of the 2000s, MCI was proposed as a politico-epistemic platform, invested

with the capacity to move AD therapeutic research toward finding and validating "disease-modifying drugs," two decades later, it is mostly seen as a useful categorical instrument to legitimize subjective concerns and provide personalized health advice.

In the first section of the chapter, I explored how it has become increasingly difficult to maintain the "circuits of translation" that uphold the AD bioclinical collective. I suggested that the assembling of this collective had relied on the power of conventional standards such as the McKhann criteria to facilitate the circulation of materials between clinics and laboratories. I then argued that with focus on biomarkers, memory clinics are increasingly working with what can be labeled "old" diagnostic technologies, classification systems, and categories such as MCI. Whereas memory clinics and their diagnostic work used to be easily linked to the wider, promising domain of AD, now this field of research is characterized by deep uncertainty about the value of existing therapeutic solutions and the destructuring of a pharmaceutical market. The question that then arises is, why is the category of MCI still used if its link with the disease model of dementia has been extensively weakened?

In the second section of the chapter, I suggested that the survival and classificatory drift of MCI can be explained by the role ascribed to "subjective memory complaints" in enacting a particular configuration of health care driven by consumer choice and the "logic of the market." Drawing on interviews with researchers-clinicians in North America and Europe, I proposed to analyze interviewees' reflections on MCI as a *members* sociology of diagnosis, as these were and are constitutive of the epistemic, technological, and institutional apparatus that brings MCI to bear in the clinic. I focused on how practitioners identified a "completely different type of person," an idealized new sort of patient whose characteristics facilitated their reasserting of clinical authority. The generational, educational, and social positioning of this new type of person with memory complaints justified a new form of clinical "responsiveness." These were "expectant consumers," looking for technological solutions for extended functionality and health across the life span. Paradoxically, what MCI diagnosis entailed was nontechnological, but nonetheless commodified, advice on lifestyle and health. MCI was, I argued, from the outset, a form of tailoring health care to particular persons. In this respect, it worked to enact market identities and entities such as "subjective memory complaints" in dementia care.

What are the possible consequences of this classificatory drift for persons diagnosed with MCI? As discussed above, in research on MCI diagnosis from the perspective of patients and caregivers, there is uncertainty about whether the stigmatizing outcome of the diagnosis can be balanced by the legitimizing protection it offers. However, as MCI loses its capacity to

identify a specific etiology and is increasingly unstable as a categorization, with a significant proportion of "persons diagnosed with MCI . . . reverting to normal," it is likely that diagnostic uncertainty will impact patients' self-concept and wellbeing, enhancing the liminality of their experience (Lock 2013), and constituting persons with memory problems as what Timmermans and Buchbinder (2010) conceptualized as "patients-in-waiting." Such reclassification raises crucial ethical questions, the justification for uncertainty experienced by patients in the present hinging on the possibility of future technological developments (Schermer and Richard 2019). However, as 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. Where once was hope, persons diagnosed with MCI may now find themselves increasingly outside the network, defined by a classificatory box that no longer connects to the wider grid, grappling with continued medical surveillance and the mundane complexities of managing their own condition.

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7 THE PREVENTIVE UNCERTAINTY OF MILD COGNITIVE IMPAIRMENT (MCI)

The Experts, the Market, and the Subjects of Diagnosis

Stephen Katz, Kevin R. Peters, and Peri J. Ballantyne

Mild cognitive impairment, or MCI, is a predementia condition considered a risk for Alzheimer's disease (AD). As such, its diagnosis and study has become a primary opportunity in research and practice for prevention and intervention. However, a growing literature of debates and critiques has also revealed the inherent uncertainty and instability of MCI as a diagnostic category that sheds light on the etiology of Alzheimer's disease itself. This chapter contributes to this literature by drawing together and juxtaposing data from the experts, the market, and subjects of diagnosis as three social realms where brain health, aging, cognitive impairment, and caregiving are assembled.

In "The Experts," we summarize the problems and issues about MCI articulated by experts in the field, supported by some of the interviews with nine leading researchers published by authors Stephen Katz and Kevin R. Peters in a special issue of *Dementia: The International Journal of Social Research and Practice* (2015).[1] In reviewing the MCI field, we highlight where researchers, experts, practitioners, and critics share common concerns about diagnostic inconsistencies, biomarker uncertainty, and pharmaceutical capitalization, all central themes to discussions about AD prevention as well. In "The Market," we look at selected rhetorics and products representing a new and lucrative memory market promoting "cognitive fitness" as a lifelong pursuit against the risks of dementia. The commercialization of memory products, foods, games, and exercises, and the incorporation of lifestyle intervention in health science and policy, both create and fill the gaps for hope and optimism for those seeking to manage their brain health. In "The Subjects of Diagnosis," we develop an interpretive analysis of data with twelve focus groups that were led by author Peri J. Ballantyne with people affected by MCI and AD diagnoses, highlighting their metaphorical

and narrative skills at making disruption and apprehension meaningful and coherent. Here we are also concerned with the relationship between the professional landscapes of MCI and dementia-related diagnoses and subjective and lay experiences.

These three parts of the chapter together raise the question of what MCI and other predementia categories actually mean and accomplish in a medical culture that, through diagnostic testing and preventive interventions, goes beyond the clinic to connect biographies, families, communities, services, and networks. If AD has become one of the most dreaded diseases of our time, then practitioners should be encouraged to consider how diagnosis is an ethical, as well as a clinical, process, observable in lived situations where personal resources are called upon to make sense of it. Thus, the experts, the market, and the subjects of diagnosis are purposively juxtaposed in this chapter not only as social locations of MCI and prevention knowledge-making, but as part of a wider diagram of uncertainty by which MCI, early detection technologies, and dementia campaigns are redrawing the health politics of aging. Conclusions consider the relationship between these politics and new divisive states of vulnerable, at-risk, and unsettled life.

The Experts

Katz and Peters titled their special issue of *Dementia: The International Journal of Social Research and Practice* "Voices from the Field: Expert Reflections on Mild Cognitive Impairment" (2015) because MCI and dementia are not just disease categories, but constitute a social field of networks of experts, research agencies, policy agendas, pharmaceutical interests, medical practices, popular images, and public social media that converge to mark out new cognitive and life-world boundaries between normal and pathological, functional and dysfunctional, and successful and unsuccessful aging.[2] As background, there have been many different MCI-type labels put forth over the years, with Kral's (1962) distinction between "benign" and "senescent" forgetfulness being one of the earliest.[3] Today, the common definition of MCI is that it presents a measurable degree of cognitive impairment that does not meet the diagnostic criteria for dementia. Thus, individuals diagnosed with MCI fit somewhere between normal and pathological, depending upon the diagnostic interpretation of descriptive and clinical criteria. And it is precisely this in-between status and liminal space that lay behind the uncertainty of MCI.

Currently, the most popular MCI clinical criteria are those put forward by Ronald Petersen and his colleagues (Petersen, Smith, et al. 1999). These initial criteria focused exclusively on memory impairment. These research-

ers subsequently expanded the MCI construct beyond just memory impairment by proposing the following three MCI subtypes: "MCI-Amnestic," "MCI-Multiple Domains Slightly Impaired," and "MCI-Single Nonmemory Domain" (Petersen, Doody, et al. 2001). The amnestic subtype became the major one in MCI research. In the spring of 2011, three important papers were published in the journal *Alzheimer's and Dementia* by American working groups established by the National Institute on Aging (NIA) and the American Alzheimer's Association, whose tasks were to revise diagnostic criteria for "dementia due to Alzheimer's disease" (McKhann et al. 2011), "mild cognitive impairment due to Alzheimer's disease" (Albert et al. 2011), and "preclinical Alzheimer's disease" (Sperling et al. 2011). These papers reified a place for MCI and preclinical AD along a proposed continuum of cognitive function, thus serving to legitimize the research push into early AD diagnosis, along with promoting the potential benefits of diagnostic biomarkers (e.g., MRI brain scans and cerebrospinal fluid [CSF] testing).

Although the fifth *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (American Psychiatric Association 2013) replaced MCI with "mild neurocognitive disorder," MCI has remained a highly popular clinical label as an underlying cause of AD, in part because of its relevance to prevention, even as important questions have emerged regarding its detection methods and the validity of associated biomarkers (Brown et al. 2011). Other critiques have focused on how MCI has been constructed through language and biased by scientific enterprise (Visser and Brodaty 2006; Whitehouse and Moody 2006), and have pointed out the ethical risks of MCI diagnoses and biomarker testing at increasingly younger ages, since AD is a late-onset disease (Corner and Bond 2006; Leibing 2014; Lock 2013a; Manthorpe et al. 2011; Moreira et al. 2008). At a macro-social level, MCI detection and dementia prevention are mediated by health-care policy, pharmaceutical interests, and public demands for better treatment.

Given this controversial background about MCI and its diagnostic uncertainties, why does it persist as such a successful disease entity? Our interviewed experts and others in the field offer three main reasons.

First, there is a need for some kind of diagnostic stage that precedes dementia in order to allow for early intervention, since a significant number of individuals with MCI progress to dementia, although neurodegenerative conditions such as AD itself can be slow to progress. One does not just wake up one day with AD; there must have been earlier signs. But conversion rates vary—not surprisingly, they are higher in clinic-based than in population-based samples—as do reports that between 14 and 41 percent of individuals with MCI revert back to "normal" cognitive functioning (Ganguli et al. 2004; Gao et al. 2014; Kaduszkiewicz et al. 2014; Manly et al. 2008; Ritchie, Artero, and Touchon 2001). Other inconsistencies have

divided the MCI field as some researchers, such as Mary Ganguli (2014), recommend refining MCI definitions since not all studies use the same ones, while others, such as Ronald Petersen (2015), continue to see MCI as a promising anchor for more precise data, although questions remain as to when and what kind of early testing is optimum for supporting intervention. As Carol Brayne and her colleagues have argued, we need to stop confusing "early" with "timely" diagnosis, because "there is currently no high-quality evidence that diagnosis before the usual point of clinical presentation leads to long term improvements for people with dementia and their families" (Brayne et al. 2013: 1). The medical logic that assumes "the earlier the better" can also overlook the aggressive imposition of medical screening with neither timely reason nor researched justification. And, as Constantine Lyketsos (2015: 323) told us in his interview, "If screening is applied to detect dementia at an early stage, then it needs to be related to helpful interventions for people."

Second, MCI satisfies a biomarker hypothesis, since diagnosed individuals have been found to have intermediate biomarker scores/values linked to AD (e.g., see De Santi et al. 2001; Pennanen et al. 2004; Xu et al. 2000). These results support the notion that MCI is a transitional phase between normal aging and dementia, as well as theories that the underlying factors associated with AD are the two neuropathological features of plaques (composed of the amyloid protein) and tangles (involving the tau protein). Predictive research also suggests that biomarker changes indicating features of AD can occur ten to fifteen years before the onset of any cognitive or clinical symptoms. However, the biomarker hypothesis in MCI and preclinical AD has been challenged in cases where no clinical symptoms are present (see Rockwood 2010; Sperling and Johnson 2010) or where biomarker abnormalities may not be specific to AD and amyloid and tau abnormalities may not be the cause of AD (Lock 2013b; Whitehouse and George 2008; Wright et al. 2009). Such debate challenges the use of biomarkers in diagnosing milder conditions such as MCI and preclinical AD, even as reliance on biomarker measures is becoming paramount in cases of asymptomatic preclinical AD. Epidemiologically, as Carol Brayne (2015: 356) comments, "until we have studies which are in truly unselected populations and follow them up for long enough, we will not know whether they [biomarkers] are actually predictors of dementia outcomes. . . . So the question is what is the value added of the biomarkers over the things that we already know enhance the risk for dementia just through education or family risk."

One particularly interesting finding has been that up to 30 percent of individuals who are cognitively "normal" have been found to have AD-related pathology, and this number has been found in postmortem studies as well

(see Aizenstein et al. 2008; Knopman et al. 2003; Price and Morris 1999; Snowden 2001). In addition, some studies have documented the deposition rate of amyloid in the brain of individuals who are initially cognitively normal, suggesting that cognitively normal individuals who are biomarker-positive may or may not be in the preclinical stages of AD or other types of dementia. Future research, therefore, more closely needs to examine the actual connections between biomarker results, prognostic reliability, and levels of care for people with AD.

Third, there is the critical issue of connection between MCI and pharmaceutical influence and capitalization. According to the website clinical trials.gov, there are hundreds of pharmacological and nonpharmacological registered trials related to MCI and Alzheimer's disease, indicating sizable investment in intervention. (At the time of our study, there were 233 trials open.) The cholinesterase inhibitors (i.e., donepezil, rivastigmine, and galantamine) and memantine are drugs already being prescribed for MCI, even where reported benefits are modest at best. In fact, there is some evidence of an increased risk of adverse events with these drugs (Russ and Morling 2012). Of the current drugs under development for AD, most are aimed at lowering amyloid levels in the brain. However, health research mandates for prevention fuel a pharma sector geared to narrowing the boundary between MCI and normal cognitive status and expanding the pool of "at-risk" older populations. The drug companies are racing ahead with growing the capitalization of dementia, even as the measurement and meaning of biomarkers have yet to be fully standardized across laboratories and clinics. Further, many drug trials involve very large sample sizes, which increase the chances of obtaining a statistically significant result. Yet even these small statistically significant effects may not be clinically meaningful (see Graham 2008; Peters 2013). While the research community agrees that early identification of MCI would be ideal if there were a safe and effective treatment for it, at this point there is no drug for MCI nor AD, and looking to the pharmaceutical industry for dementia care may well turn out to be an expensively flawed pursuit, as critical researchers predicted (Ballenger et al. 2009), especially if nonmedical approaches are excluded (see Basting 2009). In the end, as David Healy admonishes, we should think about what harm treating every illness for older people with drugs can create. "What we need is a new framework with guidelines for people, not illnesses" (Healy 2015: 365).

These three areas of research debate and contention regarding the uncertainty of MCI and predementia testing, the reliability of the biomarker hypothesis, and the influence of pharmaceutical capitalization support our conviction that understanding the strengths and weaknesses of the MCI disease model requires interdisciplinary breadth and plural sources of

knowledge, especially if preventive cognitive testing will be a pervasive part of our aging futures. The MCI and predementia field, as it continues to grow in research, funding, and technology, has also left unaddressed questions of improved care and attention to the everyday consequences of diagnoses. As Holly Tuokko (2015: 315) asks, "So what if I say that someone has MCI or dementia? We still have to provide support for this person after they leave the clinic or GP's office." And while research on MCI seems like a reasonable scientific response to public anxiety about protecting the aging brain from memory loss, it exists in a culture that has turned AD into a calamitous epidemic. The promise that medicine can intervene in the progress of AD at increasingly earlier points of life and at least prevent some of its risks—as it has done with diabetes, cancer, hypertension, and other chronic diseases—needs to be gauged against this cultural background. Part 2 of this chapter explores how a market of anti-aging industries has filled the gaps around hope and care left largely vacant by the health and medical sciences and created its own forms of commercialized expertise on managing brain health and cognitive "fitness" in relation to preventing dementia.

The Market

Today, cognitive health, a vague term in itself, is increasingly added to other health statuses (physical, functional, sexual, etc.), as evidenced by a growing focus on brain care in the lifestyle literature on exercise, diet, stress, sleep, and work-life balance. Such literature acts as a public pedagogy to educate readers about the wonders of brain-"boosting" foods, vitamins, daily exercises, and optimizing mental "workouts." Most importantly, it provides a sense that AD might be preventable; thus, the markets share a language with public health promotion agencies that mandate active lifestyles as disease preventive regimes. For example, the Alzheimer Society of Canada (2011), in the authors' home country, advises older people to "keep your brain active every day" and "that a healthy brain can withstand illness better." But how can we really know when our brains are "active" or "healthy" or "fit," let alone keep them that way? As Stephen Katz and others have investigated, the commercial inundation of products, programs, and advice about maintaining brain health and preventing age-related memory loss are based on contestable and culturally fabricated meanings of cognitive life itself (Katz and Marshall 2018; Williams, Higgs, and Katz 2012).

These meanings also have a political dimension. While there is a long history of mind and memory training with deep roots in theology, philosophy, and science (Danziger 2008; Katz 2013), today there is a cognitopolitics that reaches out to what Rose and Abi-Rached (2013) call "futurity,"

the governance of the future by way of controlling population risks in the present. For example, in 2009, the American National Institutes of Health (NIH) was spending nearly 20 percent of its total budget on brain-related projects (Carey 2009). In the United States, Humana and MetLife have programs to encourage clients to optimize brain health (Thornton 2013: 9), as public expectations for cognitive performance and boosting "mental capital" (cf. Foresight Report 2008) align to other market-driven standards of productivity, efficiency, speed, and unerring memory. The evidence of a coalescence between the brain sciences, futuristic cognito-politics, the neurocommodity market, and lifestyle preventive practices appears in overarching discourses about the brain that represent a new human nature (Rose and Abi-Rached 2013) and create what Fernando Vidal (2009) calls "cerebral subjects," who learn to express their identity in neuroscientific terms (see Pickersgill and Van Keulen 2011). Yet a key feature of these discourses is their lack of clear distinctions between states of cognitive improvement, enhancement, optimization, and wellness, even as these terms are ubiquitous in the promotion of brain-based marketing.

Scientific researchers advise caution about the marketed promises of an exciting lifestyle frontier aimed at preventing cognitive decline, especially where it is tethered to misunderstood appropriations of *brain plasticity*, an attractive idea that the brain can change itself or can be trained to do so. Plasticity signifies human character as flexible, mobile, dynamic, and adaptable, traits that also articulate human capacity and labor with neoliberal and global capitalist strategies (Pitts-Taylor 2010, 2016). As with physical fitness training and its metric quantification, brain training "is based mainly on recent neuroscientific findings that the brain is less like a blank slate or a computer-processing center (as metaphors of old would have it) and more like a muscle that can undergo atrophy or hypertrophy depending on its stimulation" (Millington 2014: 495). Images of the plastic brain-as-muscle permeate the commercial field of cognitive advice, "neuro" stimulants and protectors (e.g., LifeExtension's Cognitex, BrainStrong's Memory Support), "brain-boosting" programs (e.g., BrainAge 2, HAPPYNeuron), and brain "gym" and "spa" memberships (e.g., Mindspa). This is a hugely lucrative field that was forecast to become a $6 billion market in 2020 and expected to entice increasing numbers of consumers interested in cognitive fitness and influenced by the dictum that aging is inevitably accompanied by cognitive decline unless an individual does something about it (Fernandez 2013).[4] Thus, brain-fitness marketing language "renders the 3-pound organ in our heads both an object of alterity and veneration" (George and Whitehouse 2011: 591).

The lifestyle marketing and health politics around the aging brain overlie a deep anxiety about aging with dementia, again buoyed by apocalyptic

media images of "tides," "tsunamis," "storms," and "bombs" that depict growing older populations as social threats (Behuniak 2011). While it is often wrongly assumed that older people self-rate their memory more negatively than younger people (Shmotkin et al. 2013), the fear of dementia has become as explosive as the number of diagnoses reported for it. And, if older individuals choose not to buy into the commercialized promises of brain work, they become stigmatized as vulnerable to cognitive decline, poor health outcomes, and entry into the "fourth age" (Gilleard and Higgs 2010), just as do those who refuse to be physically "active" and remain "sedentary." Further, the public is aware that currently available drugs, treatments, and tests, despite the inflation of research funding and pharmaceutical investment in dementia-related diseases, are hardly proving effective to prevent them, let alone provide definitive cures. What, then, are the subjective experiences of people who have been or might be diagnosed with MCI or dementia and must incorporate this culture of fear, risk, and confusion into their own ways of interpreting and narrating their lives. These are questions we now turn to address in part 3 of this chapter.

The Subjects of Diagnosis

As discussed above, preventive diagnoses of predementia associated with the risk of progression to AD are riven with uncertainty, especially as biomarker research in some countries, such as Germany, are becoming increasingly part of common clinical practice (Schweda et al. 2018). As Gomersall et al. (2015: 907) discovered in their qualitative study of patients' accounts of ambiguity created by an MCI diagnosis, "It was not only the perception of MCI as a prodromal form of dementia that led to future-oriented anxiety; concerns were also raised around the uncertainty of the label." In some everyday encounters between patients and practitioners, the uncertainty of cognitive testing in memory clinics can be advantageous, as Swallow and Hillman (2018) investigate in their ethnographic research in the United Kingdom. Here "tinkering practices" around testing technologies and the "thickening of time" purposively used to slow down diagnostic disclosure become ways for professional staff to diminish patient anxiety about diagnosis. The authors conclude that, "as well as drawing on uncertainty in the diagnostic process, routines and mundane practices of clinical work can also be utilised to manage and traverse the presence of fear and anxiety and perhaps to protect practitioners from 'too much' emotion" (Swallow and Hillman 2018: 12). Thus, a more flexible diagnosis and less determinate labeling might also benefit people who are motivated by it to make

healthy changes in their lifestyle or work habits. MCI, in such cases, can be diagnosed in the sense of an alert, a warning sign to encourage healthier aging practices.

However, where clinicians might provide this more positive potential of diagnostic uncertainty, they still encounter their patients' dread of such testing if it portends an AD-foreclosed future, especially if exacerbated in poor communication practices about informed consent, disclosure practices, and false-positive results. Although dementia research demarcates MCI from AD, an MCI diagnosis is *experienced* as inseparable from AD because it carries the threat of it and already detours memory problems into a pathological state. As Renée L. Beard argues in her book *Living with Alzheimer's: Managing Memory Loss, Identity, and Illness* (2016), the MCI label is part of the same clinical and service worlds as AD. Indeed, someone complaining of memory problems and then diagnosed with MCI is already suspected of mental incompetence (Beard 2016: 56). Margaret Lock (2013a: 91) also emphasizes that an MCI diagnosis becomes a liminalizing and stigmatizing experience since the person becomes neither normal nor demented. Whether or not their MCI progresses to AD, a model of progress is insinuated. And as a person becomes a case for MCI and a clinical patient with cognitive problems, they must revise their personal identity and biography accordingly.

Hence, for people who are tested and diagnosed with MCI or at risk of AD, it is difficult to bridge the gap between the medical world, with its technical terms and uncertainties, and their subjective identification with cognitive decline labels (Campbell et al. 2016). Yet they are obliged to make sense of their age-related memory loss and come to terms with the likely need to depend on others for support and care. Since there is a woeful lack of research in the dementia field on the personal effects of diagnostic labeling or how it spreads and affects other spheres of life, there is little emotional counseling for diagnosed individuals to draw on or read about outside of commonsensical and marketed advice about prevention, diet, exercise, sleep, and stress reduction (although support groups can help). Yet such advice hardly considers how deeply disturbing and isolating the consequences of an MCI diagnosis can become (see Parikh et al. 2016; Stites et al. 2017) or how women and men can respond differently to their diagnostic status (Tolhurst and Weicht 2017).[5]

In our research with twelve focus groups of selected older individuals, family members, caregivers, and professionals, conducted by author Peri J. Ballantyne at Trent University (Canada), we learned how the ambiguities and uncertainties of MCI and dementia diagnoses are negotiated and rendered meaningful in the conversations, relationships, identities, and

routines of the people affected by it. These observations accord with gerontological research on metaphor (Kenyon, Birren, and Schroots 1991), discourse (Nikander 2002), narrative (de Medeiros 2014; Hubble and Tew 2013), and everyday sense-making (Gubrium and Holstein 2009) that shows how wider cultural ideologies and expert knowledges are fractured, translated, recombined, and adapted within people's everyday vocabularies and interactions.[6] Thus, in the remaining part of this chapter, we concentrate on examples where participants inventively use metaphor and narrative to account for their living with cognitive impairment. In particular we focus on recurring themes of what we classify as diagnostic "it," biographical disruption, and narrative collision.

This Diagnostic "It"

MCI and AD diagnoses happen largely in brief, anxious meetings with little attention given to postdiagnosis consequences. When people come to a clinic because of a memory complaint and learn they might have a serious medical condition and a possibly threatened future, the impact and uncertainty of the diagnosis can be experienced as an intrusion by an overpowering but amorphous "thing" in their lives. This is similar to the accounts offered by participants in Cox and McKellin's (1999) powerful study of Huntington's disease, where predictive genetic testing created a new affective entity within households around which family obligation, responsibility, routine, and care were organized. While, on the one hand, MCI or AD and Huntington's disease are obviously very different conditions, on the other hand, there are parallels in the language and affective presence of the disease(s) for those diagnosed. Just as the reference to Huntington's disease risk was expressed as "this thing in our family" in Cox and McKellin's study, in our research, an MCI or AD diagnosis produced a new and fearful presence marked by contradictions between the known and the unknown. The following excerpts are examples of how our focus group participants created a workable and lay relationship with this diagnostic presence and its contradictory nature by using the referent "it" (author emphasis italicized).

> Patient Mr. M: I didn't think too much about *it* until my wife realized that I was starting to forget a few things and we decided we would get diagnosed, to see if *it* actually was there. And of course, *it* proved positive, so it was just a matter to find out as much as we could, to postpone *it* . . . because there really isn't any cure. I don't try and hide *it* . . . I'm trying to get on with life. Now that I'm more aware of *it* I try and explain *it* to people . . . I don't think we need to be in denial about *it*.

Spousal caregiver Ms. G: The doctor had given him [spouse] an x-ray . . . I met with his doctor, "what was the result of that x-ray?" He says "he has dementia." I said, "well what can we do?" He says, "oh nothing much, you can't do anything about *it*."

Spousal caregiver Ms. D: He [spouse] arranged for a meeting with Dr. X and she confirmed *it* was Alzheimer's. I didn't call it Alzheimer's with him, I just said "oh you've got a bit of memory loss." And then slowly I worked the Alzheimer's in with him until he accepted the fact that he had *it*.

Spousal caregiver Ms. S: He [spouse] got fired from a job and he was extremely upset, but when I think back . . . maybe that's when *it* started, but when I really first noticed *it* we had belonged to a club and had a speaker there about the Alzheimer's Society . . . they said look at specifics . . . if they do things that they've never done before, and Mr. A. started to do things that he'd never done before. That was a good thing because that was in the early stages.

Volunteer caregiver Ms. T: I don't believe there is anything you can do to stop *it*. I think *it* is programmed in, I think it is a genetic thing and if you're going to get *it*, then you're going to get *it*. Maybe something to slow *it* down, but I don't think can stop *it*.

Biographical Disruption

The use of metaphorical language such as "thing" or "it" to refer or adapt to the onset of disease and suffering is connected to biographical disruption, a problem well documented in medical sociology. In her book *Disruptive Lives*, Gay Becker (1997: 60) points out the importance of metaphors in narratives of disrupted lives for linking the present to the past and reconnecting a person to their community or family by providing a "transforming bridge between the image of the old life and the new one." Even in cases where life becomes permanently disrupted and unpredictable, metaphors can be a resource for narrative sense-making by integrating suffering and loss into coherent explanatory patterns. In their study of strokes, Faircloth et al. (2005) examine the various metaphorical and narrative practices that stroke survivors use to come to terms with their experiences of sudden and massive disruption. MCI or AD diagnosis can be also particularly disruptive because it can reset the narrative flow of biographical life between the before and after of diagnosis. Here diagnosis is multifaceted, both predicting a potentially terrifying future as well as inspiring changes in health behaviors. However, when disruption follows from the diagnostic moment itself, it is often shocking and unmediated, as the following excerpts portray.

> Patient Mr. M.: I was up at the clinic and being diagnosed, then I had my sleep test and after three days, and it was just boom, boom, boom and they diagnosed *it*.
>
> Spousal caregiver Ms. G.: It was just sheer accident. I happened to be there seeing my own doctor, because we didn't have the same doctor. I bumped into him and asked him and he said, "Oh, he's [husband] got dementia."
>
> Spousal caregiver Ms. M: I noticed that he [husband] wasn't remembering things. We went to his doctor who said "I'll do a mini mental test." He also wanted to do some blood work. The doctor called soon after and said, "yes he has some the beginning of Alzheimer's." He said that he would give him Aricept. He really didn't talk about it too much. The next day there was a mail delivery to the house with Aricept in it.
>
> Older women's community focus group member Ms. M.: There was a woman who lived across the street and she was maybe 50-something, really fit and alert. I saw her outside, working in the yard or something. I called over, "how are you doing," and she went into the house and came out with this piece of paper that said that she has early Alzheimer's disease, she couldn't remember exactly what it was called. And then she lost all her vocabulary almost right away.

The following excerpts are related examples of how biographical and family history is recounted to help mollify disruption (authors emphasis of metaphorical language italicized).

> Spousal caregiver Ms. M: I think we can all look at our family histories, our extended family histories and say, you know grandma had *it*, you know my mother's *dingy*, great Aunt Mabel had *it* for sure, Uncle Harold had *it*, I probably got *it somewhere in there*, so we already at a gut level know that *we're marked*, down the road.
>
> Spousal caregiver Ms. C: On reflection the disease must have started years ago . . . the family always thought it was all his [spouse] arguments and idiosyncrasies, but as time unfolds you realize this was the beginning of Alzheimer's. I knew he had Alzheimer's long before the doctor said . . . you just know . . . you lived with the person all these years and you see the changes; you know something's up.
>
> Daughter Ms. P: [Talking about her mother's experience with memory loss]. It's the little *shift*, she says I've lived a full life and I have a wonderful family and I'm content with my life now.

In comparison, when we talked to a physician about diagnosis, he had his own way of narrating and dealing with biographical disruption for patients.

Dr. R: Typically, if I identify a patient with early cognitive changes and I'll bring the family in even if they're at an early stage. I'll introduce or give them insight *into the progression and having an idea of getting prepared right*. So it won't just be, well you know you're slowly going to decline, no; you need to get ready, right? So I'll instruct them on getting their will together, finding out who is going to be the POA [Power of Attorney], a substitute decision maker, ensure that there's safety in the home, the driving issue, and then further down the road, where are you going to live?

Because those things . . . *you plant the seed early right so people have a chance to prepare*. The crisis is when people ignore all of that and they end up in a hospital, right, because they're too far along. Then I'll have a follow-up visit and I'll say "so how far along have you come with the suggestions I made the last week?" And they'll say "not very far" or some will say "well at least we went to the lawyer and got something done."

Narrative Collision

If diagnosis can create disruption, sometimes the narratives through which it is expressed diverge and collide with each other and the diagnosed subject's own experience, due to the different interpretive strategies of family members, friends, and spouses. Here we borrow the term "narrative collision" from Tolhurst, Weicht, and Kingston (2017), who describe the differing and colliding accounts between friends and family members in cases of dementia-related diagnoses. As in the above focus group excerpts, the narrative work we listened to here was about creating composite and livable accounts of uncertain conditions (author emphasis of metaphorical language italicized).

Daughter caregiver Ms. M: My brother is my mother's major caregiver. He doesn't think there is anything wrong with her, but for those of us who don't see her every day, *we see the decline happening*. He insists she's fine, but she no longer socializes and she can't find words to speak when she wants to talk, maybe part of that is the mini strokes part . . . It's just sort of a *general slowdown*, she can watch the same documentary on TV over and over and thinks it's brand new.

Mother caregiver Ms. S**:** My other son has prostate cancer and when I see things that he's doing, I think more of the cancer. He downsized his home, his backyard, he's too tired to do all the work. My other son sees it as dementia. He's afraid, he's 58 and my other son is afraid that it is dementia starting. I would be worried more about the cancer than the dementia.

Spousal caregiver Mr. J: I've been married 34 years to a terrific girl who has a phenomenal memory, and because she's got a phenomenal memory, I frustrate the hell out of her with my memory loss, so I'm starting to feel depres-

> sion because if I said to her, "what does that cognitive mean," she would say "J., I already told you yesterday." I wish I didn't ask the question.
>
> Spousal caregiver Mr. G: I noticed my wife starting to use strange language about 15 years ago. It was just one or two little items and a few little choices that she made here and there. [After I went to meetings for caregiver support,] she thought I had betrayed her . . . it took a long time to convince her that I was coming for my own reasons. . . . She knows she *has decline* . . . but she won't buy it if I use words "dementia" or "Alzheimer's," so I don't use those words.

Doctors and diagnosticians in their practice face colliding narratives as well.

> Dr. A: A man appeared for the appointment with his wife; I asked "why are you here?" and the man said, "I'm doing fine" and the wife said "I'm a little concerned about what's happening to my husband, his memory is not so good." The man says, "I don't forget things" and his wife says "remember you came to pick me up at the mall the other day and you couldn't find me." It's the unawareness of the person who's afflicted, they're not looking for information because they think they're fine.

The import of our focus group data is to remind us that clinical testing, assessment, and diagnosis of cognitive decline may tell us what it is, but not how to reconcile ourselves to it. This gap creates a kind of ethical fallout, an absence that must be filled outside the clinic in everyday life where subjective and narrative resources are called forth to settle such unsettling circumstances. Even if diagnostic labeling is uncertain, it still creates a troubling aftermath. As one respondent told us, "My concern is if I were to end up with Alzheimer's, I would be dumped into what I call a dumping ground . . . that what scares me the most, because if I did get Alzheimer's I would want to be treated with dignity, right to the very end, treated as a person. Maybe I won't understand things . . . but I still have a heart, I still have a soul."

Conclusions

This chapter has juxtaposed the three social spheres of "the experts," "the market," and "the subjects of diagnosis" to present a sense of the complexity of "early" and "mild" dementia not only as disease categories of aging brains, but also as social assemblages of spaces, relationships, discourses, technologies, labels, products, statuses, ethics, authorities, and hopes. These assemblages are opportunities to consider how and why certain knowledges,

modes of care, and styles of life have become problems for older people. We have focused on the uncertainties of MCI labeling and preventive intervention because they effect service gaps between the clinic and the community, resulting in a postdiagnostic ethical fallout of personal support. The haste to develop tests and therapies of prevention and intervention for dementia and the rapid growth of sciences of "early," "pre-," and "mild" stages, has meant that younger but larger groups of people become categories of risk within the AD epidemic imaginary and as subjects of what Leibing (2018) calls the troubling "new dementia" of preventable risk.

If posed as an ethical and collective question, what does living with the uncertainties of cognitive impairment mean? One response comes from writers such as Judith Butler (2016), who advocates that we reverse the objectification and alienation of uncertainty, vulnerability, and dependence and see these as shared human conditions. Indeed, for Butler (2016: 14), what makes life sustainable and livable is the recognition that it *is* uncertain and precarious for all of us, and that we all depend on others and on social supports. Grenier, Lloyd. and Phillipson (2017: 325) adapt Butler's work to argue for an interdependent and relational model in dementia care practices that contest "the social and political conditions which shape a devaluing of subjects by means of their physical or cognitive impairments." These ideas offer a shift in critical perspective about the nature of fragility, dependency, and impairment that may come with aging, since these are or will be probable challenges for all of us. Taken to the domain of cognitive testing and diagnoses for MCI and dementia, this perspective also suggests how we might better humanize dementia as a collective responsibility through diagnostic practices that include support, dialogue, and compassion as bulwarks against the rising fears and risks promulgated by the coercive politics of self-care and regimes of prevention. To this end, this chapter has explored the value of sociological research into the subjective and narrative practices of individuals, families, and communities whose various journeys from memory complaint to dementia diagnosis wind across the debates of the experts, the prognostications of the clinic, the promises of the market, and the dilemmas of uncertainty.

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Notes

1. This special *Dementia* journal issue consists of nine interviews conducted during 2012–2013 as part of a project at Trent University (Canada) funded by the Canadian Institutes of Health Research (CIHR) on "Perceptions and Realities of Mild Cognitive Impairment: Diagnosis and Treatment of Older Individuals." The interviewees are neuroscientists Ronald Petersen, John C. Morris, and Peter J. Whitehouse, psychiatrists Constantine Lyketsos and David Healy, psychologist Holly Tuokko, epidemiologist Carol Brayne, sociologist John Bond, and Humanities scholar and dramatist Anne Davis Basting.
2. See Katz 1995 and Moreira 2017 for field histories of gerontology, and Whitehouse and George 2008 on the field of Alzheimer's disease.
3. There are recent predementia categories based on subject memory complaints and behavior, such as subjective cognitive decline (SCD) and mild behavioral impairment (MBI), which this chapter does not examine. However, these and related conditions share with MCI problems of vague definition and inconsistent predictive testing (Canevelli et al. 2016), as well as having become targets of pharmaceutical intervention (Leibing 2009).
4. The scope of this chapter does not permit a fuller elaboration of the growth in alternative regimes and movements emerging around cognitive health. While most involve dietary restrictions, physical exercise, and mental stimulation, others, such as Dale Bredersen's protocol and "cognoscopy" testing, signal a more comprehensive and biotechnological regime (see Marsa 2018).

5. The general exclusion of sex and gender factors in AD research, prevention, detection, and treatment is a significant bias; for example, the neglect of the impact on cognitive decline of hormonal differences between men and women (see Nebel et al. 2018)
6. While not theoretically applied here, the anthropological subfield of narrative medicine and its emphasis on patient stories and experiences is well established (see Charon 2006; Frank 1995; Kleinman 1988).

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PART III

Conceptual Premises and Normative Claims of Prevention

8 STAGING PREVENTION, ARRESTING PROGRESS

Chronic Disease Prevention and the Lifestyle Frame

Kirsten Bell

Introduction

TODAY, WE ARE INCREASINGLY TOLD that dementia can be prevented. According to the recent Lancet Commission on Dementia Prevention, Intervention, and Care, "Dementia is by no means an inevitable consequence of reaching retirement age, or even of entering the ninth decade. Lifestyle factors might reduce, or increase, an individual's risk of developing dementia" (Livingston et al. 2017: 2674). But one needs only to look at older editions of the *Lancet* to see how new this view of dementia is: thirty years ago, publications in the journal regularly questioned whether senile dementia was a normal aspect of aging or a disease process (e.g., "Senile Dementia of Alzheimer's Type" 1989). As Annette Leibing (2014) notes, the past decade has witnessed a profound shift in discourses on the possibility of preventing dementia, despite the fact that the primary risk factors, biomarkers, and medications have remained largely unchanged since the early 1990s.

Although the incorporation of dementia into the lifestyle frame is recent, "lifestyle" has been an intensive preoccupation in the fields of public health and health promotion since the 1970s[1] (Crawford 1977; Petersen and Lupton 1996; Bell, McNaughton, and Salmon 2011). Today, "lifestyle risk factors"—especially diet, exercise, tobacco use, and alcohol consumption—are deemed responsible for all manner of chronic diseases, including the three biggest "killers": cardiovascular disease, diabetes, and cancer. Thus, dementia is merely the latest in a long line of conditions to be drawn into this frame—a frame that relies on a number of underlying transformations in the ways we conceptualize chronic disease, prevention, and lifestyle.

My goal in this chapter is to situate recent shifts in conceptions of dementia within this larger historical and genealogical frame. In light of the significance of the United States in establishing chronic disease as a large-scale public and political concern, I focus primarily on the activities of the Commission on Chronic Illness, whose influence in mapping out this terrain extended well beyond the US context (see Weisz 2014). I demonstrate that new methods and approaches for studying health and disease, an accompanying shift from an emphasis on mechanical causes to probabilistic risk factors, and the rise of the notion of "chronic illness" evolved synergistically to converge in an emphasis on lifestyle as a core—really, *the* core—problem confronting public health. This, I suggest, provides necessary context for the rise of dementia prevention, although it simultaneously raises a number of questions about why the disease has been so recently drawn into the lifestyle frame. While various scholars have begun to explore what "conditions of possibility" (Foucault 1980) needed to be in place in order for the concept of preventing dementia to flourish, I offer a few preliminary thoughts via some broad comparisons with cancer—another recent entrant to the lifestyle frame, and a disease that offers some useful points of similarity and contrast to dementia itself.

Chronic Illness and the Concept of Prevention

If sanitation and infectious disease preoccupied the field of public health in the nineteenth century, the twentieth century was characterized by an intense concern with the health status of populations more broadly, and its predominant focus shifted to chronic disease. According to David Armstrong (2014) and George Weisz (2014), this transformation was the result not just of shifting patterns of disease itself (e.g., the much-touted "epidemiological transition"), but changes in how diseases were conceptualized and the key apparatuses used to understand and respond to them.

Critical to this shift was the concept of "chronic illness" itself, which came to take on new meanings in the twentieth century. Armstrong (2014) argues that in the late nineteenth and early twentieth century, the term referred exclusively to the duration of disease and was one among many characteristics by which diseases might be compared. However, from the 1930s, "chronic illness" started to be used as a kind of master disease category. What differentiated it from prior usage was the incorporation of a new attribute: one that identified it with disabling illness. Thus, for Armstrong, chronic disease was the emergence of a new form of morbidity based less on pathology and more on the patient's capacity to function.

Weisz (2014), in contrast, argues that it was not so much that the concept of chronic disease itself was new, but rather that it acquired new meanings in the twentieth century. Flagged as one of the most serious problems facing national health-care systems, the new focus on chronic disease—especially in the United States—entailed a rejection of the hopelessness and inevitability that had characterized approaches to "chronics" in prior centuries, instead transforming such conditions "into targets of intervention and amelioration" (Weisz 2014: 9).

This new orientation toward chronic disease is strongly evident in the work of the US Commission on Chronic Illness, which was established in May 1949 as a joint creation of the American Hospital Association, the American Medical Association, the American Public Health Association, and the American Public Welfare Association (Roberts 1954).[2] The goal of the commission was to gather and share information on how to deal with the problem of chronic illness, which was defined as any impairment characterized by at least one of the following: permanence, residual disability, originating in irreversible pathological alteration, or requiring extended care or supervision (Edwards 2013; Weisz 2014). Remarkable is the breadth of diseases the commission included under the chronic disease label, from arthritis, cancer, cardiovascular diseases, and cerebral palsy, to epilepsy, tuberculosis, mental illness, multiple sclerosis, and blindness (Roberts 1954; Commission on Chronic Illness 1957). However, despite broad acknowledgment of the differences between the aforementioned conditions, "chronic diseases" were conceptualized in singular terms: they were seen to share a number of features and could be tackled through a unified approach. As Weisz (2014: 107) observes, "Perhaps the chief function of "chronic disease" during the postwar era was to transform a series of independent and discrete problems into a single, complex, and multifaceted issue, requiring massive coordination on the national and local levels."

Stimulated in part by a concern with ostensibly rising rates of chronic disease and the escalating costs associated with it (Weisz 2014), the commission aimed to "pave the way for dynamic programs to prevent chronic illness, minimize its disabling effects, and restore victims to a socially productive place in the community" (Roberts 1954: 296). In light of its mandate to gather and share information on chronic illness, research was a central component of the commission's work, with a number of survey studies and surveillance activities carried out with the aim of understanding the prevalence of chronic illness and needs for care (Roberts 1954; Weisz 2014). Surveys were conducted in rural and urban locales, in nursing homes and home care programs, in order to identify the scope of chronic disease, the extent of disability it produced, and the kinds of care

patients received. Studies were also conducted with representative samples of patients with chronic disease and those who were well in order to understand the differences between these populations (Roberts 1954; Weisz 2014). In this respect, the commission's approach to research and surveillance reflects the rise of the "new" epidemiology in the era following World War II, which subsequently colonized public health to such a degree that it is now commonly considered its basic science (Petersen and Lupton 1996; Inhorn and Whittle 2001; Kabat 2008). The field focused attention on questions of comparative risk and excess mortality, with researchers recognizing that there were hundreds of variables affecting the incidence of disease (Brandt 2007). These studies provided the foundations of contemporary epidemiology and served to legitimize it as a distinct discipline (Brandt 1997, 2007; Fitzpatrick 2001; Kabat 2008); they also served to create new disease categories—a process to which the nascent pharmaceutical industry contributed (Weisz 2014).

The effects of these studies were threefold. First, as Armstrong (2014: 22) notes, they "marked the appearance of a crack in the edifice of natural ageing," with the line demarcating the domains of pathological processes and natural aging becoming increasingly blurred as a result of the differences found in chronic disease patterns across populations. What had previously been known as degenerative diseases began to discursively metamorphose into preventable and/or treatable—even curable—pathological ones. Thus, "myocardial degeneration" became "coronary artery disease," cancer became a pathological rather than a degenerative condition, and "senility" became "dementia" (although, as I will discuss in more detail below, this shift happened much later). Second, these studies served to fundamentally transform notions of disease causality in both public health and biomedicine (Brandt 1997, 2007; Susser and Stein 2009). A central premise of germ theory medicine was the notion of a single process in which A leads to B; however, the rise of the new epidemiology was accompanied by an emphasis on multiple causation in explaining the roots of disease (Krieger 1994, 2011; Brandt 1997, 2007; Susser and Stein 2009). Third, the variations these studies revealed in the prevalence of chronic diseases within populations, and the implication that these might be due to factors such as smoking, paved the way for the later emphasis on "lifestyle behaviors"—offering the prospect that many chronic diseases might be radically reduced by curtailing such behaviors (Brandt 2007; Kabat 2008). Although the lifestyle frame did not take hold for another twenty-odd years, the studies conducted during the postwar period created the conceptual space in which the notion of a "lifestyle risk factor" and its role in chronic disease prevention could ultimately flourish.

Subdividing Prevention

While the idea that chronic disease might be prevented was central to the commission's mandate, equally significant was its role in popularizing the notion that prevention could happen at several points in the disease trajectory, taking either "primary" or "secondary" form. The former was defined as prevention practiced to avert the occurrence of disease, and the latter was defined as halting the progression of a disease in its early unrecognized stage (Commission on Chronic Illness 1957), although a third term, "tertiary prevention"—rehabilitation after the disease has caused disability in order to prevent sequelae and further deterioration—was introduced shortly afterwards (Gordon 1983). Indeed, the influence of the latter model can be seen in a 1956 publication by the chief of the chronic disease program in the US Public Health Service, in which he noted: "We can prevent the inception of certain diseases [primary prevention]. We can prevent the progress of certain other diseases by early detection and early therapy [secondary prevention]. We can prevent or delay the onset of premature death or premature disability due to known or existing disease by diagnosis, treatment and rehabilitation [tertiary prevention]" (Kurlander 1956: 91). Despite the caveats presented, an assumption underpinning this model of prevention was that chronic diseases have latent, early, and late manifestations, and that intervention toward the beginning of this natural history can change, or even prevent, an otherwise-assured outcome[3] (Armstrong 2012). A consequence of the new typology was the introduction of a distinct temporality to the idea of chronic illness, which assumed that such diseases unfolded in a predictable way—from a latent period when they could be detected but had not yet caused harm, with a progressive worsening of symptoms over time in the absence of treatment. Thus, intervention at any point in the disease trajectory—even *after* it had emerged clinically—was deemed to be beneficial in averting, or at least delaying, its effects.

Nevertheless, despite the early identification of three stages of chronic disease prevention, efforts in the 1950s focused largely on the area of secondary prevention—in the form of screening programs and health examinations. This emphasis was based on the recognition that opportunities for primary prevention were limited until further research "discloses the intricate interrelations among the various causes that seem to be involved in nearly all chronic illnesses" (Commission on Chronic Illness 1957: 17). However, screening programs arguably paved the way for the subsequent shift to lifestyle as a core focus of primary prevention, serving as they did to dissolve the distinction between the sick and the well and attendant con-

ceptions of normality and abnormality (Armstrong 1995). Moreover, while the lifestyle frame was not yet evident in the realm of primary prevention, it was clearly apparent in the commission's emphasis on health promotion, which it conceptualized as an important complement to prevention itself (Commission on Chronic Illness 1957).

It was not until the 1970s that "lifestyle" became a central focus in the field of public health—partly as a consequence of the growing importance of health promotion: a field primarily concerned with identifying and changing "risky" lifestyles[4] via education about their deleterious health effects (Bunton 1992; Lupton 1995; Petersen and Lupton 1996; Bunton, Nettleton, and Burrows 2003). During this period, we begin to see intensive articulations of the notion that if people refrained from smoking, drank less, consumed healthier diets, were more active, and so on, the social and financial burden of chronic disease would be dramatically reduced (Petersen and Lupton 1996; Fitzpatrick 2001; Bell, McNaughton, and Salmon 2011). The rise of the field of health economics had an important role to play in this shift, although the economic costs of chronic disease had, of course, been a driving policy force for decades—including in the creation of the Commission on Chronic Illness itself. To quote from the influential US health economist Victor Fuchs's 1974 book *Who Shall Live? Health, Economics and Social Choice*, "Differences in diet, smoking, exercise, automobile driving and other manifestations of 'life-style' have emerged as the major determinants of health" ([1974] 2011: 6).

The growing emphasis on lifestyle during this period does not mean that biomedical approaches to chronic disease prevention were ignored; rather, they developed synergistically with the lifestyle frame. For example, the links between cardiovascular disease and diet stimulated new lines of medical and pharmaceutical research, such as the development of cholesterol-lowering drugs in the 1980s (Leibing and Kampf 2013). Likewise, the genetic approaches to disease that became increasingly prominent in the late 1990s stimulated a growing interest in lifestyle-gene interactions (e.g., Kolonel, Althshuler, and Henderson 2004; Franks et al. 2007). Indeed, education about the importance of lifestyle change has become an important complement to medical interventions for those with active disease, especially via the chronic disease self-management programs that were advocated as a core component of tertiary prevention from the mid-to-late 1990s (e.g., Lorig 1996).[5] As Morden, Jinks, and Ong (2012) observe, the logic of such programs is minimizing lifestyle risk factors with a view to ensuring "correct" health outcomes.

Lifestyle, in this framework, posits the subject as a rational, calculating actor who, by adopting a prudent attitude to risk in response to public health information, is autonomous, self-regulating, and responsible

(Petersen and Lupton 1996). For many, the contemporary pervasiveness of the lifestyle frame is therefore a product of neoliberalism—used as conceptual shorthand for the entrenchment of market solutions and the privatization of governance, with individuals made responsible for their own health (e.g., Lupton 1995; Petersen and Lupton 1996; Petersen and Bunton 1997; Bunton, Nettleton, and Burrows 2003; Brown and Baker 2013). While this view has considerable merit, the neoliberalism frame has a tendency to become so totalizing and monolithic that it starts to assume causal properties in its own right (see Bell and Green 2016). Although the contemporary regulation of lifestyle in the name of chronic disease prevention may be a "mechanism for deterring vice and for disciplining society as a whole" (Fitzpatrick 2001: 8), I have illustrated that the epidemiological edifice supporting it required fundamental changes in conceptions of the object of public health and new understandings of disease causality before "lifestyle" in its contemporary sense was able to emerge as both a cause of chronic disease and a key means of preventing it. Moreover, neoliberalism does little to help us understand the distinct ways in which diseases were drawn into the lifestyle frame; as I will demonstrate below, the trajectories of individual conditions were rather different in this respect.

Cancer, Dementia, and the Lifestyle Frame

In light of the centrality of lifestyle to the concept of chronic disease prevention, more surprising than the idea that dementia might be prevented via lifestyle modifications is that it happened so recently. Thus, in many respects, a question of equal importance to that of why dementia has been drawn into the prevention frame is *why the shift did not happen earlier*. Clearly, while "chronic illnesses" followed a broad trajectory in terms of how prevention was conceptualized, discourses on prevention must also be located within the shifting contexts of individual diseases themselves. Here, cancer and dementia provide useful contrastive cases.

Both cancer and dementia have a complicated, rather than clear-cut, relationship with the concept of chronic illness. First, they are both diseases of aging—their primary risk factor is age. However, by the postwar period, cancer, unlike dementia, had clearly moved from the degenerative to the chronic disease frame—as evidenced by the Commission on Chronic Illness's inclusion of cancer as one of its core chronic illness categories. Yet, despite the commission's focus on sites where patients with dementia would presumably have been common (e.g., nursing homes), and the fact that "mental illness" was part of its mandate, senile dementia was noticeably absent from the commission's purview—mental illness was iden-

tified purely in terms of "emotional disorders" ranging from neurosis to psychosis.

This is deserving of comment not just because of the association of both cancer and dementia with aging, but because senile dementia arguably fits the "chronic illness" category more readily than cancer itself. Recall that central to the definition of chronic illness was the emphasis on *disabling impact*—chronic diseases were permanent, irreversible, created residual disability, and required extended care or supervision. While dementia is characterized by its progressive nature, disabling impact, and the loss of autonomy it engenders, cancer, on the other hand, does not sit comfortably with any of these attributes. As Tritter and Calnan (2002) observe, first, the term "cancer" covers a variety of diseases with radically different etiologies—some of which can be cured and some of which cannot. Second, it entails complex treatments involving a number of different medical specialists—unlike most diseases under the chronic disease label, "the initial diagnosis of cancer is clearly acute and yields a speedy and often fast-tracked response" (Tritter and Calnan 2002: 163). Third, it has distinctive cultural meanings—a cancer diagnosis evokes a far stronger sense of existential threat than more "typical" chronic diseases such as diabetes or cardiovascular disease.

The idea that cancer can be prevented via lifestyle changes—beyond, obviously, smoking itself—did not take solid shape in the field of public health until the 1990s. Indeed, while the link between lung cancer and smoking was noted in the commission reports as a cause of cancer, tobacco smoke was conceptualized as an environmental carcinogen[6] rather than a lifestyle factor (CCI 1957). Although this had clearly begun to change by the 1970s, claims regarding the broader relationship between cancer and lifestyle (especially in the form of diet and exercise) emanated more from the holistic health movement than the field of public health itself (see Crawford 1980; Leibing and Kampf 2013). If anything, the emphasis on lifestyle as a means of preventing cancer was marginal rather than mainstream until the 1990s. However, this focus subsequently intensified with the more formal incorporation of cancer into the chronic disease frame—a shift that happened in the mid-2000s with the rise of "cancer survivorship"[7] as a distinct phase in the cancer trajectory (see Bell 2017). At this point, "lifestyle" began to be invoked across the prevention continuum, with evidence on the relationship between lifestyle and primary cancer prevention used to speak straightforwardly to the relationship between lifestyle and tertiary cancer prevention (see Bell and Ristovski-Slijepcevic 2015).

The fact that dementia was drawn into the prevention frame well after this process had begun for cancer remains something of a puzzle—although a few possible answers present themselves. While dementia clearly

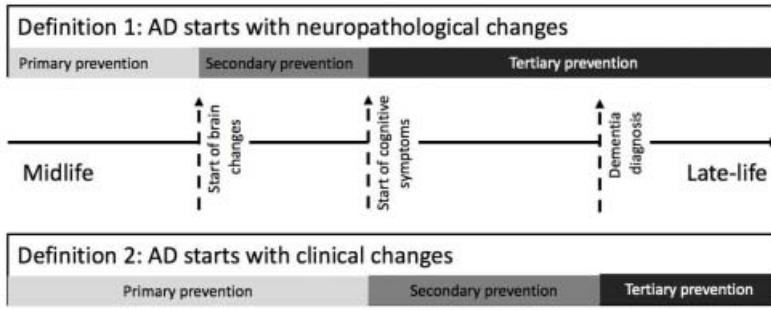

FIGURE 8.1. Prevention of Alzheimer's disease (adapted from Solomon et al. 2014).

qualifies as a "disabling illness," the lack of an established pathology for the disease—as well as the ongoing confusion about whether its roots are mental or physical—is one possible explanation for its relatively late importation to the chronic disease field. As Solomon et al. (2014: 232) observe of Alzheimer's disease, "In other research fields such as cancer, the pathological changes usually define the disease onset. In the dementia field this traditional definition is debatable given that many elderly individuals die with intact cognition but a sufficient number of AD-related pathological signs in their brain to be classified as AD cases." According to the authors, depending on how the roots of dementia are identified, what constitutes primary, secondary, and tertiary prevention looks rather different. For example, if Alzheimer's disease starts with neuropathological changes, then cognitive symptoms of decline would be the target of tertiary prevention; but if the disease starts with clinical symptoms, then targeting these symptoms would be a form of secondary prevention instead (see figure 8.1). However, as mentioned at the outset, knowledge of the underlying pathological signs (if any) of dementia have changed little since the 1990s, yet discourses on the possibility of preventing dementia have shifted dramatically. Moreover, many of the "mental illnesses" mentioned in the Commission on Chronic Illness had no clear organic pathology, so this does not seem to have been an insurmountable barrier to inclusion as a chronic disease—especially given how inclusive and flexible the commission's definition was (Weisz 2014).

According to Leibing and Kampf (2013), critical to understanding the emergence of the idea that dementia might be prevented is the rise of a "cardiovascular logic" in the field of public health. They use this term to describe a widespread and readily accepted etiological construct invoked to explain a growing number of health conditions that are seen to be "interconnected through a common underlying cardiovascular pathway" (Leibing and Kampf 2013: 62). As they illustrate, this cardiovascular logic was

critical to the ways that cancer itself was drawn into the lifestyle frame. Thus, we appear to be witnessing the colonizing tendencies of this logic, as it has moved from "classic" chronic illnesses, such diabetes and cardiovascular disease, to those falling more ambiguously into this category, such as cancer and, more recently, dementia. Indeed, the introduction of this cardiovascular logic in the field of cancer was arguably critical for its subsequent expansion into dementia—although a growing emphasis on cardiovascular disease and diabetes themselves as risk factors for dementia is probably also significant, with the risks associated with the former straightforwardly transposed to the latter.

This cardiovascular logic has an important political function as well. Laurie Edwards (2013: 36) argues that the focus on lifestyle in the area of chronic illness serves to separate "certain chronic conditions and the patients who live with them from the forward momentum of medical science: we can kill bacteria, we can eradicate diseases through vaccination, we can transplant organs, but the treatment and prevention of many chronic conditions is the responsibility of the patient." Or, perhaps more accurately, lifestyle, in this framing, becomes *part* of the forward momentum of medical science. As Leibing and Kampf (2013: 66) note, in the fields of cancer and dementia, lifestyle has effectively been reinvented as "cutting-edge biomedical science." Lifestyle research thus becomes an important means of showing that "Something Is Being Done" (Jain 2013: 185) about conditions where science reaches the limits of its knowledge.

This is a prominent contemporary theme in the fields of both cancer and dementia prevention. For example, the American Institute for Cancer Research notes that "only decades ago, most believed that cancer simply strikes the unlucky—and that nothing can be done about it. Today . . . the world knows better. Our research sheds unique light on the cancer process—and pinpoints the specific lifestyle choices that will save hundreds of thousands of lives every year in the US alone" (AICR 2019). Likewise, the United Kingdom's National Health Service similarly emphasizes that while "there's no certain way to prevent all types of dementia . . . , there's good evidence that a healthy lifestyle can help reduce your risk of developing dementia when you're older" (NHS 2019). These assertions about the power of lifestyle change speak to the distinctive "political economy of hope" (DelVecchio Good et al. 1990; Novas 2006) that today marks the complex network of alliances between patient advocacy groups, disease charities, government agencies, and corporate entities. As Carlos Novas (2006: 292) observes, the discourse on hope mobilizes "a range of rhetorical, organizational and material resources to create direction and convince others of what the future may bring." Thus, in an environment of uncertainty about feared conditions such as cancer and dementia, "lifestyle" can become a

strategically useful response[8]—even if it effectively operates as a "good lie" (see Fitzpatrick 2001).

A final interconnected dimension that seems to be shaping conceptions of both cancer and dementia is changing perceptions of aging, and the ways in which the normative template of old age has been radically rewritten via discourses on "successful aging," "active aging," and "new aging" (see Katz 2000, 2001, 2013). According to Stephen Katz (2013), lifestyle is narrowly perceived in these frameworks as a set of choices that determine lifespan; in other words, *how* one lives is seen to affect *how long* one lives. These discourses, with their emphasis on autonomy, choice, and wellbeing in aging, appear to be influencing conceptions of cancer and dementia and the possibilities of arresting disease progression in both areas. For example, writing on popular discourses around breast cancer survivorship,[9] Sinding and Gray (2005: 148) observe that "shifts in bodily and social realities around breast cancer parallels in a broad way shifts around aging . . . . Images of decline and dependency have been replaced with images of activity, autonomy and wellbeing in older age." Likewise, focusing on emergent neurocultures, Williams, Higgs, and Katz (2012) highlight the convergence between discourses on active aging and cognitive health, especially in terms of the expectation that later life can—and should—be prepared for in earlier life in order to avoid a feared future of debility and decline.

Conclusion

While the lifestyle roots of health and illness have been a preoccupation for centuries, a number of precursors clearly needed to be in place for the idea of chronic disease prevention to take hold. In other words, we have not just replaced the language of "sin" with the language of "science"; instead, new conceptions of disease and disease causality were required in order for the concept of lifestyle in its contemporary sense to flourish. I have argued that the critical groundwork was laid in the postwar era in the United States, especially with the rise of the concept of chronic illness as a master disease category and the temporal model of prevention it entailed. This is not because other countries were uninterested in the diseases encapsulated within this frame, but because they chose different meta-concepts through which to tackle them—such as "exclusion" and "handicap" (Weisz 2014: 11). Indeed, the World Health Organization was just as likely to speak in the 1980s about a "disabling" illness as a "chronic" one (e.g., WHO 1980), and, since the 1990s, they have oscillated between the terminology of "chronic" and "non-communicable" disease (see Herrick 2019). Nevertheless, the conceptual foundations laid by the US Commission on Chronic

Illness in terms of its preventive approach to chronic disease, and the subsequent rise of the lifestyle frame, have been fundamental to the strategies of international agencies such as the World Health Organization—as its series of "Global Action Plans for the Control and Prevention of Non-Communicable Diseases" readily attest.

It is noteworthy that dementia managed to escape the lifestyle frame during the period when the contours of chronic illness were being systematically outlined in the United States and beyond. Its ambiguity as a pathological versus natural process is clearly part of the reason why it was a late entrant to the realm of "preventable chronic diseases," although I have argued that this does not entirely explain its initial absence. Ultimately, the rise of the idea of preventing dementia seems to be partially an artifact of the colonizing tendencies of the lifestyle frame—especially once it moved outside the realm of chronic disease proper and into those conditions, such as cancer, that had never sat very comfortably within it. The view of dementia as a kind of secondary effect of other chronic conditions such as diabetes and cardiovascular disease also seems important to this shift, along with changing conceptions of aging and new configurations of medical research and advocacy. These events suggest a strong degree of contingency in terms of how discourses on dementia prevention have evolved and point to the importance of further research into their emergence, along with the question of how they have been taken up beyond the US context and under what conditions.

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Notes

1. Although the intensive focus on lifestyle in the field of public health is recent, the idea that lifestyle impacts health has far older roots. Focusing on the US context, the historian Ruth Clifford Engs (2000) argues that contemporary attitudes toward lifestyle in the field of public health share marked similarities with the cyclical "clean living" movements that have periodically emerged during the last two hundred years. She defines these as "broad periods in history when concerns about alcohol, tobacco, other mood-altering substances, sexuality, diet, physical fitness, diseases and other health-related issues have manifested themselves on multiple fronts" (Engs 2000: 24).
2. See Weisz 2014 for an overview of the circumstances of the creation of the commission.
3. While this logic may be accurate for some diseases, we simply do not know enough about the etiology of various diseases for this statement to be universally true.
4. Although some have asserted that the rise of the "new public health" since the 1970s has served to erode the emphasis on lifestyle by drawing attention to the social determinants of health (e.g., Baum 2008), many scholars have argued that this broadened scope has not displaced the underlying individualism of mainstream epidemiological theory (e.g., Petersen and Lupton 1996; Krieger 1994, 2008, 2011; Bell, McNaughton, and Salmon 2011; Bell 2017).
5. The growth of such programs since this period can be readily illustrated through the lens of Stanford University's Chronic Disease Self-Management Program. Born in 1978 as an arthritis self-management program, its success led in 1990 to the development of a pilot chronic disease self-management program that claimed to increase healthful behaviors, improve health status, and reduce health care utilization (SMRC 2018). Further adaptations followed, including specialized programs for people living with HIV (mid-1990s), chronic pain (mid-1990s), diabetes (mid-2000s), caregivers of people with cognitive conditions (post-2010), and cancer survivors (post-2012) (SMRC 2018).
6. What is striking about the commission's reports is the emphasis on environmental factors in preventing chronic disease; these are far more of a focus than "lifestyle" in its behavioral formulation. This challenges the widespread view that there was a straightforward shift from an emphasis on lifestyle risk factors in the 1950s to a "new" public health focusing on the social determinants of health in the 1970s (e.g., Baum 2008). At the very least, it suggests that conceptions of lifestyle in the field of public health have changed over the past half century; after all, lifestyle is ultimately a mixture of both behavior and environment. Indeed, as Katz (2013) observes, in sociological formulations of lifestyle, it was intimately connected with social structures and the notion of life chances as a consequence of such.
7. The term is typically used to refer to a phase when the patient has completed primary treatment and has been declared cancer-free but is still at risk of cancer re-

currence and is dealing with the ongoing effects of treatment and its psychosocial consequences. Although the concept has been around since the 1980s, it did not become a mainstream focus in the field of clinical oncology until the mid to late 2000s (see Bell and Ristovski-Slijepcevic 2013).

8. I am not intending to suggest that patient advocacy groups are necessarily content with facile answers. There are numerous examples of health social movements that have challenged political power and scientific and professional authority (see Brown et al. 2012), in some cases, highly successfully, such as in the case of AIDS activism (Epstein 1996). However, health movements generally entail a number of distinct but overlapping "cultures of action," as Maren Klawiter (2008) has illustrated for breast cancer. According to Klawiter, the US breast cancer movement involved groups with three distinct agendas: cancer detection and screening advocacy, women's health advocacy, and activism around cancer prevention. These groups differed significantly in terms of their politics and where they thought the focus of advocacy efforts should lie. However, the form of "pink ribbon" breast cancer activism that has become most visible, primarily as a result of its palatability to governments and corporations, is very much based on messages of hope, personal empowerment, and individual transformation (see King 2006; Sulik 2011).
9. Likewise, focusing on male cancer survivors, Hammond et al. (2012) point to the intersections between the decline and progress discourses that increasingly dominate both aging and cancer.

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9 RESPONSIBILIZATION OF AGING?

An Ethical Analysis of the Moral Economy of Prevention

Mark Schweda and Larissa Pfaller

Introduction

"OUR MAIN MESSAGE IS THAT we can have a dramatic impact on our own success or failure in aging," John Rowe and Robert Kahn (1998: 18) stated in their seminal contribution to the gerontological debate on "successful aging." For them, the answer to the question of maintaining health, activity, and performance in old age is "surprisingly simple": "good old-fashioned hard work" (Rowe and Kahn 1998: 17). As both explain, "To succeed . . . means having desired it, planned it, worked for it" (37). Phrased in biological and biomedical terms, the anti-aging movement starting in the 1990s has raised similar claims. Thus, according to Ronald Klatz and Robert Goldman (2003: 16), the founders of the American Academy for Anti-Aging Medicine (A4M), "if you're willing to make some simple lifestyle changes, to work with a doctor who can prescribe appropriate anti-aging treatments, and to commit yourself to a longer and healthier life, you too can stop the clock." In this perspective, "you, yourself, are your most important tool—you, your mind, and your body" (Klatz and Goldman 2003: 16).

These examples indicate that the debate on dementia prevention has to be contextualized in overarching contemporary discourses. They show how the rise of the paradigm of prevention (Petersen and Lupton 1996) has begun to transform images and expectations regarding aging and old age in at least two crucial respects. From a *prospective* perspective, later life is turning into a projection screen for individual and social predictions, prognoses, scenarios, and plans. Aging no longer appears as a matter of unalterable fate or unfathomable luck but as a process that must be actively shaped and prudently modeled by means of circumspect decisions and determined preventative actions (Schweda et al. 2017). Accordingly, from a

retrospective point of view, looking back upon the course of an individual life, old age is becoming the decisive litmus test for the seriousness, intensity, and effectivity of the preventative efforts invested in previous phases of life. It appears as the final moment of truth and justice, the ultimate moral payoff of a life of caution, planning, discipline and self-management—or neglect, indulgence, and carelessness. As the author of *God's Anti-Aging Plan* explains, "What we sow is what we reap" (King 2017).

In critical gerontology and the sociology of aging, this development has been described and criticized as a symptom of a general "responsibilization of aging" in the present era (Cardona 2008; Moulaert and Biggs 2013). According to this theoretical perspective, pervasive policy shifts in the traditional allocation of roles and functions between the individual and society are increasingly redefining aging and old age in terms of individual responsibility. Political strategies of safeguarding public welfare and social security are transformed, and individuals are called upon to act as active citizens who are personally in charge of looking after their own health, wellbeing, and socioeconomic subsistence in later life (Lessenich 2008). This development apparently also implies a new "will to health" and an expanding obligation to monitor and manage one's own health: "Every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being" (Rose 2001: 6). As a consequence, the last stage of life—which was once mainly seen in the light of well-earned retirement, social disengagement, and biological decline—is now assigned with attributes such as "health" (WHO 2015), "activity" (Walker 2002), "productivity" (Butler and Gleason 1985), and "success" (Rowe and Kahn 1987, 1998; Baltes and Carstensen 1996).

From an ethical point of view, it is important to acknowledge that assigning responsibilities is not, per se, problematic. Instead, what is needed is a differentiated analysis and discussion of responsibility ascriptions. Hence, the present chapter is aimed at an ethical analysis of the "responsibilization of aging" in the age of prevention. We focus on the two pertinent expert discourses already mentioned above: the first one, the gerontological discourse on "successful aging," challenges previous deficit-oriented models of aging by emphasizing the resources and potentials of older people; the second one, the biomedical "anti-aging" discourse, addresses the lifestyle of self-caring subjects and relays medical advice for combatting senescence and leading a healthy and long life. Starting from an explorative analysis of these two discourses and their entanglements and similarities, we first give an overview of current trends toward a responsibilization of aging and of the main lines of their academic sociological and gerontological critique. Against this backdrop, we provide an ethical elaboration of the concept of responsibility itself and the criteria of justified responsibility ascriptions.

On this basis, we discuss the legitimate scope and limits of responsibility in the context of aging and old age. Contextualizing the topic of dementia prevention within these larger discourses, we finally draw conclusions for a differentiated discussion of responsibilization of aging and the moral economy of prevention in contemporary society.

Successful Aging, Anti-Aging, and the Paradigm of Prevention

Although the programs of successful aging and the anti-aging movement are based on different scientific foundations and pursue different practical approaches, both can be considered symptomatic for the (re-)negotiation of aging under the paradigm of prevention (e.g., van Dyk 2014). Of course, the relation between mainstream (bio-)gerontology and anti-aging medicine is often characterized by intensive disciplinary "boundary work" (Binstock 2003: 5; Fishman, Binstock, and Lambrix 2008: 299) and global antagonisms (Flatt et al. 2013: 944). However, while the science and technology may differ, the spirit and goals of successful aging and anti-aging medicine converge in the idea of prevention of age-associated diseases and syndromes such as frailty or dementia, and in the vision of healthy, active, and productive old age (Flatt et al. 2013: 944).

From a historical point of view, both endeavors are rooted in the same sociocultural contexts. Thus, Flatt and colleagues (2013) interpret the emergence of anti-aging medicine as the outcome of a lively successful aging discourse that contributes to a general positive redefinition of aging. In their understanding, the "successful aging" paradigm eventually spread into other domains, also infusing medicine and culture (Flatt et al. 2013: 951). Cardona also locates the origins of the anti-aging movement in Western societies' powerful narrative of successful aging (Cardona 2008: 478). Both paradigms fit into the cultural ideals of personal autonomy and responsibility, which present the life course as modifiable and controllable through individual decisions (Flatt et al. 2013: 944). Thus, successful aging and anti-aging medicine both share and reproduce the same narratives of Western societies on the significance of health (Cardona 2008: 478) and the preventability of aging (Kaufman, Shim, and Russ 2004). In these respects, successful aging and anti-aging appear as "two sides of the same coin" (Flatt et al. 2013).

Successful aging is not only seen as a "dominant construct" (Martinson and Berridge 2015: 65) but as "one of the most vibrant intellectual traditions" (Flatt et al. 2013: 944) and "almost ubiquitous" (Dillaway and Byrnes 2009: 703) in contemporary gerontology. The concept can be traced back to the 1940s when Georg Lawton published *Aging Successfully*

(1946). Robert J. Havighurst (1961) prominently presented the concept in the inaugural issue of the *Gerontologist*. The idea was further popularized in the late 1980s by Rowe and Kahn (1987), and, since then, it is mainly associated with their names. There have been a growing number of publications on successful aging, and over a hundred variations of the model can be identified (Rowe and Kahn 2015: 593). The Rowe and Kahn model defines three components of successful aging: avoiding disease and disability, maintaining high cognitive and physical functioning, and continuing engagement with life (Rowe and Kahn 1997). Another prominent approach of successful aging was established by Baltes and Baltes (1990b). Their so-called SOC-model (Baltes and Baltes 1990a; Baltes and Carstensen 1996) conceptualizes successful aging as an individual adaption to the aging process that leads to the maximization of gains and the minimization of losses through selective optimization with compensation (SOC). Until today, the intensive academic debate on successful aging continues. Rowe and Kahn have updated their model as "successful aging 2.0" (Rowe and Kahn 2015), and two special issues of prominent gerontology journals were dedicated to the topic in recent years ("Successful Aging" 2015; "Successful Aging" 2017), thus confirming its status as a discursive leitmotif.

By comparison, the anti-aging movement is younger. Of course, there is a long-standing tradition of medical approaches to rejuvenation and life extension that dates back to antiquity (e.g., Haycock 2008). However, the neologism "anti-aging," as well as the corresponding project of a biomedical fight against human senescence, are phenomena of the twentieth century.[1] The A4M was one of the first institutions whose public relations activities contributed to the dissemination of the idea in the 1990s (Mykytyn 2009). The domain of anti-aging medicine is commonly characterized as a "contested field" (Settersten, Flatt, and Ponsaran 2008) with a "complicated cartography" (Mykytyn 2006). Different actors represent different approaches, and there is disagreement between the professions involved regarding the definition and the objectives of anti-aging. All of them have in common a view of aging as a medical problem, a meta-disease, or a major risk factor for diseases and thus a process that needs to be fought, slowed down, or stopped (Mykytyn 2006). At least three main types of goals addressed by anti-aging medicine can be reconstructed: the preservation of a youthful appearance, the maintenance of high levels of physical and cognitive functioning, and the extension of life expectancy or even life span (Schweda and Pfaller 2017). The methods used to achieve these goals also comprise a wide range of largely preventative medical measures, from dietary supplements and lifestyle adaptations to antioxidants, hormone replacement, or caloric restriction, to more radical biomedical interventions involving gene therapy or regenerative medicine (Stuckelberger 2008). In the meantime, the label

"anti-aging" has also gained worldwide prominence as a marketing strategy for the cosmetics and health industry (BCC Research 2013).

As indicated, both successful aging and anti-aging appear symptomatic for the contemporary paradigm of prevention in several respects. It is not the primary aim of prevention to achieve a particular positive state but to avoid the occurrence of negative states (Bröckling 2008: 39). Accordingly, the idea of successful aging is mainly characterized by "avoiding" disease and disability and "maintaining" cognitive and physical functioning and social engagement (Rowe and Kahn 1997). The same holds true in the context of anti-aging. The wording already conveys the defensive orientation. Global players such as the SENSE Foundation frame their mission as a "war on aging" (de Grey 2004; see also sense.org). The promotional slogan of Google's daughter Calico (California Life Company) reads "We're tackling aging" (calicolabs.com). Furthermore, prevention is always directed toward the future and the control of its contingencies and thus always refers to risks connected to one's own decisions and actions (Bröckling 2008: 40). Indeed, successful aging sets out to control the risks of disease and physical or cognitive dysfunctions in old age. And anti-aging medicine involves manifold forecasts, promises, and interventions regarding the individual future and future biomedical developments (Schweda and Pfaller 2017). It frames old age as a major risk factor for diseases and public health burdens and presents itself as a strategy of medical risk prevention and risk management (Spindler 2014). However, in order to prevent something, one must know the conditions and probabilities under which it occurs (Bröckling 2008: 43). In this context, experts and expert knowledge play a crucial role. Thus, in his landmark article, Havighurst (1961: 8) explains the role of the concept of successful aging with regard to gerontology's aim "to provide society and individuals with advice." Protagonists of the anti-aging movement even describe their endeavor as the "vanguard of biomedicine" (Fishman, Settersten, and Flatt 2010) committed to cutting-edge research. Finally, prevention is also linked to cost-benefit calculations (Bröckling 2008: 46). Especially in the field of health prevention, it is deemed an irrefutable fact that prevention is better than cure. Above all, prevention—from a health economy point of view—appears simply cheaper than the treatment of diseases that have already occurred. Thus, successful aging paradigms and corresponding active aging policies are presented in terms of a "win-win situation" (van Dyk 2014: 94). Individuals can maximize their health in old age and therefore their quality of life, while society can avoid costs associated with early retirement, illness, and care (Walker 2002: 137). In a similar vein, Klatz and Goldman (2003: 13) promote anti-aging medicine not only by reference to individual functioning and quality of life but also with regard to its socioeconomic benefits and

"great dividends": "When anti-aging medicine is able to delay admission to nursing homes by just one month, the US health care system will see $3 billion in savings a year!"

Responsibilization and Its Critiques: The Moral Economy of Prevention

Both successful aging and anti-aging have come into the focus of critical gerontology and sociology of aging (Katz and Calasanti 2015). In the respective approaches, special attention is paid to the problem of "responsibilization" that seems to be entangled with prevention (Cardona 2008; Moulaert and Biggs 2013). Responsibilization is not necessarily understood to mean the general process of ascribing responsibility, but rather the shifting of responsibilities—and thus the corresponding risks—to individual subjects (Lemke 2002: 59). In this vein, Moulaert and Biggs define responsibilization as "the transfer of responsibilities from a group or society to an individual" (Moulaert and Biggs 2013: 33).

At the same time, the significance of personal responsibility (Flatt et al. 2013: 952; Holstein and Minkler 2003) in successful aging and anti-aging is interpreted in the context of larger social and cultural developments in contemporary Western societies. Regardless of variations due to different national settings and frames of reference, especially two general theoretical paradigms and lines of critique play an important role: the idea of an increasing activation and disciplining of older people under regimes of activating social policies or neoliberal governmentalities (van Dyk 2014; Leedham and Hendricks 2006; Powell and Biggs 2000; Katz 2000) and the theorem of a (bio-)medicalization of aging (Larkin 2011; Kaufman, Shim and Russ 2004; Estes and Binney 1989). Both frameworks serve to analyze and discuss the effects of cultural norms shaping the experience of aging and the identities of older people today (Holstein and Minkler 2003: 791). They help explore how the "ethos of responsibility" (Cardona 2008: 482) is producing a corresponding "responsible self" (Cardona 2008: 478).

For the purposes of an ethical evaluation, it is particularly important to specify in more detail what exactly the respective approaches in critical gerontology and the sociology of aging consider problematic with regard to the "responsibilization of aging" and for what reasons. Thus, at closer inspection, it becomes clear that the commentators usually do not criticize the mere fact that the question of responsibility is raised at all. Instead, they rather problematize the *moral economy* (Hendricks and Leedham 1992) within which responsibility is discussed and attributed—that is, the system of "normative ideas of reciprocity, justice and obligations [that] influence

the way people understand their rights and responsibilities as members of a political community" (Nilsson 2017: 79). In this perspective, at least four interwoven lines of critique can be distinguished, referring to (1) an *individualization*, (2) *overexpansion*, (3) *instrumentalization* and *ideologization*, and (4) *stigmatization* of responsibility.

The first concern is *individualization*—that is, the reduction of "social phenomena to the aggregate of individual actions" (Rose 2001: 2). The prominent models of successful aging focus on individual characteristics (Rowe and Kahn 1997) or competences (Baltes and Baltes 1990a), classifying health, as well as physical and cognitive functioning, as a capacity and achievement of the individual. The same holds true for anti-aging medicine. The concrete practice focuses on individual bodies and attributed risk factors and accordingly offers highly individualized tailor-made options and interventions (Fishman, Settersten, and Flatt 2010). For both, the most significant determinant influencing the aging process is individual lifestyle. As a consequence, successful aging and anti-aging have drawn criticism for reducing complex social interrelations to individual actions and choices (Katz and Calasanti 2015: 28; Katz 2013). Relevant political and organizational structures, social contexts, and social inequalities that permeate biographies and have an increasing impact as one grows older are being trivialized or ignored (e.g., Holstein and Minkler 2003). Also environmental conditions and social relations of power in terms of "biopolitics" fail to be acknowledged (Katz and Calasanti 2015: 28). This narrow focus on individuals is characterized as "hegemonic" (Holstein and Minkler 2003: 794). Here, successful aging and anti-aging discourses not only reduce the two-faced nature of old age as a source of risks as well as a chance for liberation, but also the conception of responsibility (Cardona 2008: 480). By hiding socioeconomic factors and not providing adequate resources for managing related threats, responsibilization in the context of successful aging and anti-aging therefore seems one-dimensional. It can "burden rather than liberate older people" (Holstein and Minkler 2003: 794) and lead to a feeling of "obligation" (Cardona 2008: 481) to stay healthy. In effect, the attribution of responsibility is not associated with more agency and empowerment (Emirbayer and Mische 1998), but only with bearing the consequences of respective risks.

The second line of argument focusing on the *overexpansion* of responsibility contends that many ascriptions of individual responsibility in the context of health and aging are not sufficiently covered by reliable empirical evidence. According to this critique, it is not even clear to what extent interventions in the aging process are empirically founded and practically feasible. Thus, the scientific empirical and methodological foundations of the paradigm of successful aging are frequently challenged within geron-

tology (Katz and Calasanti 2015). In a similar way, biomedical anti-aging research is faced with criticism. At the turn of the millennium, the academic debates evolving around the anti-aging movement were even perceived as a "war on anti-aging medicine" (Binstock 2003). Prominent US (bio-)gerontologists attacked the A4M with harsh arguments regarding the effectiveness of the anti-aging methods they marketed. Since there was no sufficient empirical evidence for the efficacy (or at least innocuousness) of the measures offered, the protagonists of anti-aging medicine were denounced as "swindlers, hucksters and snake oil salesmen" (Butler et al. 2002; Olshansky, Hayflick, and Carnes 2002a, 2002b). Against this backdrop, the attribution of a responsibility to intervene in the aging process appears not only unjustified but also dangerous: "Treatments that practitioners might portray as 'cutting edge' may be unproven, ineffective, and even harmful" (Flatt et al. 2013: 925). This is all the more problematic as the ethos of responsibility pushes aging people into the traps of anti-aging medicine, i.e., the "tyranny of youth-preserving technologies and lifestyles" (Holstein and Minkler 2003: 794). As a consequence, the attribution of responsibility seems to be less based on empirical knowledge than driven by social ideas and standards, especially "an ethos of management and control over the aging process" (Flatt et al. 2013: 944).

The third line of argument addressing the economic *instrumentalization* and political *ideologization* of responsibility focuses on the "political economy" (Estes 1979) of responsibilization—that is, the interrelations of power and knowledge in the assignment of responsibility. Thus, Cardona (2008) highlights the interdependence of political (healthy aging), scientific (successful aging), and economic (anti-aging) complexes and the resulting regimes of knowledge. In order to understand the "successful aging" discourse, it is important to identify the inventors of the concept and the political and historical settings (Dillaway and Byrnes 2009). Therefore, some authors reconstruct the personal ties between the proponents and their political and economic entanglements. An important factor in this context is the influence of the MacArthur Foundation with their ten-million-dollar *Study on Successful Aging*, in which the conception of Rowe and Kahn was established (Holstein and Minkler 2003: 787). The authors themselves eventually call their model the "MacArthur model" (Rowe and Kahn 2015: 594). In the context of anti-aging medicine, the interdependence of science and industry appears even more obvious. Petersen and Seear (2009) identify the main players in the field and explain the (commercial) success of anti-aging medicine by exploring the political-economic forces behind it. In a political perspective, the emphasis on personal responsibility has also been challenged as an ideological manifestation of a global shift in aging policies. According to this line of thought,

activating social policies or neoliberal governance dismantle traditional welfare systems and at the same time identify retired people as a social resource to be activated and exploited (van Dyk 2014). Framing this renegotiation of aging as a "win-win situation" (van Dyk 2014: 94)—with benefits for both individuals and society—is debunked as an "empty rhetoric" (Boudiny 2013). The emphasis on personal responsibility appears as a mere cover-up of social welfare cuts and shifting risks and costs to the individual. Thus, while "new gerontology" may present its own standpoint as purely scientific and therefore neutral (Holstein and Minkler 2003: 788), it actually turns out to be highly *ideological* (Cardona 2008). In the context of anti-aging, the ideological mechanisms appear similarly problematic as the underlying commercial and political interests are masked in terms of objective biomedical facts (Petersen and Seear 2009).

Finally, the related *stigmatization* line of critique addresses the evaluative and "affective economies" (Ahmed 2004) of responsibilization processes. In particular, evoking a normative and emotional setting can be understood as a strong instrument of power and governance. As already indicated, successful aging models and anti-aging approaches are not "neutral" but hold a "normative vision" (Holstein and Minkler 2003: 787). In this normativity, the authors see the threat of new forms of ageism since it goes hand in hand with the valuation of certain behaviors and personal characteristics that are not based on the free choice of individuals but are attributable to structural conditions (class, race, gender) (Holstein and Minkler 2003: 787; Katz and Calasanti 2015). Cardona reconstructs that by simultaneously confronting individuals with risks and making them responsible for their consequences, the "ethos of responsibility" makes use of the widespread "anxieties of growing old in Western societies" (Cardona 2008: 475). The popular discourse around "aging societies" is based on an "alarmist" (Katz 1992) or "apocalyptic" (Gee and Gutman 2000) demography (see also Katz and Whitehouse 2017). Thus, as critical gerontology points out, ideas of active, productive, or successful aging promote new positive images of later life but at the same time also intensify the devaluation of aging and old age (van Dyk 2014: 96). Anti-aging practitioners are faced with the same accusation of exploiting cultural fears of aging (Flatt et al. 2013: 944; Vincent, Tulle, and Bond 2008). Thus, Cardona (2018) speaks of "three main anxieties" addressed in anti-aging discourses: the loss of functionality and attractiveness, unemployment, and poverty (Cardona 2008: 480). Kemp and Denton also highlight that the desire to be independent corresponds with morally laden fears of becoming—or being perceived as—a burden (Kemp and Denton 2003: 756). Gilleard and Higgs point out that it is specifically the abject nature of the fourth age characterized by frailty and dementia that fuels the fear of old age. This fear is related

to the loss of agency and the horrifying feeling of social death (Gilleard and Higgs 2010: 125). Thus, the imaginary of the fourth age and especially the risk of cognitive decline stand for everything that does not fit in the paradigm of successful aging. It represents the opposite of the autonomous, active, and responsible self. Eventually, shifting responsibility is accompanied by the blaming of those who did not "age successfully" (Cardona 2008). Moreover, those who do not meet the criteria of successful aging engage in self-blame (Kemp and Denton 2003: 756). Fear, shame, and guilt are the emotions accompanying the corresponding cultural imaginary of old age.

Toward an Ethical Analysis of Responsibility Claims

Under the buzz phrase "responsibilization of aging," sociology of aging and critical gerontology discuss trends toward individualization, overexpansion, instrumentalization and ideologization, and stigmatization of responsibility ascriptions in the contexts of successful aging and anti-aging discourses. This critique makes important points regarding the contemporary culture of aging. At the same time, its moral underpinnings often remain almost as unclear as those of the criticized discourses themselves. From an ethical point of view, assigning responsibilities is not per se problematic. On the contrary, it constitutes a necessary precondition for ethical judgments and discussions. An ethical analysis of responsibility ascriptions and their moral implications can help clarify the debate and sharpen and substantiate the arguments of critical gerontology. We have to be able to assess and discuss to what extent claims about responsibility are justified or not. To this purpose, we need a systematic reflection on the concept of responsibility.

There are various theoretical models of responsibility (e.g., Baier 1991; French 1991a,b). They all conceptualize "responsibility" as a relational concept. This means that talking about responsibility always implies a relation between several different entities. At least three relata are required: a subject, an object, and an instance. Someone (the subject of responsibility) is responsible for someone or something (the object) against someone (the instance). However, on closer inspection, more relata are necessary in order to reconstruct and analyze common uses of the concept "responsibility." For the subsequent analysis of its role in the context of prevention and aging, we rely on a conception developed by Schicktanz and Schweda (2012) involving seven relata: someone (*subject*) is responsible for something/someone (*object*) against someone (norm-proofing *instance*) on the basis of certain standards (*norms*) in a particular time frame (*time*) retrospectively/prospectively (*temporal direction*) with certain consequences (*sanctions or rewards*) (see figure 9.1).

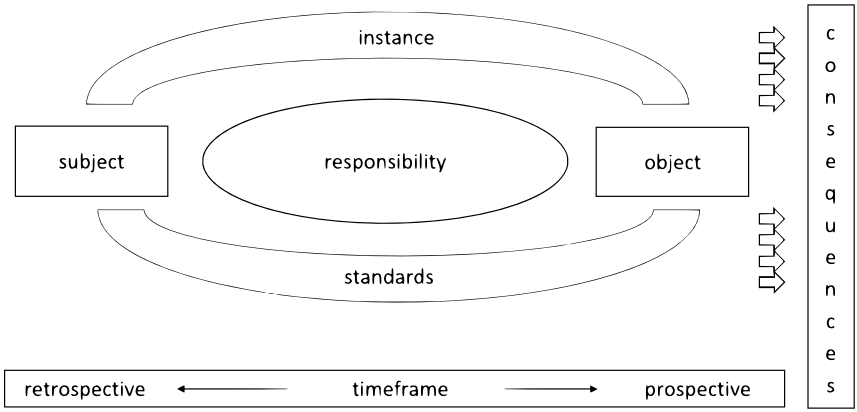

FIGURE 9.1. Relational structure of responsibility based on the concept of Schicktanz and Schweda (2012).

Each relatum involves complex questions.[2] Thus, it is debated whether only individuals or also collectives (e.g., families, corporations, states, etc.) can be *subjects* of responsibility (French 1991a,b). With regard to *objects*, there are also different candidates: one can be responsible for people, animals, plants; for tasks such as cleaning the dishes or providing for a family; and for abstract issues such as population health or world peace. The *instance* is the authority that judges whether a responsibility has been fulfilled. Thus, courts count as instances for legal responsibility. In the moral domain, there are other authorities, such as God, individual conscience, or the community. *Standards* refers to the norms on which responsibilities are based. These can be general (e.g., to respect others, avoid harm, etc.) or concrete and context-specific (e.g., professional virtues such as confidentiality, or institutional rules such as efficiency). The *time frame* and *temporal direction* are important, too. In the legal context, responsibility is primarily discussed from a *retrospective* point of view as guilt. In a prospective sense, being responsible means being in charge of or taking care of future events. Finally, *consequences* result from meeting one's responsibilities or not—that is, reward or punishment, social recognition or exclusion, pride or shame.

Against this backdrop, the analysis of notions of responsibility allows and at the same time requires a careful examination of the relationship between different actors and their tasks and capacities, the instance and its power, and the underlying moral standards and their validity and binding character. Depending on the context, "being responsible" can also be defined in terms of duty, obligation, right, or virtue. While "responsibility" as such is a relational term, these moral concepts refer to entitlements to

treat or to be treated in a particular way. However, especially in modern, functionally differentiated and therefore complex societies, they cannot define the whole social, relational context of application and consequences. Therefore, the proper use of "responsibility" or "being responsible" always requires a thorough definition and analysis of the relata—and if relata are undefined or under-determined, this calls for an in-depth inquiry.

As we have already seen, the first and foremost objection in the social gerontological critique of the "responsibilization of aging" is concerned with the adequate allocation of the *subject* and *object* position of responsibility. The accusation of *individualization* refers to the fact that individuals and maybe their families and closer social relations are more and more in the focus of responsibility ascriptions regarding aging and old age, while other potential moral agents, such as the health-care system, the solidary community, or the welfare state, are increasingly eliminated from the picture. However, while this may arguably be an appropriate description of the respective social processes addressed by political and sociological diagnoses, it does not per se explain what is ethically problematic with these processes. After all, one could argue that the traditional welfare state had wrongfully usurped many individual competences and responsibilities, thus ignoring individual agency and effectively patronizing, disempowering, and incapacitating its citizens (Wikler 1987). From this perspective, it would appear perfectly reasonable and justified to shift the individual back to the center of the discussion.

Thus, in order to explain what may be wrong with the individualization of the responsibility for aging and old age, we have to take a closer look at the criteria and preconditions of individual responsibility. Under what conditions are we justified in ascribing responsibility to a single person? In the tradition of philosophical ethics, at least three interrelated criteria are usually mentioned: knowledge, intention, and causal control (French 1991a,b). First, in order to be able to assume responsibility for something, a person has to be aware of the relevant facts and interrelations. Thus, if I do not know (and could not be reasonably expected to know) that a decision or course of behavior could have certain problematic consequences, I cannot be held morally responsible for these consequences. This requirement of knowledge is closely linked to the second aspect of intention: if I caused something inadvertently and accidentally—for example, because of an unfortunate and unforeseeable coincidence of events—I prima facie cannot be held morally responsible for the effect (leaving aside the important but complicated issues of negligence or recklessness). Finally, the criterion of control refers to the possibility of actually influencing a given process and its outcomes. Thus, while I may be well aware of the causal mechanisms leading to a particular event, and even may have the wish to interfere and

stop the process, I may still lack the ability or power to actually do so. In this case, it would not be fair to hold me morally responsible.

It appears obvious how these criteria apply to the "responsibilization of aging" and especially to the problem of an *overextension* of responsibility claims. First, in light of fundamental knowledge gaps and controversies in the state of scientific research on the biological and physiological mechanisms of aging, it is unclear to what extent we can really claim to have the relevant knowledge to fully understand what causes aging and age-associated diseases and physical or cognitive impairments. Of course, most of us are aware that excessive smoking and drinking puts our future health in jeopardy. Apart from such rather generic knowledge, however, the concrete causal mechanisms of biological senescence or age-associated processes like frailty or dementia are still not sufficiently understood. Many of the things we do or do not do may influence our aging process without our knowledge. Nevertheless, successful aging as well as anti-aging discourses provide a plethora of examples for dubious bits of alleged "knowledge" on aging and respective recommendations for its prevention, which are constantly circulated and revoked—for example, from disengagement to activity (Achenbaum and Bengtson 1994), from sex hormones to antioxidants (Olshansky, Hayflick, and Carnes 2002a), or from "brain jogging" to nootropic medication (Lawless and Augoustinos 2017). Furthermore, it is unclear how the individual person can actually identify, access, and utilize reliable knowledge that becomes available. Here, the individual is clearly dependent on the provision of suitable health education (health literacy) and authoritative and trustworthy knowledge resources, but also on economic and technical framework conditions (Estes 1979). Finally, although there may be some knowledge or at least statistical information on factors involved in the aging process, this does not mean that the individual is able to effectively control this process. While we know that senescence and accompanying conditions such as dementia are associated with certain risk factors, these are not necessarily a matter of choice or lifestyle but are often beyond our control. In the case of dementia, for example, potentially modifiable risk factors are believed to amount to 35 percent (Livingston et al. 2017). In addition, the individual will frequently depend on other actors—for example, the family, the community, or the state—to exert an influence on relevant processes. This includes technical and financial support for health prevention, such as medical expertise and financial subventions for checkups and effective preventive measures, but also broader framework conditions, for example, the social living situation or environmental circumstances.

These considerations on knowledge and control are also of high relevance for the question of the temporal dimension and consequences of responsi-

bility for aging involved in the objections against the *stigmatization* and the "blaming and shaming" at work in responsibility ascriptions. Prima facie, retrospective and prospective responsibility seem to be categorically different. Retrospective responsibility requires that something went badly or a consequence is assessed as morally wrong, while prospective responsibility focuses on doing morally right or at least avoiding doing wrongs. However, moral actions must be understood in a temporal continuum, in which backward and future-oriented views often complement each other. Indeed, there is usually a fairly direct moral connection between prospective and retrospective responsibility: if I am prospectively in charge of something, then I am also retrospectively blameworthy for failing to fulfill the pertinent tasks. In this sense, prospective responsibilities for preventive practices and lifestyles can result over time in retrospective liabilities if a person did not do enough to prevent a disease. Thus, according to Veatch (1980), new health care choices and technical opportunities always bear the risk that disease is seen as a personal fault because someone failed to do something against it. However, in light of the problematic scope of scientific knowledge on, and practical control of, aging and old age, prospective responsibility cannot be automatically turned into retrospective blaming. Prevention may be a good and advisable thing, but its failure usually cannot be definitely traced back to causal factors of individual mistake or misconduct. For Yoder (2002), the crucial and problematic part of dealing with responsibility is that information and risks, the epistemic dimension of assessing consequences and exerting control, are usually considered a matter of objectives facts. However, much of the information we actually do have from aging research has a rather problematic epistemic status. It refers to statistical correlations that do not permit a deterministic interpretation in terms of a direct relation between cause and effect but only allow for probabilistic conclusions in terms of chances and risks. We have to acknowledge that there are limits to our knowledge of outcomes and also limits to causal explanations and interventions. Thus, while there may be a justified expectation for people to make reasonable efforts to stay healthy—for example, to behave and live in a healthy way (within certain limits of acceptability)—there can hardly be a moral duty to stay healthy because achieving or maintaining the state of health is simply beyond our causal control.

The aspect of the reasonable acceptability of the "costs" of preventive measures already points to the decisive importance of relevant instances and standards for the discussion of responsibility claims. To counteract the problematic *instrumentalization* and *ideologization* of responsibility, these aspects need to be made explicit, discussed, and justified (or criticized). Thus, there is the evaluative question of the adequate weighing and prioritization of health prevention compared to other important things in life. In ethi-

cal terms, this is a eudemonistic question addressing the conditions and ingredients of a good life in the double sense of subjective happiness and objective accomplishment and flourishing. From this point of view, especially the profound ageism and the ideology of "healthism"—the presumed status of health as an ultimate and absolute goal in life—underlying the responsibilization of aging have to be called into question and put into perspective (Crawford 1980). This is especially true when the epistemic status of the relevant knowledge and the prospects of the corresponding preventive practices and interventions are rather doubtful. Most of us would not find it reasonable to subordinate one's whole life to the prevention of diseases and dysfunction in old age—that is, to renounce any pleasures, invest a fortune, or even take serious risks (e.g., of hormone treatment). All the more so if the best outcome to hope for is a fairly dubious and remote chance of better health in later life. Health may have great value or even be a "transcendental good." However, it is definitely not the only or even most important thing in life. In fact, we may be willing and even justified to put our health at risk for the sake of greater goods—for example, dangerous activities involving joy and pleasure, a great professional or artistic achievement that promises enduring honor and glory, or simply raising children and taking care of old parents (Pfaller and Schweda 2019).

Furthermore, the acceptability of responsibility claims also depends on underlying normative standards determining the system, allocation, and balance of moral roles and expectations between different actors and parties. From an ethical point of view, these standards are centered on ideas of justice and fairness—for example, between individuals, communities, and the state, or toward future generations. In the case of successful aging and anti-aging medicine, it has to be questioned whether the underlying distribution of responsibilities to the individual is really fair and balanced given the limitations of individual knowledge and control and the crucial role of other moral agents at the interpersonal, community, and policy level, let alone the significance of economic and political interests. Another dimension of normative standards pertains to ideas of intergenerational relations and the respective balances and transfers between generations. Thus, underlying conceptions of intergenerational justice determine what members of different generations morally owe each other, not only in terms of financial and other resources, but also in terms of responsibilities for prevention and care. From a perspective of sustainability of social security systems, these intergenerational responsibilities can even extend to future generations (Tremmel 2009). However, in many of the ongoing debates, more or less subtle forms of ageism seem to be at work. This is the case when demographic aging is framed as a kind of unavoidable natural catastrophe and older people are singled out as the obvious scapegoats for the resulting so-

cial problems (Minkler 1997). This not only perpetuates negative images of aging and old age as an individual disaster and a social burden, but also ignores that there is no direct causal impact between demographic aging and social problems but rather a complex field comprising manifold factors and switch points for individual and policy decisions (Binney and Estes 1988).

Conclusions: Analyzing the Moral Economy of Prevention

Discourses of successful aging and anti-aging express and promote a comprehensive change of perspectives on later life in contemporary Western societies. In particular, they are aimed to overcome traditional deficit-oriented models of aging in terms of decline and degeneration by highlighting the resources and potentials of later life. Yet, paradoxically, this renewed outlook is often accompanied by particularly negative images and interpretations of old age (Katz 2001). It seems to be the primary task of the individual to prevent all the diseases, disabilities, and physical and cognitive impairments often associated with the fourth age. Dementia in particular frequently appears as a worst-case scenario of later life, the ultimate demise of the rationally planning, autonomous, and accountable self—a process that needs to be prevented by any means (Latimer 2018).

In the sociology of aging and critical gerontology, this development is critically discussed in terms of a comprehensive "responsibilization of aging." According to our analysis, this discussion involves at least four different lines of argument addressing issues of *individualization*, *overextension*, *instrumentalization* and *ideologization*, and *stigmatization*. Furthermore, we have argued that these lines of critique can benefit from a theoretical elaboration of the concept of responsibility itself and a differentiated ethical perspective on the relevant moral questions and difficulties. Introducing a relational conception, we have pointed out that the subject, object, instance, timeframe, and consequences involved in the ascription of responsibilities deserve closer examination. Last but not least, the underlying evaluative and normative standards also require explicit reflection and discussion in ethical terms. In particular, this calls for an ethical reflection on the value of prevention and health in the perspective of a good life, as well as for a deliberation on the fair distribution of roles and claims between individuals, communities, and the state.

In addition, a combination of ethical considerations with sociological perspectives can further contribute to the analysis by uncovering the social positions, interrelations, and constellations presupposed by these standards of responsibility and discussing their plausibility and legitimacy. Thus, a closer investigation focusing on these "moral economies" of pre-

vention can help to sensitize normative ethical reflection for the complex interplay of individual interests and social interrelations, functions, and power structures permeating the field of morality. At the same time, it makes clear that the moral standards and social constellations influencing our discussions of responsibilities can vary strongly with different national contexts and their specific traditions and sociopolitical framework conditions. In a largely privatized health-care system, for example, insufficient health prevention for old age may simply appear as an expression of personal imprudence and carelessness that deserves pity or reproach. By contrast, in a public health-care system, the same behavior can also be judged as a serious moral misconduct involving a problematic degree of recklessness and an illegitimate lack of social solidarity.

In the public health debate, a more differentiated perspective on responsibility for health is supported by ecological approaches to health prevention that neither focus on "the individual" nor concentrate on "the society" alone but rather try to analyze and utilize the complex interaction of the different individual, communal, social, and political actors and factors influencing health and old age (McLeroy et al. 1988). In a corresponding vein, Minkler (1999) and Holstein and Minkler (2003) propose the concept of individual "response-ability" as an alternative to address the role of the manifold actors and (inter-)dependencies that have to be taken into account when the concept of individual responsibility is used. "Response-ability" can be understood as "the capacity of individuals for building on their strengths and meeting the challenges posed by the environment" (Minkler 1999: 124). As this capacity is embedded in and dependent on a complex web of other individuals, the community, and state policies, "response-abilization" would mean a truly empowering approach engaging all these actors in order to strengthen and support individuals' response-ability and thus enable them to accept and exert their fair share of responsibility.

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Notes

1. The historical origins of the expression "anti-aging" have not yet been systematically clarified. It is well known that the US osteopath Ronald Klatz describes himself as the creator of the term "anti-aging medicine" (drklatz.net) in the early 1990s (Schweda and Pfaller 2017). However, we already find earlier publications that explicitly use the word and associate it with medical questions. The first one dates back to 1948 and is dedicated to "effects of vitamins as anti-aging factors" (Gardner 1948).
2. For a more detailed discussion, see Schicktanz and Schweda 2012.

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10 GOVERNING THROUGH PREVENTION
Lifestyle and the Health Field Concept

Thomas Foth

Introduction

According to the World Health Organization (WHO), dementia affected 47 million people globally in 2015, and this number is expected to increase to 132 million by 2050 (WHO 2017). The WHO estimated the direct medical, social, and informal care costs in 2015 at US$818 billion, or 1.1 percent of global gross domestic product, and these costs are expected to rise to US$2 trillion by 2030. Seen against the backdrop of increasing financial pressure on the health-care system, the WHO declared dementia a "public health priority." Furthermore, no definitive pharmaceutical solution for the treatment of dementia exists, and so far, more than two hundred drugs have failed in development in the last thirty years (Solomon et al. 2014). Even newer anti-amyloid therapeutic trials of drugs for Alzheimer's disease have also led to upsetting results (Doody et al. 2014; Karran and Hardy 2014; Salloway et al. 2014). Some scholars (Feldman and Estabrooks 2017) warn that many pharmaceutical companies are leaving the field of research given the costs of development failure. These dire predictions are coming at a time when social services, including health-care systems, are being transformed all over the (Western) world through the injection of "economic rationality into social spheres and practices that previously were primarily free of economic logics and pressures" (Hardt and Negri 2017: 219). Large parts of populations are experiencing increasing precarity with the creeping privatization of formerly publicly funded and administered social and health-care services. Health-care professionals are being replaced by unlicensed assistants or underqualified personnel.

The WHO's (2017: 4) action plan is meant to help realize a "world in which dementia is prevented," a somewhat surprising statement given that until recently, dementia was diagnosed after first symptoms were detected. Treatments tend to start only postdiagnosis and generally consist of med-

ications in combination with psychiatric drugs, and sometimes psychosocial interventions. The WHO's somewhat optimistic vision is based on newer research that demonstrated a correlation between the development of cognitive impairment and what the action plan calls "lifestyle-related risk factors." Related also to chronic diseases like diabetes (especially type 2) and hypertension, these risk factors include physical inactivity, obesity, an unbalanced diet, tobacco use, and abuse of alcohol. Risk factors specific to dementia include midlife depression, low educational attainment, social isolation, and cognitive inactivity. In order to attain its ambitious goal, the action plan emphasizes the need to reduce the level of exposure of "individuals and populations to these potentially modifiable risk factors, beginning in childhood and extending throughout life," by supporting them "to make healthier choices and to follow lifestyle patterns that foster good health" (WHO 2017: 18) .

Thus, the WHO's ideas on prevention of dementia is closely related to its Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2020. Dementia, once considered a person's fate, is now understood as preventable, provided the individual engages in a lifelong process that begins in early childhood. This process not only alludes to a physically healthy lifestyle but touches on all aspects of life. For example, individuals are encouraged to pursue activities to stimulate the brain, like learning to play a musical instrument, reading a book, or going to the theater. They should be socially active, participating in service clubs or doing volunteer work (Alzheimer Society Canada 2018). Some research emphasizes the strong correlation between dementia and poor social engagement (Vernooij-Dassen and Jeon 2016), whereas other research (Ihle et al. 2016) suggests that even a cognitively engaged lifestyle is not enough because it does not consider the personality dimension of the individual. Individuals with a high openness to experience may have been more engaged in stimulating activities in early life, increasing their cognitive reserve, which in turn enhances their cognitive performance level in old age. A Finnish randomized controlled proof-of-concept trial (Ngandu et al. 2015) confirmed the association between the different risk factors and concluded that one-third of Alzheimer's cases worldwide are attributable to seven modifiable factors (see also Feldman and Estabrooks 2017). The findings of the Finnish FINGER study suggest that it is not enough to focus only on one aspect of lifestyle change, but that all the different dimensions need to be addressed at the same time if dementia is to be successfully prevented. Thus, recommendations for the prevention of dementia comprise normative and moral requirements of how subjects should behave responsibly in living their lives. The idea of responsibility thereby refers not only to one's personal way of life, but also to society at large, given the financial burdens

arising from the increase of dementia. Furthermore, the responsible self has to engage in continuous work of the self on the self. Health insurance in Canada and other countries increasingly use reward systems to promote healthy lifestyles. Under the slogan "Do More—Get More. Get Apple Watch. Get Active. Get Rewarded," insurance companies like Manulife in Canada encourage policyholders to track their physical activities to earn so-called vitality points, allowing them discounts on their health insurance (and incidentally providing the insurer with valuable personal data free of charge) (Manulife 2019).

What is strangely missing in these concepts are socioeconomic conditions and the so-called social determinants of health, despite the fact that the prevalence of dementia is not equally distributed globally or locally throughout all segments of populations. In the WHO action plan, the term "social determinants of health" is mentioned only once and socioeconomic factors are not discussed at all; likewise, in much of the research on risk factors, social determinants of health are mentioned only in passing, if at all. Studies of dementia in Canada, for example, have demonstrated not only higher prevalence rates in First Nations communities as compared to others, but that this rate also rose more quickly, and disproportionally affects younger age groups and males, in First Nations populations (Jacklin, Walker, and Shawande 2013). Research from Australia on the prevalence of dementia among Indigenous peoples there came to comparable conclusions (see, e.g., Smith et al. 2008). Nearly 60 percent of people living with dementia currently live in low- and middle-income countries, and most of the expected new cases (71 percent) will occur in these countries (WHO 2017). The omission of socioeconomic factors is not attributable just to neglect on the part of authors but is more due to the (neo)liberal rationale, in which societal disparities are part and parcel of a society that is based on competition, and where citizens are conceptualized as autonomous rational actors (*homo oeconomicus*) with personal responsibility for their health.

In this paper, I develop a critical perspective on the concept of lifestyle by providing what Foucault called the "history of the present" (see, e.g., Foucault 1980, 1995; Foucault and Perrot 1980). This genealogical inquiry aims to critically question how the concept of lifestyle evolved into such a taken-for-granted assumption in the context of the prevention of chronic diseases—including dementia. In order to determine what is politically at stake if dementia is thought of as a disease determined in large part by the way of life one lives, it is necessary to better understand the rationale that led to the adoption and implementation of this way of thinking in public health and the political and economic conditions within which it became the leading paradigm. Thus, I will trace how the concept of lifestyle, based on the idea that people did not die because they lacked access to medical

care but because they lived a life prone to personal risk taking, was integrated into a new preventive strategy in the Canadian context.

In 1974, the Long Range Health Planning Branch (LRHPB) of the Department of National Health and Welfare released a green paper titled *A New Perspective on the Health of Canadians: A Working Document*. This report, better known as the Lalonde Report after the health minister at that time, was not a policy declaration but rather a thought experiment meant to formulate perspectives on health for then prime minister Pierre Trudeau's liberal government. As McKay (2000: 3) contends in her study, *Making the Lalonde Report*, the report officially inaugurated a "paradigm shift" by "giving birth to health promotion." She rightfully emphasizes that "fate was replaced by risk" (17). I choose the Lalonde report as the starting point of my analysis because even though this document did not receive much media attention in Canada, Hubert Laframboise, the director general of the LRHPB, stated that by 1978, "the Working Document had become an integral element of health policy planning not only in Canada but in many other countries" (Laframboise 1978 as cited in McKay 2000: 2). And indeed, the main concepts and ideas developed in this report became the foundation of public health policies in many different European countries and the United States (see, e.g., Larsen 2012) at a time when neoliberalism became the underlying rational in the transformation of the welfare state in general, and health-care systems more specifically.

However, the concept of lifestyle was only one component in what the authors of the Lalonde report called the Health Field Concept, which connected lifestyle with the subjects' environment, biology, and the organization of the health-care system. Improving public health, according to the Health Field Concept, meant for public health authorities to adopt specific strategies in order to govern the respective four dimensions, maintaining the state as an important player despite delegating responsibility for healthy lifestyles to the individual. Already in 1988, the WHO adopted the Canadian conceptualization of health prevention, and since then it has been perpetuated in the organization's global strategies for the prevention of chronic diseases and dementia prevention.

Although I agree with scholars who criticize the use of the concept neoliberalism in the context of public health, turning it into a "totalizing and monolithic" entity and "reifying it into a globally dominant force or stage of history" (Bell and Green 2016: 240–241), I am convinced that "naming neo-liberalism is *politically* necessary to give the resistance to its onward march content, focus, and a cutting edge" (Hall 2011: 206; see also Peck 2010). From my perspective, neoliberal governance is a "governing rationality that cannot be understood merely in terms of its general economic policies: the privatization of public services and industries, the deregulation

of markets and firms, the destruction of labor unions, and so forth" (Hardt and Negri 2017: 222). Instead, neoliberal transformations have changed the way we understand ourselves and our health, and have emphasized our responsibility to stay healthy through everything from mindful practices like yoga and meditation to regular workouts in the gym. These transformations also have changed our perception of what causes chronic illnesses and how we should conduct ourselves to prevent them.

Thus, the Lalonde report assumed that health is no longer something that happens to a person but is created through a personally chosen lifestyle; one is expected to assume responsibility for one's behavior (see, e.g., Glouberman 2001). Stephen Katz (2013), who analyzed the use of lifestyle in the discourse of successful aging, concludes that lifestyles are conceptualized "as volitional and discretional; an assumption buoyed by empirical data favoring individualistic principles of choice and identity over processes of social constraint and historical contingency" (53), and "as a narrow and individualistic set of practices overdetermined by their relationship to empirically driven pre-dictors of successful aging" (61). Others, using Foucault's notion of biopolitics, assert that "the biopolitical rationality operating in lifestyle and in new public health strategies stresses individual responsibility for establishing a healthy lifestyle that conforms to biomedical norms despite structural forces that may or may not influence these choices" (Mayes 2017: 65). According to this perspective, the concept of lifestyle combines freedom, choice, and responsibility of citizens (see also Larsen 2012). Health becomes an infinite project that the individual must actively pursue and seek to perfect for "oneself and for the security of the population" (Mayes 2017: 65) Thus, "the lifestyle network makes a healthy lifestyle a visible indicator of the neoliberal subject's success or failure to take responsibility for their own future and that of their family and society" (65). The (neoliberal) state, so the critique goes, uses the concept of lifestyle to withdraw from health policies by empowering the subject to do what, before, the state would have done. The task left for the state is to educate individuals in order to prevent chronic diseases. According to this critique, "The individual [becomes] the *only* actor to reduce the economic and social costs of chronic disease" (62, original emphasis).

By linking health to lifestyle, individual responsibility, and self-control, other scholars have also noticed the privatization of risk management (see, e.g., LeBesco 2011; Peterson and Lupton 1997; Rose 2005, 2007a). Privatized risk management, according to these scholars, became an obligation for responsible citizens and should result in lifestyle modification based on "rational choices between healthcare needs and scarce resources" (Bell, McNaughton, and Salmon 2011: 3). Despite the fact that these authors

were well aware that the new public health approach implied a conceptualization of risks outside the individual's control, like the environment, most of them concentrated on the privatization of risks.

While I agree with these critiques, I argue that important political aspects of the concept of lifestyle are lost if it is reduced solely to the subject's responsibilization without analyzing how preventive, healthy behavior is actually produced in the first place. In other words, critiques of lifestyle tend not to analyze in much detail the fact that governments actively influence and restrict fields of possible action, making some individual choices more likely or attractive than others and sometimes prohibiting others. Thus, the concept of lifestyle must rather be understood as part of a strategy aimed at influencing the preventive behavior of individuals without necessarily forcing or coercing them; it is more about changing "individual behavior in a democratic fashion" (Lalonde 2002: 150).

Considering that the element of lifestyle was only one of four elements that made up the original comprehensive Health Field Concept of the Lalonde report, which in 1988 also became the foundation for the WHO's Global Health for All Strategy, it becomes clear that the significance of "the state" did not diminish as some critiques suggest. I would even say that quite the opposite might be true.

The decisive difference to the former politics of the welfare state was that "the state" did indeed reduce its financial investments in the provision of health-care services but was and still is heavily engaged in the three other areas of the Health Field Concept, both through legislative and regulative measures, and through research funding and interventions in organization of the health-care system. Thus, the second central point of this chapter is to contribute to a better understanding of the role the state and international organizations like the WHO played and still play in the neoliberal management of public health in general and dementia in particular. Indeed, the concept of lifestyle cannot be perceived as merely evoking the absence of the state. Only through the complex interplay among different forms of power is a politics of lifestyle feasible.

The report recommended what Laframboise (1990) called "specific courses of action" (319) and proposed five strategies (health promotion, regulatory, research, health care efficiency, and goal-setting), and seventy-four possible courses of action (Lalonde 2002). Glouberman (2001: 13) emphasized that "a great deal of health policy over the next 25 years could be described in terms of these tools. . . . [T]he tool of reorganization has been applied to every system of health care organization in Canada." Many of the recommendations made in the report became guiding principles for other governments in the transformations of their respective health-care systems (see, e.g., Larsen 2012).

These tools became as well part of the WHO strategy for the prevention of dementia. Its action plan was preceded by different global political initiatives. The 2013 G8 dementia summit held in London, for example, underscored the key nature of prevention in reducing the human, social, and economic burdens of dementia. The ministers of health particularly agreed to explore the "possibility of developing a private and philanthropic fund to support global dementia innovation" (G8 Health and Science Ministers 2013: 1) and committed to carry out twelve dementia public health policy actions, with France and Canada leading the initiative.

In what follows, I will describe what McKay (2000) called a paradigm shift of health promotion, but I will also emphasize that the Lalonde report also clearly demonstrates Foucault's definition of governmentality (see, e.g., Bröckling, Krasmann, and Lemke 2011b; Dean 2010; Foucault 2007; Walters 2012). Government understood as the "conduire des conduites" (conduct of conduct) (Foucault 2001: 1056) comprises strategies and tactics to change behavior according to specific norms and particular ends (Dean 2010). The report must be understood as a *dispositif*, something that Foucault (1994) defined as a "heterogeneous ensemble" of differential elements like discourses, institutions, architectures, regulated decisions, laws, etc.—the spoken as well as the unspoken—and a kind of operator to deal with and to resolve problematic social questions. Lalonde (2002) clearly identified the social "emergency" to which the "comprehensive Health Field Concept" was the strategic response: the rising costs of the health-care system at that time and the concern that the health status of the population was not improving in proportion to the increasing costs of health care. And, I would add, it was also the (neoliberal) conviction, as formulated by UK Secretary of State for Health and Social Security Patrick Jenkin (1981: 240), that it is not the responsibility of the authorities "to care for us from the cradle to the grave so that we have no responsibility."

Using the idea of prevention, the report contributed to a neoliberal transformation of health care despite the fact that the Canadian system of Medicare was based on the idea of universality, meaning citizens had equal access to health care independent of their socioeconomic situation. As I will demonstrate, the Lalonde report undermined this foundation and initiated a profound reorientation, not only of the health-care system, but even more importantly, it radically changed the way we think about our behavior around health-related issues. This chapter will therefore discuss this dimension of the report in some detail and relate it to Foucault's notion of subjectivity and technologies of the self. An analysis of the report also enables a better understanding of the emergence of neoliberalism as a leading governmental rationality. Instead of understanding neoliberalism as a monolithic strategy of capitalism, the Lalonde report, published before

neoliberalism became a leading rationale, demonstrates that neoliberalism must rather be understood as the result of the merging of different practices. The report also shows that often surprising coalitions emerge; in this case, the discourse about an ineffective health-care system merged with the anti-biomedical movement opposed to the unrestricted power of medicine.

In the following section, I describe the Lalonde report and the context in which it emerged. In the second section, I propose governmentality as my theoretical frame of reference for the analysis of the Health Field Concept, which will be followed by the genealogy of the concept and the significance of the lifestyle element for governing the health of populations through prevention. I will discuss the theoretical shift the authors of the Lalonde report performed by replacing the traditional historical narrative about preventive medicine with a particular biohistory based on demographic/epidemiological data. This narrative was then linked to the neoliberal reorientation of health promotion with the idea of responsibilization of individuals and the population at large for their health.

The Making of the Lalonde Report and Its International Significance

As mentioned in the introduction, the Lalonde report was named after Marc Lalonde, minister of national health and welfare between 1972 and 1977 under Pierre Trudeau's liberal government. Lalonde, who was a lawyer, was minister of justice in 1978, and in 1980 minister of energy, mines and resources. In an article in which he retrospectively evaluated the significance of the Lalonde report, he identified two major concerns the liberal government had been confronted with in the 1970s that had resulted in a necessary paradigm shift in the government of public health: the spiraling health-care costs and their failure to lead to the improved health of the population (Lalonde 2002). Mandated by Lalonde, Hubert Laframboise, a high-ranking civil servant in the federal health ministry, formed the Long Range Health Planning Branch (LRHPB) to redefine the approach to public health. The LRHPB was conceptualized as a "free-wheeling think tank" composed of epidemiologists, policy consultants, statisticians, and accountants (Laframboise 1990: 320). Basing their work on the WHO definition of health, the LRHPB committee members were tasked to "think outside the box" (Lalonde 2002:149). The result was the Lalonde report, which introduced the Health Field Concept, or a "sort of map of the health territory," as an overarching conceptual framework that included four elements: lifestyle, environment, health-care organization, and human biology (Lalonde [1974] 1981: 31).

Many of the arguments made in the 1970s regarding the inefficiency and ineffectiveness of health-care systems are similar to the ones made today in the context of dementia. As was the case in the 1970s, public health experts complain that too much money is spent on people who are already sick and not enough resources are provided for the prevention of dementia. And as was the case at the time of the Lalonde report, it is predicted that these costs will "only trend upwards" (Chow et al. 2018: 3).

International Significance of the Health Field Concept Today

As I will discuss in more detail in my analysis of the Health Field Concept, even before the official launch of the report, the concept was already aligned with both the WHO and the Pan American Health Organization (PAHO). Lalonde himself received the WHO Medal for his contribution to health policy in 1988 and became one of twelve "Public Health Heroes who have shaped the past 100 years of international public health" as selected by PAHO on the occasion of the one hundredth anniversary of the organization (Canadian Medical Association 2004). Lalonde was appointed an Officer of the Order of Canada in 1989 and was inducted into the Canadian Medical Hall of Fame in 2004.

However, the Lalonde report did not receive much media attention in Canada itself despite the fact that the government distributed fifty thousand copies of it. On the occasion of his nomination by PAHO, Lalonde (2002: 150) described the launch of the report as a "non-event." The opposition in Canada criticized the paper as "being against sin and for motherhood," and some argued that they had already known that it "was better to be slim than fat." But the reaction outside Canada was more enthusiastic, with Lalonde stating that the report was a "Canadian government 'best-seller,'" with well over two hundred thousand copies distributed. Sir George Godber, the former chief medical officer of Britain's Department of Health and Social Services, praised the report for its "worldwide effect" on governments (Godber as cited in Laframboise 1990: 316). Laframboise (1990: 316) argued that "reviews and citations in professional journals were myriad and enthusiastic," and authors such as Milton Terris (1984: 327), former president of the American Public Health Association, called the report a "world-class document" that "was and remains one of the great achievements of the modern public health movement." He even went so far as to categorize the report as a "second epidemiological revolution" that provided a "framework of an overall philosophical outlook" (327). According to Lalonde (2002: 150), French minister of health Simone Veil (1974–1979) and US secretary of health, education, and welfare under Jimmy Carter, Joseph A. Califano (1977–1979) both announced shortly after the report's publi-

cation that they would "pursue an approach similar" to the Health Field Concept. It was after the publication of the US surgeon general's report, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention 1979*, that the US government officially implemented the shift to "epidemiologically oriented health planning [and] to planning for outcomes" as propagated by the Lalonde report, and followed its "goal-setting strategy." As in the case of Canada, the Reagan-Bush administration made serious cuts in federal funds for public health services and social programs (Terris 1992: 192; see also Terris 1999).

The United States was only the first country to adopt the recommendations of the Lalonde report (Terris 1984); many other Western governments followed. At the same time as the United States shifted its policies, in the United Kingdom the Thatcher government implemented a lifestyle-oriented health policy, and Secretary of State for Health and Social Security Patrick Jenkin (1979–1981) emphasized the importance of individual responsibility and control for one's life and health. In 1979, the Australian federal minister for health, Ralph Hunt, announced, "During my period of office as Minister of Health I have become more and more convinced that continued concentration on traditional curative medicine, with its associated high costs both to the Government and the individual, can add little to improving the nation's health status. *I believe this can be achieved only by motivating individuals to take a responsible attitude for their own personal health care*" (Ralph Hunt on 25 May 1979 as cited in Mayes 2017: 61, italics in original). The government's task was to "motivate individuals and to provide the conditions for individuals to adopt a 'responsible attitude' for their own health" (Mayes 2017: 61).

However, even more important was and is the role of the WHO in the dissemination of the approach. By the 1970s, not only had the director-general of the WHO at that time, Dr. Halfdan Mahler, endorsed the concept of the Lalonde report, but it had also become the foundation of the WHO Global Health for All strategy in 1988. Since then, the Health Field Concept has been enlarged and broadened as a "holistic approach" to health. As Lalonde (2002) concluded, the WHO has over the years initiated a number of programs, pushing the concepts of "healthy public policies," "healthy cities," and "healthy communities." The first WHO International Health Promotion Conference, held in Ottawa in 1986, "led to the adoption of the now famous *Ottawa Charter on Health Promotion*" (Lalonde 2002: 150, italics in original). Baum and Saunders (2011: ii) described the charter as "the new public health Bible" because public health was not understood as solely dependent on individual healthy choices but through "government policies that change the structures people live, work and play in." Thus, these policies imply an ethical judgment about what a healthy lifestyle

should look like and how a responsible citizen should behave. I will discuss this new ethical politics as a specific dimension of neoliberal governmentality in the following section.

Governing Individuals and Populations

I use governmentality to examine the Health Field Concept as a way to exercise power as the "conduct of conduct" (Foucault 2000: 341; 2008: 186). According to Walters (2012: 11), governmentality is a "framework for analysis that begins with the observation that governance is a very widespread phenomenon, in no way confined to the sphere of the state, but something that goes on whenever individuals and groups seek to shape their own conduct or the conduct of others (e.g., within families, workplaces, schools, etc.)." However, for the genealogy of prevention, understood as the choice of a responsible lifestyle, I will focus on (neo)liberalism as a particular form of governmentality. The specificity of liberal forms of governments is that they "replace external regulation by inner production" (Bröckling, Krasmann, and Lemke 2011a: 5). Liberalism "organizes the conditions under which individuals can make use of their freedoms," or in other words, freedom is not contrary to liberal governmentality but rather one of its tactical starting points of action. To make use of freedom as a mechanism of liberal governmentality means that the one governed is comprehended as an autonomous actor who is able to act and reason in numerous ways that are often unpredictable by authorities. Thus, to govern is to influence the field of possible actions and to work on the abilities to act—of selves and others (Miller and Rose 2009b; Rose 2005; Rose and Miller 1992). It involves the reinforcement and modeling of energies in both individual bodies and the population at large that seem otherwise to be unproductive or even self-destructive (Dean 2010). Therefore, government "is any more or less calculated activity, undertaken by a multiplicity of authorities and agencies, employing a variety of techniques and forms of knowledge, that seeks to shape conduct by working through the desires, aspirations, interests and beliefs of various actors, for definite but shifting ends and with diverse sets of relatively unpredictable consequences, effects and outcomes" (Dean 2010: 18). According to Foucault (2000: 341), this form of governing "incites, it induces, it seduces, it makes easier or more difficult; it releases or contrives, makes more probable or less . . . but it is always a way of acting upon one or more acting subjects by virtue of their acting or being capable of action. A set of actions upon other actions."

Thus, liberal governmentality embraces the idea of the individual problematizing his or her conduct; governmentality is not only about the exer-

cise of authority over others but also implies the ability to govern oneself. This becomes the ethical dimension of governmentality: the action of the self on self (Rose 1993, 2005; Rose and Miller 1992). Therefore, government does not merely imply power relations and an external authority but additionally raises questions around identity and self. The focus of an analysis of governmentality is therefore on "the interrelations between regimes of self-government and technologies of controlling and shaping the conduct of individuals and collectives" (Bröckling et al. 2011a: 13). As I will demonstrate in my analysis of the Health Field Concept, the fundamental idea of the Lalonde report is how to convince and direct citizens to live healthier lives—not primarily through coercive and disciplinary means but through their free choice. Rose (2005: 170) emphasized that this form of governmentality is linked to ethico-politics, which mediates between the respect of subjects' autonomy and the need to implement authoritative judgments about right and wrong. The Lalonde report must be understood as a specific "technology of government" (Dean 1996) that enabled the realization of this ethico-politics through the inscription of knowledge within practices by merging "cultural aspirations, images and desires about a healthier way of living ... to a whole host of very quotidian techniques of inscription and self-management" (Walters 2012: 62). In what follows, I will demonstrate that the ethico-political governing of public health through the responsibilization of citizens was only made possible through the complex interplay within the concept of lifestyle, which in turn was linked to epidemiological data, social marketing, biomedical research, regulations, and the law.

However, in recent years scholars have criticized the "state phobia" in many studies of governmentality, meaning that the diagnoses of "neoliberal" or "advanced liberal government" (Miller and Rose 2009a, 2009b; Rabinow and Rose 2006; Rose 2005, 2007b), particularly in the earlier works on governmentality, often neglected the role of the state as the "center of control by political agents or classes and the exercise of power" (Dean and Villadsen 2016: 2; see also Alliez and Lazzarato 2016; Harcourt 2018; see also Villadsen and Dean 2012). Instead, these scholars often focused on programs, strategies, and rationales that are realized through the interplay between multiple experts and actors like community groups and for-profit and not-for-profit organizations, etc., in order to instill forms of self-government and responsibility, as is the case with the lifestyle analyses mentioned earlier (see, e.g., Larsen 2012; Mayes 2017). These analyses provided valuable and different critical perspectives on how power is exercised in our societies, but the question remains whether these authors "went too far in the evacuation of the form of the state in political analyses and displacement of sovereignty" (Dean and Villadsen 2016). The Lalonde report and the

dementia prevention strategies of the WHO clearly demonstrate that prevention is only thinkable and feasible through and with the support of "the state" or international governance structures—despite the fact that these programs aim to shift responsibility to individuals.

The Health Field Concept: Changing the Historical Narrative on Prevention and the Lalonde Report's Regime of Truth

Both in the introduction to the official Lalonde report and in Laframboise's publications on its making, the work of demographic historian McKeown and colleagues (McLachlan and McKeown 1971; McKeown 1971; McKeown, Brown, and Record 1972) is mentioned as the decisive theoretical foundation. Their work also became the central argument against the universally funded Canadian health-care system, which had been based on the idea that the health of the population would improve through the development of medical services and universal access to them. McKeown and colleagues reversed the predominant narrative in the 1970s, arguing that the history of prevention was basically a heroic history of medical discoveries. Medical historians such as Harry Wain (1970: 187) described the emergence of germ theory as the "basic medical discovery that changed the course of the world by introducing it to the concept of disease prevention," enabling the first immunology work of Edward Jenner. According to this perspective, the history of preventive medicine can be captured as the scientific development of immunology and a deeper understanding of the underlying mechanisms of communicable diseases that led to modern epidemiology. According to Wain and others, scientific epidemiology succeeded in preventing diseases such as smallpox and typhoid and justified a certain optimism that medicine would be able one day to prevent and eradicate all communicable diseases. Again, following this narrative, the success of this preventive medicine, combined with the economic upturn in most Western societies after WWII, led to decreasing mortality rates in most so-called developed countries of the Western world. Thus, as the demographic composition of these societies shifted to an aging population, chronic, degenerative diseases slowly increased. This shift made a change in prevention strategies necessary, and it was in this context that the concept of lifestyle emerged that connected chronic degenerative diseases to people's way of life.

McKeown, Brown, and Record (1972) disputed this view. Based on epidemiological data, they explicitly denied that "the continued growth of population in the late nineteenth and twentieth centuries in the presence of a declining birthrate is explained by the reduction of mortality largely

from infectious disease brought about by hygienic improvements from about 1870 and by specific medical measures after the introduction of chemotherapy in 1935. The enormous growth of population between the 1700s and the mid-nineteenth century" could only be explained through the complex relationship "between agricultural and industrial developments or between both and the general improvement of living" (McKeown, Brown, and Record 1972: 357). McKeown (1971: 29) also provided a fundamental critique of medical knowledge:

> Nature was conceived in mechanistic terms, which in biology led to the idea that a living organism could be regarded as a machine which might be taken apart and reassembled if its structure and function were fully understood. In medicine the same concept led further to the belief that an understanding of disease processes and of the body's response to them would make it possible to intervene therapeutically, mainly by physical (surgical), chemical, or electrical methods.

Laframboise (1990: 318) argued McKeown "proved that the improvement of the health status of the people was far more a consequence of changes in lifestyle and the environment than it was a consequence of advances in medical sciences." This would also explain that whereas Canadian statistics showed significant improvements in health during the 1950s and 1960s, the correlation between expenditures and health improvement became less direct after the 1960s, despite the fact that public hospitals and health insurance (Medicare) had been implemented (Lalonde 2002). Thus, in a first step, LRHPB epidemiologists and policy analysts produced a series of pie charts in 1973 titled "Panorama of Mortality in Canada, 1971," that later became the visual centerpiece of the Lalonde report. These charts, compiled from statistical and epidemiological data on the causes of death according to age and sex, provided, according to Laframboise (1990: 318), "stunning proof that premature deaths derived principally from individual self-imposed hazards. [Seventy-five percent] of deaths between the ages of 5 and 30 were found to be due to automobile accidents, other accidents and suicide," and twice as many men compared to women died. As McKay (2000: 7) stated, McKeown had argued that "people were not dying due to a lack of access to medical care but "because they lived a life prone to personal risk taking. People did not live longer because of advancements in bio-medical knowledge; the increase in longevity was rather linked to the way of living and the environment." In short, "medical intervention could do little to save victims of traffic accidents, coronary artery disease or suicide" (McKay 2000: 7).

In cooperation with Statistics Canada, the policy consultants developed a formula for ranking the gravity of various causes of death. Each

cause of death was factored in "to obtain the Potential Years of Life Lost (PYLL) relative to age 70." Laframboise (1990: 318) argued that if someone died at age 20 from "individual self-imposed hazards," the loss of 50 years of potential life "far outweighs, in gravity, a death from a stroke at age 65." Based on these epidemiological data and the demographic historical perspective, the authors of the report assumed that health care had advanced to the point that it could no longer contribute to the improvement of health. Political planning consultant Joe Hauser (as quoted in McKay 2000: 8) stated that "in spite of a large infusion of funds into the health care delivery system, the overall health status of Canadians did not appear to have significantly improved." As I will discuss later in more detail, this statement anticipated the neoliberal argument about the inefficient and costly delivery of social services and provided a rationale for the cutbacks in federal funding of Medicare. Before the report was tabled in the House of Commons, the LHRPB performed several "preliminary tests of the concept" with "specialized groups," such as the 1973 WHO conference in Geneva and the Pan American Health Organization (PAHO) conference in Ottawa. It was also already endorsed by the federal-provincial conference of health ministers in Canada in 1974 (Lalonde 2002: 150).

The Four Elements of the Health Field Concept

Lifestyle, Power, and Subjectivation

With the idea of "individually self-imposed hazards," the LRHPB developed the concept of "lifestyle," connecting personal behavior and habits to the individual health condition. Laframboise (1973: 388) contended that this element was the "most neglected aspect of health," defining it as "the agglomeration of decisions taken by individuals which have a significant effect on their health." The problem for him was that these decisions were based on "social values, many of which have been inherited from the past but some of which are shaped by contemporary society" (388). Thus, the basic idea of lifestyle was that individual "behaviour was an area of self-determination that could be changed" (McKay 2000: 9)—or, from a governmentality perspective, lifestyle was based on the idea of the "conduct of conduct" and "technologies of self," as I discussed in the theoretical section.

Congruent with this definition of lifestyle is the (neo)liberal conceptualization of subjects as rational actors with the vision to use empowerment in order to initiate social change. Lifestyle is, according to Laframboise (1973:

389), "at least partly related to morale," and the enemy of lifestyle health is "private pleasure, what Odin Anderson called 'a short-range hedonistic model.'" Thus, the Lalonde report is the materialization of what I called, with reference to Rose (1999), the "ethopolitical" governing of societies. The Lalonde report summarized this perspective as follows: "Most Canadians by far prefer good health to illness, and a long life to a short one but, while individuals are prepared to sacrifice a certain amount of immediate pleasure in order to stay healthy, they are not prepared to forego all self-indulgence nor to tolerate all inconvenience in the interest of preventing illness" (Lalonde [1974] 1981: 15). Furthermore, Laframboise (1973: 389) argued, North Americans in particular had too much faith in the "restorative power of doctors, hospitals and medical technology." The problem, said Laframboise (1973: 389) was that the "technological advances of clinical medicine, the prepayment and organization of health services and the removal of health pollutants, have little effect on the decision of an obese person to reach for another piece of strawberry shortcake."

Interestingly, Laframboise (1973) explicitly connected the concept of lifestyle (and victim blaming) with a critique of the "prepayment" of health services—again anticipating the neoliberal critique of Medicare. However, his critique was even more pronounced when he emphasized that the "system often seems to demand that a person first be sick before he [*sic*] becomes an object of concern, and the preponderance of attention and resources is given to the 'sick care' system" (Laframboise 1973: 389). However, these ideas also highlighted the fact that sometimes surprising coalitions emerge. Ivan Illich (2007), one of the most distinguished and radical social critics of medical power in the 1970s, who had criticized the biomedical management of living and the power of medicine in Western societies, mentioned the report in a footnote in his book, *Medical Nemesis*. The report demonstrated the necessity of a complex interplay of different technologies to combat "short-range pleasure" with "long-range health" perspectives.

Joe Hauser, the Planning Consultant for Lifestyle, along with other policy consultants in the LRHPB, directed many qualitative and quantitative studies to prove that personal health habits were the underlying causes of ill-health. Investigations between fatal motor-vehicle accidents and the use of seat belts, for example, concluded that seat belts save lives. Other research studied the impact of tobacco on cardiovascular disease or the consequences of alcohol abuse. "In each instance, whether seatbelts, alcohol or tobacco, it was individual lifestyle choices that were seen to cause or avoid illness and death" (McKay 2000: 9). The big challenge for governing the health of the population through lifestyle was how to convince people to pay the price for

good health "in terms of discipline and sacrifice," both of which depended on societal and individual values (Laframboise 1973: 393).

Studies of governmentality can help clarify the rationale through which the Lalonde report envisioned behavior modifications. The policy consultants of the LRHPB understood that lifestyle decisions could not be influenced through legislative measures alone but that they needed to be complemented by a complex interplay of different technologies and techniques. Television as a technique of persuasion could be "employed to modify behaviour," and "social marketing was promoted as a new hope that could change self-destructive health habits of Canadians" (McKay 2000: 9). "The philosophical issue" was "whether, and to what extent, government can get involved in the business of modifying human behaviour, even if it does so to improve health"; the Lalonde report concluded that "society, through government, owes it to itself to develop protective marketing techniques" (Lalonde [1974] 1981: 37). In 1973, for example, the Department of National Health invested in research on the possibility of changing the behavior of obese people through social marketing. One of the first proponents of using mass communication was research psychologist G. D. Wiebe (1951: 679), who had argued that it was possible to "'sell' broad social objectives via radio or television" and that media could be used to mold behavior and habit in "areas like citizenship responsibility and community participation." He contended that, in principle, it was possible to sell rational thinking like soap (679). He concluded that "given a reasonable amount of receptivity among audience members, radio or television programs can produce forceful motivation," and if certain conditions are met, the results expected could be "comparable with those of a commercial sponsor" (691).

These insights were developed further in the context of public health under the label of "health marketing," which referred "to health promotion programs that are developed to satisfy consumer needs, strategized to reach as broad an audience as is in need of the program, and thereby enhance the organization's ability to effect population-wide changes in targeted risk behaviors" (Lefebvre and Flora 1988: 302). Marketing should be oriented toward growing consumer satisfaction by producing a better quality of life and wellbeing, higher self-esteem, more social contacts, etc., while simultaneously increasing benefits to health promotion agencies by meeting organizational goals and increased funding for more research (Lefebvre and Flora 1988: 303). Thus, the proponents emphasized, social marketing is not about "blaming the victims" but rather about more effective and efficient use of resources through analysis, planning, implementation, and control of agency operations. But persuasion had to compete with all the

other "behaviour modification measures" underway. Laframboise (1973: 389) suggested that new, "largely unexplored," legislative measures should also be tried, "such as the compulsory treatment of drug abusers and the compulsory use of seat belts." He concluded that these measures would "not prevent all people from slow self-destruction but they can reduce the number and put breaks on the process" (389).

The last dimension of the lifestyle approach was the idea of empowerment. The consultants of the LRHPB recognized a surge of interest in fitness and health clubs. Joe Hauser, who organized the First National Conference on Fitness and Health in 1972, undertook a study tour to Sweden with the Fitness and Amateur Branch in order to observe how that government supported lifestyle modifications through the construction of bicycle paths and sport facilities. Sweden was the paradigm for the LRHPB because its population was prepared to make personal sacrifices to prevent diseases and therefore was the leading nation in regard to health status indicators.

The idea of using empowerment in a systematic way in order to activate citizens to modify their lifestyle was institutionalized in Canada in 1978/79 with the creation of the Health Promotion Directorate (HPD). The directorate's mandate was the development and implementation of programs that "promote health and encourage the avoidance of health risks" (Health Promotion Directorate 1988: 42). The directorate developed crosscutting health promotion initiatives that focused attention on healthy lifestyle choices with national, provincial, and local governmental agencies and in partnership with professional and voluntary organizations and community groups. The way empowerment is invoked in the report is an example of how power works "beyond the state" (Miller and Rose 2009a, 2009b; Rose 2005). In her book, *The Will to Empower*, Barbara Cruikshank (1999: 1, 152) argued "that individuals in a democracy" are transformed "into self-governing citizens through" what she called "technologies of citizenship," such as "discourses, programs, and other tactics aimed at making individuals politically active and capable of self-government" through everyday practices of "voluntary associations, reform movements, and social service programs." As in the case of the HPD, empowerment is always a rapport founded on expertise and is a "democratically unaccountable exercise of power in that the relationship is typically initiated by one party seeking to empower another" (Cruikshank 1999: 72). Thus, the HPD materialized the dimension of liberal governmentality that governs through freedom. Subjects need to first of all perceive themselves as actors with the capacities to act and think, because only then a field for possible action opens up that can be governed though indirect means—by structuring the field of possible actions.

Environment

Closely related to the question of how to modify health behavior is the physical and social environment "under which an individual [lives] and [in] which she or he has little or no personal choice in avoiding, such as the air breathed" (Laframboise 1973: 388). The Lalonde report suggested that food, water, and other aspects of the environment that affect humans should be controlled and safeguarded (Lalonde [1974] 1981: 32). Laframboise (1973: 389) emphasized that environmental elements are often considered "'trade-offs' between health protection, on the one hand, and economic, technological, social or personal advantages on the other"; for example, the control of pollutants in automobile emissions will raise the cost of cars. But he also emphasized that control of the environment was almost all under the power of the government through legislative measures. However, he warned against corruption, because "governments are especially vulnerable to pressure groups" who might "[over-react] to a health hazard, causing grave economic or social damage in order to protect the public against a relatively minor hazard" (Laframboise 1973: 389). The way the Lalonde report approached the question of prevention, health promotion, and health care through the environment is congruent with how Foucault (2008: 3–4) described the "art of governing" as a "complex of means and things" discussed in the theoretical considerations.

Health-Care Organization

This element of the health-care system is traditionally considered the most important aspect of population health and prevention and has been subjected to many analyses and reports. In the Lalonde report, this element was "limited to the quantity, quality, arrangement, nature, and relationships of people and resources in the field of health case [sic] services" (Laframboise 1973: 388). Despite the large amount of data outlining its shortcomings, the health system had been unresponsive to the recommendations made in many reports, which Laframboise attributed to the weak demand for major reforms by the public, health professions, and health institutions. According to him, the only ones who were concerned about the rising health-care costs were elected representatives and bureaucrats.

The authors of the report identified several major problems of the Canadian health-care system. The most important was the rate of cost escalation that was "far in excess of the economic growth of the country." Another was the shared cost formula between the federal and provincial governments that encouraged the construction and use of hospitals, with expensive acute-care beds, without considering alternative health-care fa-

cilities and treatments. The focus remained on treating existing illnesses without any increase in funding for spreading information on health preventive measures. The authors also believed that the Canadian health-care system harbored "conflicting goals," especially with the aim of "trying to control costs while removing all incentives to patients, physicians and hospitals to do so." They argued that the fee-for-service system led to "many physicians and dentists carrying out tasks which could be done by others, at a lower cost." They also stated that physicians were unevenly distributed among the specialties "as well as between urban and rural areas" (Lalonde [1974] 1981: 28–29). To address these problems, Laframboise (1973: 390) suggested lowering costs by reducing the number of acute hospitals beds as well as the number of expensive clinical personnel, along with finding alternatives to fee-for-service payments for them. He also advocated for establishing district boards headed by nonmedical personnel with authority over the provision, levels, and standards of care of all medical services, and for community clinics run on a team-medicine basis. Most tellingly, he wanted people involved in looking after their own health (Laframboise 1973: 390). Both Laframboise and the Lalonde report also proposed that the federal government should increase pressure on the provinces to pursue these health-system reforms by putting "federal financing on a per capita basis" (Laframboise 1973: 390). Instead of using its financial power to enforce the foundational principles of Medicare of universality, comprehensiveness, and portability, implementing the new cost-sharing agreements would reduce the influence of the federal government on the provinces and would allow for variation among them (McKay 2000: 13).

This section clearly demonstrates one of the actual intents of the Lalonde report: transform Medicare by implementing elements of new governance through undermining the licensure system of professionals, introducing free market principles through financial incentives, shifting responsibility from the health-care and social system to individual citizens, reducing "big government" through regionalization, and using economic incentives to reduce the costs of health-care provision. The "problems" identified in the report and the remedies proposed thus follow the neoliberal script, and ongoing transformations of Medicare are still using the arguments made in the Lalonde report (see, e.g., Clemens and Nadeem 2014; Kirby 2003; Romanow 2002). I mention this aspect here because programs like the WHO action plan against dementia also always include demands for the transformation of health-care systems, in particular by calling for more public private partnerships (3Ps) and more research collaboration with the drug industry. The meta-analysis by Chow et al. (2018), *National Dementia Strategies: What Should Canada Learn?*, explicitly demands public private partnerships (174) and the implementation of new governance models in public health (205).

Human Biology

This element included all aspects of an individual's physical and mental health developed as a result of basic human biology (Lalonde [1974] 1981: 31). The section was devoted to medico-technological research—the development of vaccines and antibiotics, or chemotherapy for mental illness or organ transplants—and explicitly referred to the "applied research in the lifestyle, environmental and health care organizational categories" (Laframboise 1973: 391).

At the beginning of the 1970s, the LRHPB completed a "Delphi study on the future of genetics," which "foresaw an explosion of knowledge and interest in the micro aspects of *human biology*" (Laframboise 1990: 318, emphasis in original).

The Conceptual Model as a Mode of Governing

These four elements are brought together in what Laframboise (1973: 389) called a "comprehensive" conceptual model that could be used as a tool for analysis. All activities and problems could be allocated to one or another of the four elements, and each element or quadrant could be linked to specific policy instruments. To solve lifestyle health problems, "organized persuasion" (390) was the adequate policy instrument; protection of health from environmental factors depended mainly on legislation; improvement of the health-care system would come from reorganization; human biology was connected to scientific methods.

In order to demonstrate how the model could be used in practice, Laframboise (1973) applied the model to automobile accidents. According to him, data clearly demonstrated that deaths and injuries from automobile accidents could "be attributed to a large extent to the behaviour of individuals. Lifestyle choices of speeding, careless driving, impaired driving and failure to use seat belts" (391) were the primary factors. However, the gravity of these accidents also depended on environmental factors, like the construction of vehicles and the design of highways. Organization, with its focus on health-care delivery, provided ambulance services and helicopters, as well as treatments in emergency departments. And finally, human biology concerned the development of "new life-saving technologies, treatment methods, attention to accidents in medical school curricula" (391), and the like. However, the analysis clearly revealed that lifestyle was the principal underlying cause. Thus, Laframboise concluded that "if, as can be foreseen, acts of individuals dominate, measures for using persuasion or coercion to alter the pattern of individual decision can be considered as well as legislative measures for protecting the individual against himself

[*sic*]" (391). To mitigate deaths and injuries due to automobile accidents therefore required "a whole array" of measures "including the compulsory use of seat-belts, enforcement of traffic laws, random roadblock breathaliser tests, compulsory completion of a defensive driving course before licensing and so on" (391).

The WHO's (2017) *Global Action Plan on the Public Health Response to Dementia* uses a similar way to analyze dementia (and other noncommunicable diseases) as a public health problem. The plan identifies four groups that need to be included for the realization of goals in different "action areas": development agencies on the international, regional, and subregional level; academic institutions and research agencies; "civil society, including people with dementia"; "the private sector, health insurance, and the media" (WHO 2017: 3–5). According to the WHO (2017: 6), the "roles of these four groups often overlap and can include multiple actions cutting across the areas of governance, health and social care, promotion of understanding and prevention in dementia, and information, evidence and research." These roles encompass the four elements of the Health Field Concept. Governance is part of the element of environment, which is linked to legislation; health and social care is part of the element of health-care organization, which needs to be reorganized in order to face the challenge posed by dementia; civil society is part of lifestyle and can be influenced through information campaigns in the media; and evidence and research is part of human biology.

Here we have another clear example of what is implied in governing, understood as the right disposition of things; governing means to influence the context of subjects in order to change their behavior in the right direction. Last but not least, the way governing is defined here also highlights the complex interplay of very different kinds of power and instruments used for the governing of individuals and populations. The measures listed in the Laframboise article and in the WHO action plan are a combination of disciplinary means targeting the individual (educating the individual to choose a healthy lifestyle in order to prevent dementia), sovereign power (legislating against smoking in public spaces or increasing taxation on cigarettes, etc.), and government (using social marketing, empowerment, and, most important, persuasion or technologies of the self to convince the subject to behave in a responsible way or to commit to personal sacrifices to prevent disease). This complex interplay of different forms of power is what characterizes governmentality. Foucault (2007) emphasized that his analysis was not meant to imply that societies of sovereignty were replaced by disciplinary societies, which were then replaced by societies of governance. He used the image of the triangle to show the interplay of "sovereignty-discipline-government, which has as its primary target the population and as its essential mechanism apparatuses of security" (Foucault 2007: 219).

Conclusion

The last sentence brings my argument full circle. I began my chapter by outlining the "new" preventive approach to dementia as formulated in the WHO Global Action Plan and ended my discussion by demonstrating how the Canadian "Health Field Concept," better known as the Lalonde report, became the foundation of global public health policies—basically understood as preventive. I also wanted to show that it is not enough to focus merely on the element of lifestyle, often understood as the responsibilization of citizens for their own health by implementing the idea of prevention in their everyday life. Although important, this critique often emphasizes the withdrawal of the state in the managing of public health. Rather, I wanted to show that lifestyle is better understood as part of a dispositif, meaning it is the result of a complex interplay of institutions, legislation, scientific discourses, experts, community groups, governments, etc. If seen from this perspective, the significance of "the state" in prevention politics does not diminish, but its role changes.

A genealogical analysis of the Health Field Concept enables us to better understand how the notion of prevention is part of a neoliberal rationale on how to govern the health behavior of a population. It seems that most studies in the area of the prevention of dementia do not question the concept of lifestyle because it has become a taken-for-granted assumption. A genealogical analysis of the Lalonde report highlights the specific historical (power) formation behind the Health Field Concept. In doing so, the analysis asks how our present understanding of the prevention of dementia is formed and thus "enables us to realize that what has become our reality was only one option that prevailed by ruling out other options" (Scott 2007: 28).

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This chapter uses sections of an article published first in *Nursing Philosophy* 19, no. 4 (2018): e12222, Epub 11 September 2018, DOI: 10.1111/nup.12222, that discussed the Lalonde report as a technology in the transformation of liberal democracy through the ideas of new governance.

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AFTERWORD
Looking Forward

Peter J. Whitehouse and Daniel R. George

Etymology can inform futurology. In other words, understanding how the meanings of words change through time helps us understand not only how we use them now, but also how they might become tools to imagine and create different futures. As this book, *Preventing Dementia? Critical Perspectives on a New Paradigm of Preparing for Old Age*, ably demonstrates, words like "Alzheimer's" and "dementia," and even "aging" itself, have changed over time, and undoubtedly will (and should) change in the future. But what about the word "prevention" itself? And how does it compare to "cure"—the apparent dominant goal of medicine and in the brain-focused disciplines of neurology and psychiatry?

"Prevention" is a word that literally means "anticipate the future." In the context of health, it guides our actions toward identifying and maintaining wellbeing in the present to avoid future suffering and disease. Juxtaposed with the meaning of "prevention" is the concept of "cure." This word points toward identifying, fixing, and eliminating a disease even in older people in the latter stages of life, including those who are near death. Such is the case with so-called Alzheimer's disease, an illness that had its origins long in the past. Cure is fundamentally about diagnosis and therapeutics rather than maintaining health, although it can also represent an effort to return to a healthier nondiseased state. As opposed to prevention, which looks to the future, "cure" connotes returning to a desired past state.

The Alzheimer's Association and its aligned experts in the United States and elsewhere often state the ultimate goal of research is "finding a cure." Claims have been made for decades that we will possess something like a cure in just a few years; conventionally, predictions are projected to arrive at the end or mid-point of decades (e.g. 2020, 2025). These arbitrary and false promises drive their fund-raising efforts. Whereas the field tends to be organized around this logic, we believe it represents an unrealistic objective and a misalignment of priorities. The prospect of "curing" an age-related

dementia raises key conceptual and practical questions. For instance, to what healthier state and age would a person be expected to return? If we cure diseases, can they not reoccur and—if we were to cure all diseases—would we be preventing death itself?

Prevention occupies a different conceptual/practical space. It is not necessarily concerned with "defeating" death but rather developing strategies to delay it and to improve quality of life. In broad evolutionary contexts, death is a part of a species adapting to environmental changes by bringing new genetic combinations into the population through sexual reproduction and replacement of older with younger organisms. Seen this way, death is not an enemy to be vanquished through salutary consumer and physician choices.

But cure has a hidden side. The root in the Latin is "cura" meaning "care," "concern," or "trouble." So when we separate out, as modern medicine too often does, caring from curing, have we have obscured a key part of the etymologic lineage? When the Alzheimer's Association calls for "Care today; cure tomorrow," just what are they asking for—a permanent absolute cure today so we need no care tomorrow? And one might ask, where does prevention fit in this mantra?

Prevention efforts are dynamic and ongoing and can occur at any point in the process of disruption of health (primary, secondary, tertiary) in an individual or in a community. In the case of dementia, we are referring to maintaining brain and cognitive health. How can we stay mentally healthy together? Prevention also points to ecology because it requires a healthy relationship to the natural world for humans to enjoy full wellbeing (for example, forest fires and drought do not create conditions conducive to preventing illness). The Covid-19 pandemic has also served as a wakeup call about the importance of public health, the vulnerability of the elderly (particularly with dementia), and the essential workers in our society who are often unappreciated and underpaid (including caregivers in residential care). The global crisis caused by the virus perhaps foreshadows the even greater challenge of climate change and resultant weather weirding that lay ahead. At an individual level, interacting with nature has been shown to provide health benefits. At a population level, exposure to toxic and unsafe environments are deleterious for communities. Community programs and social engagement through supportive relationships are also keys to preventing illness. Discrete diagnoses and labels are not as critical for prevention as for medical practice where an allegedly precise diagnosis leads to a specific drug or biologics. Prevention is broader in scope; efforts directed at brain health will help heart health and vice versa.

Models of health need to include biological levels, psychological aspects, and social factors. The word "biopsychosocial" is often used to point be-

yond a purely biomedical model of health. But as we look to the future, an even better concept may be "ecopsychosocial," which suggests that ecology, rather than the usual molecular/pharmaceutical reductionist framework, is the way to frame the biological aspects of health. The foundation for ultimate effective prevention is evolutionary medicine, where genetic and environmental interactions are studied over time. For example, we could prevent much more brain disease from infections if we understand how bacteria, viruses, and fungi interact with human bodies and evolve over time, including developing resistance to our drugs through genetic mutations.

In our era, efforts at both cure and prevention of dementia are commonly associated with individual health. Capitalism has powerfully shaped us as discrete entities, and has set up a proposition whereby "prevention" of memory loss is a function of individual consumption habits or lifestyle choices. But other meanings are possible, especially if we make a stronger effort to break from the dominant model of individual lifestyle adjustment and regard prevention as a collective endeavor. Such a reconceptualization demands that we situate prevention not within free markets but in terms of community and public health. In order to enhance our public health efforts toward population health and prevention, we need to understand more about our near-obsession with large-scale funding efforts to find cures for brain and other diseases.

The Misunderstandings of Cure

Biomedicine claims to be seeking cures—such is the promised product of molecular genetic medicine and big data analytics. But cure of chronic age-related diseases is extraordinarily challenging, and perhaps, some would say, a quest for fool's gold. As alluded to above, are we in effect trying to cure aging when we tackle such conditions? The quackery of the anti-aging medicine field certainly promises such possibilities. And too often the goal of medical care is to delay death rather than enhance remaining quality of life. Moreover, curing often means treating early (or so the experts say), so we get not only diagnoses of disease, but pre-diseases. So now we must treat mild cognitive impairment (which represents some objective intellectual decline with no effect on function in daily life) and even subjective cognitive impairment (no problems on neurological or psychological testing or function). These labels make more people diseased by applying an arbitrary threshold to cognitive decline. But the therapeutic fanatics want to go further and treat "normal" people with risk factors and/or often unreliable and unvalidated biomarker findings.

Ultimately, the alliances among fame-motivated academic experts, profit-seeking pharmaceutical companies, and branding-oriented lay organizations exaggerate the likelihood of, and benefit from, finding such cures. Not only that, they usurp the true hope of effective public health models, of prevention through educational and community interventions. Their focus is on treating individuals to allow financial gains to flow to a few, instead of focusing on social benefits for many.

Why do doctors talk about cure more than prevention? Could it be that cure has intellectual property, possible commercialization, and professional power associated with it? The attraction of fame and fortune offered by the unholy alliance of unskeptical scientism and unbridled capitalism is strong. Prevention is more the province of individuals and communities and more often of nonprofit organizations than for-profits. Of course, some nonprofit groups are shills for commercial concerns, but generally art, music, public health departments, and many other elements of society are part of our preventive health infrastructure. Even so, these areas are relatively unfunded compared to the almost 20 percent of gross national product we spend on medicine—likely because preventive measures are more difficult to monetize than cures. Doctors, researchers, and diagnostic companies may "own" diseases, but we all own health.

In this volume, the authors help us interrogate prevention in the dementia field not only with broad strokes, but also in fine detail. Collectively, their work reminds us that prevention is a contested space which, when explored, challenges us to understand more deeply just what the object of our prevention efforts (Alzheimer's disease and dementia) are all about. It is important to foster such inquiry into our concepts of prevention in our current milieu. Again, an investigation of etymology—the powerful meanings words have to guide our actions in a given historical-cultural moment—can be a gateway to better meanings and actions for the future.

The Dominant Language of Cure

Most of the "cure" language in both the lay press and academic literature focuses on Alzheimer's rather than dementia. Here, the illusion can be created, although increasingly difficult to maintain, that a single condition can be met by the appropriate powerful single intervention. This understanding—which we have deemed a "myth" as it pertains to brain aging (Whitehouse and George 2008)—is now failing to the point of folly. Speaking of etymology, practically no one thinks "Alzheimer's" is a singular noun unrelated to aging anymore. Instead, decades of research have taught us that it/they is/are heterogeneous and clearly related to aging. Were we to

advance our definition of the concept, we would more properly refer to "Alzheimer's diseases" (plural) or "Alzheimer's syndrome"—constructs that better reflect the mixed nature of most dementias.

Some claim to want to "cure dementia," but they are either confusing the words "dementia" and "Alzheimer's" and/or being illogical. "Dementia" by definition includes a variety of (overlapping) conditions. Again, objectively, curing either Alzheimer's or dementia would require *cures* (plural). Experts claim that the clinical response to this heterogeneity in dementia will require employing a panel of diagnostic biomarkers to characterize each patient and to match the pattern of results to individualized therapeutic "cocktails" (multiple drugs and biologics). But at what cost we might ask? Tens of thousands of dollars per year per patient repeated over decades? But the opportunity costs to imagination are even greater. Prevention offers not only more bang for the buck but a social transformation that would in itself be healthier than current market-driven promised solutions. Improvements in the quality of air and water, better public transportation, full employment, more opportunities for formal education and social learning, healthier food, anti-smoking campaigns, robust social welfare (and the list goes on) would not only benefit those with dementia or at risk but people with other health conditions.

In the past few years, the on-and-off-again, non-transparent process by which we have been led on by the major pharmaceutical company Biogen about its failed, and then resurrected, studies of the drug aducanumab (an anti-amyloid antibody and alleged "disease-modifying therapy") and the company's promised, but delayed, submission to the FDA illustrate the distorting profit-oriented approaches of pharma. Ultimately, such machinations of the private market lead us to see that we would be wise to resist the dominance of current unhealthy biomedical models and instead reconfigure the economic and political power structure in society. Prevention benefits the many, and cure, the few. Touted cures that do not deliver benefit even fewer.

The Politics of Cure

"Neoliberalism" is the current label for the convergence of political, social, and economic forces that, since the 1970s, have fueled the dominance of global capitalism and the retrenchment of the state from public life. The two essential aspects of neoliberalism are promoting individual responsibility over collective caring, and enacting market fundamentalism that expands free enterprise, deregulates market economies, weakens organized labor, and defunds the social welfare state. Neoliberalism regards unfettered

free markets—rather than governments—as the most efficient means of organizing society and meeting the needs of individuals. As such, its proponents believe the state ought to pull back from social and economic affairs, reduce public spending, and let markets function autonomously, fueled by profit and competition. Such hypercapitalistic conditions precipitated the Great Recession that cratered the global economy, ushering in an era of massive inequality and austerity that has destabilized the world and left us vulnerable to ongoing economic shocks.

So, too, has neoliberalism shaped the Alzheimer's space, and, as alluded to above, the predominant emphasis on individual lifestyle to prevent dementia rather than community health efforts is a key example. Asking individuals to eat a better diet or wear a fit-bit and exercise more is fine except when such opportunities are not available in poor communities (for example, neighborhoods that are food deserts and where it is unsafe to walk, or workplaces that require hours spent sitting a day). Asking individuals to take charge of their own prevention is virtually impossible when they live in communities like Flint, Michigan, that have lost massive numbers of jobs and have endured austerity politics that have produced public health crises like lead poisoning in urban drinking water, damaging the brains of community members (mostly the poor and people of color). Attempts at "preventing Alzheimer's" can no longer ignore these critical structural factors that degrade peoples' brains, and we cannot continue allowing market-based, individualist approaches to brain health to depoliticize the clear political-economic contributions to illness across peoples' life spans (George and Whitehouse, forthcoming).

Further, deregulated or poorly regulated markets, like the ones governing supplements and nutraceuticals, may produce massive wealth for companies but present dangers to those concerned about prevention. Companies have too often seduced people into buying unproven products that essentially promise miracle cures, leveraging the credulity of desperate consumers and exploiting the lack of oversight. So, too, is the digital world full of expensive brain fitness computer games that exaggerate their claims to improve cognitive performance in life or even prevent dementia. Digital technologies, mixed augmented and virtual realities, smart homes and communities, and social networks will be part of the answer to human cognitive challenges, but we need help to evaluate what is truly helpful and what is likely harmful. People with dementia and all of us with limited memories can be assisted by digital assistant devices and perhaps even eventually robots. Safety at home can be monitored and social isolation potentially alleviated through smart technologies and network connectivity. But there is a danger that, as with expensive diagnostic and biologic therapeutics, the opportunity costs associated with wasting time, money, and

effort on false promises of technology are real and are a diversion from underlying social, economic, and ecological factors that affect people's brains.

The Success of Prevention

One of the more remarkable findings in the recent past is that the prevalence and incidence of dementia in some Western countries (the United States, the United Kingdom, Canada, France, Sweden, and Norway) has been trending down over the past decade. This is best attributed not to any drug or commodity produced in the vast "marketplace of memory products," but to population-level interventions in the mid-twentieth century, such as increasing public access to higher education and better quality food, reduced smoking rates, and perhaps even removing lead from gasoline. Today's elders, who had their formative years as recipients of massive state investments in public wellbeing in the era following World War II and the Great Depression, are now ostensibly enjoying the downstream benefits of those "exposures."

Such findings underscore the value of social democracy as a "preventative measure" for dementia. In contrast with the individualistic and laissez-faire ethos of neoliberalism, social democracy is committed to maintaining high levels of equitable wealth distribution and income equality, using progressive taxation to provide universal services as a right for all (health care, housing, child/elder care, and education, social security, etc.), creating the basic conditions for more humane outcomes for all its citizens. Where neoliberalism reigns, health and happiness seem to be declining, and social unrest is rising (for example, Brexit in the United Kingdom, Trump in the United States, the yellow vest movement in France). Those countries have also fared among the poorest in the world in the COVID-19 pandemic. Frustratingly, the Alzheimer's field—largely dominated by the United States—has prioritized free-market, technological solutions to the challenge, and has been largely inattentive to questions about how the social organization of our societies impacts risk for brain aging at the population level.

In many ways, approaches to Alzheimer's go beyond the disease itself because a consideration of what it means to conceptualize and prevent "Alzheimer's" can serve as a gateway to asking larger questions about what kind of societies we want to have. Medical labeling and overdiagnosis dominates our thinking about health in many other domains besides dementia and particularly in conversations about age-related conditions. If we look beyond our fear and fantasies and find true hope rather than false promises, the benefits of thinking about dementia differently will reap benefits

for all of us, regardless of health conditions. We need to take individual and collective brain health to a new level. It is not just about diet, exercise, and other self-directed consumption patterns. It is deeper and broader: it is about purpose and community, about shared investments in our collective wellbeing, about protecting our shared ecological home, planet Earth. In order to create flourishing communities that can adapt and sustain themselves into our challenging future, we need to have realistic and prioritized goals. Curing so-called Alzheimer's disease needs to be viewed in a clear-eyed way as unrealistic, and efforts cut back. Preventing dementia and enhancing brain health through public health is where the focus should be. Realigning these priorities will disrupt neoliberal medicine and society but lead to better wellbeing for all. Beginning with an exploration of the meaning of words and the meaning of our individual lives and collective life on the planet will ultimately lead to a better future.

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