



8 STAGING PREVENTION, ARRESTING PROGRESS

Chronic Disease Prevention and the Lifestyle Frame

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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 1970s¹ (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 outcome³ (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" lifestyles⁴ 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 Buntun 1997; Buntun, 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 carcinogen⁶ 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

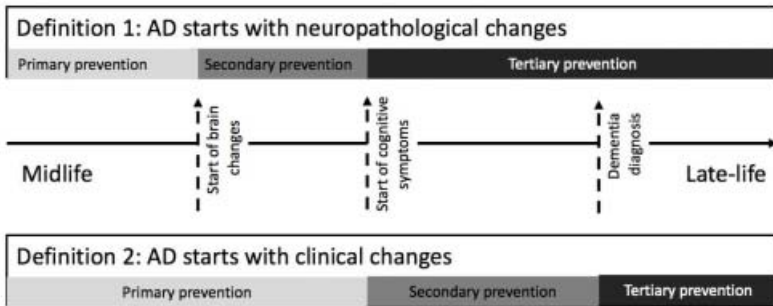


FIGURE 8.1. Prevention of Alzheimer's disease (adapted from Solomon et al. 2014).

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 as 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 response⁸—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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Kierans and Carol Kingdon (Routledge, 2016). A former editor of the journal *Critical Public Health*, she is also a coeditor of *Alcohol, Tobacco and Obesity: Morality, Mortality and the New Public Health* (Routledge, 2011).

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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