

## **4 DEMENTIA PREVENTION**

# Another Expansion of the Preventive Horizon

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#### 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). 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). 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 'victimblaming' 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." 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.<sup>5</sup> 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 vet 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:

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 socalled 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 Pasteuriza*tion 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 healthrelated 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 wellbeing (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 normal 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 dementiascreening programs based on individual biomarker testing is beautifully shown in Lock (2013: chap. 7).

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