



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 biomarkers² 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, Oyeboode, 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 Schicktzanz 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 led 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,

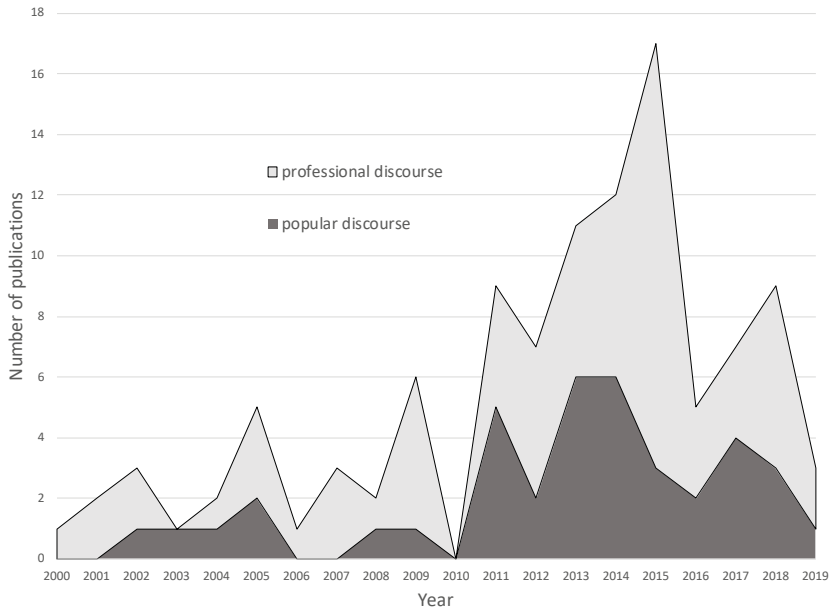


FIGURE 3.1. Results of quantitative analysis of dementia prevention discourse in German professional journals and German media for the period January 2000–January 2019.

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 responsabilization 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 neo-liberal 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 responsabilization 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 responsabilization 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.

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

Notes

1. 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 sufficiently 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 sufficiently 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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