The Experts’ Advice: Prevention and Responsibility in German Media and Scientific Discourses on Dementia

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Abstract
In the absence of effective pharmacological therapy options, the focus of dementia and Alzheimer’s research has shifted from treatment and care to risk prediction, early detection, and prevention. Public health communication and media coverage regarding dementia emphasize the individual responsibility for dementia risk management. Focusing on the social and moral implications of the new understanding and public representation of dementia, we present an analysis of medical science, nursing science, and media discourses in Germany between 2014 and 2019. We show which notions of dementia and prevention characterize the medical and nursing science debates regarding dementia and how scientific knowledge is transferred into media discourses on dementia. We further discuss how dementia risk communication interacts with contemporary social and health policies and in what ways current dementia discourses are associated with a (self-)responsibilization of cognitive aging.

Keywords
dementia; Alzheimer’s disease; prevention; active aging; responsibilization; discourse analysis; medical science; nursing science; media reports; health care; Germany

Introduction
Those who think walking is stupid should not read this text, because they are beyond help anyway. Everyone else could still change their lives before it’s too late (or before they don’t even realize anymore). Neurodegenerative diseases—i.e. dementia—are insidious epidemics of our aging society. And lack of physical activity is a definite risk factor for their development. (Dreis, 2014, p. 59)1

This remark was published in a leading German newspaper. In blaming the reader, oversimplifying scientific findings, and individualizing the responsibility for dementia risk reduction, it is emblematic of a characteristic tendency of media coverage on dementia in Germany. Over the last decade, the notions of dementia and cognitive decline in old age have changed: In light of the insight that lifestyle factors and preexisting conditions do influence the risk of developing dementia, cognitive decline and dementia are no longer perceived as a necessary part of aging or an inevitable fate. Instead, they tend to be understood as effects of individual lifestyle choices, which implies they can be delayed or possibly even prevented.2

In the context of a significant reconceptualization of Alzheimer’s disease (Schermer & Richard, 2019) and given the lack of effective curative treatment options (Mehta et al., 2017), the focus of dementia research has shifted toward very early detection, early disease stages, and prevention (Leibing, 2018). Current studies on public health communication and media coverage on cognitive aging and dementia have identified a strong emphasis on individual responsibility and lifestyle factors. People are positioned as being at risk for developing dementia and strongly encouraged to adopt a healthy way of life to prevent or delay cognitive decline (Lawless et al., 2018; see also Broer & Pickersgill, 2015; Forlini & Hall, 2017; Harris et al., 2016; Lawless & Augustinos, 2017; Mohr et al., 2021; Peel, 2014; Robillard & Feng, 2017).

Focusing on the social and moral implications of these paradigmatic shifts in the medical understanding of dementia and associated public communication, we present an analysis of medical science, nursing science,

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and media discourses on dementia in Germany. First, we provide a short overview of recent paradigmatic shifts in dementia and Alzheimer’s research as well as an outline of the current debates in social sciences regarding the interaction of current cultures of aging and dementia research. Then, we describe our sampling strategy and the discourse analytical approach we used to reconstruct the patterns of knowledge production and public communication on dementia in the fields of medical science, nursing science, and media. In the results, we show which notions of cognitive decline, dementia, and prevention shape the German scientific and media discourses, and we illustrate how framing and responsibility ascriptions differ between the different dementia discourses. We finally discuss how dementia risk communication interacts with contemporary social and health policies and in what ways current dementia discourses are associated with a (self-)responsibilization of cognitive aging.

**Background**

**From Cure to Prevention: Paradigmatic Shifts in Dementia and Alzheimer’s Research**

Despite massive research efforts, progress in the curative and effective symptomatic treatment of dementia has remained very limited in recent years (Mehta et al., 2017). In the absence of effective pharmacological therapy options, the focus has shifted from research on treatment to risk reduction and prediction. Current research and public attention are focused on primary and secondary prevention as well as detection and prediction in very early or even presymptomatic disease stages (Leibing, 2018).

In 2017, a *Lancet* report sparked a broad public discussion on dementia prevention (Livingston et al., 2017). The report showed that one out of three dementia cases could be prevented if nine risk factors were better managed. Similarly, the World Health Organization (WHO, 2019) guidelines on risk reduction of cognitive decline and dementia highlight the potentials of preventive measures and risk management. As most of the discussed risk factors, such as hypertension, obesity, hearing loss, or diabetes, are treatable or modifiable, cognitive health is more and more understood as the outcome of efficient medical risk management and individual lifestyle choices (e.g., a Mediterranean diet, physical and mental activities, and social engagement). The causal relationship between risk factors and cognitive decline is, however, not well established, and the actual effects of each preventive measure on dementia rates are continuously disputed in medical research (e.g., Kivimäki & Singh-Manoux, 2018).

The focus on prevention and risk reduction is connected to a novel understanding of AD. In recent years, a new biological conception of AD based on the underlying pathological processes has replaced the older syndromal definition of AD (Jack et al., 2018). This novel AD continuum theory assumes three stages of a slowly progressing disease. The first stage is characterized by a long asymptomatic phase without any symptomatic change; biomarker research is currently developing blood tests that can detect Alzheimer-specific protein changes at this stage, years before the first clinical symptoms appear. The disease then, in a second phase, enters a symptomatic stage involving subjectively experienced and objectively measurable mild cognitive impairment (MCI), which does not (yet) significantly affect daily activities. Eventually, in a third stage, AD develops into a clinical syndromic disease with an advanced pathology (Dubois et al., 2016; Sperling et al., 2011).

However, the clinical usefulness of disease labels such as SCI (subjective cognitive impairment) and MCI—which describe the transitional state between normal cognitive performance and dementia—as well as the social and ethical implications of predictive diagnostics are controversial (for the controversy regarding MCI, see Peters & Katz, 2015; for the ethical debates on predictive testing, see Schweda et al., 2018; Vanderschaeghe et al., 2018).

**Active Aging and Cognitive Health**

The reconceptualization of AD, the establishment of new disease labels like SCI and MCI, and the increased focus on dementia prevention coincide with a change of broader cultural images of aging and a general trend toward individual risk management. Over the past two decades, models of a well-deserved retirement and a passive and disengaged old age have been increasingly replaced by models of “productive”, “healthy”, “active”, and “successful aging” (see, for example, Pfaller & Schweda, 2019).

For German media and social-political discourses, van Dyk et al. (2013) showed how the cultural image of the *age of retirement* (dispensation from work, retreat, physical decline) has been supplemented in the late 1980s by the cultural image of *restless aging* (mobility, activity, brain plasticity) and later by the idea of *productive aging* (productivity potentials, obligation to serve the common good). In gerontological research, too, the deficit-oriented view of old age has been fundamentally questioned in recent decades; current gerontological approaches emphasize the plasticity of aging processes and highlight the activity and productivity potentials of aging persons (see, for example, Martinson & Berridge, 2015, for an overview of the gerontological debates on *successful aging* models).

Social science and critical gerontology authors repeatedly have drawn attention to the convergences and links...
between current neuroscience (dementia) research, aging cultures, and contemporary social policies (e.g., Broer & Pickersgill, 2015; Katz & Peters, 2008; Pitts-Taylor, 2010). Williams et al. (2012), for example, argued that the interaction of neuroscience research and the culture of active aging produces new notions of cognitive health and successful aging, blurs the boundaries between health and disease, and creates new medical and social perceptions of risk and responsibility. In this context, dementia is emblematic of the transition from the active, productive, healthy “third age” to the dreaded “fourth” phase of the very old, which is imagined as a period of dependency, immobility, and frailty (Higgs & Gillear, 2015; Williams et al., 2012). Whereas cognitive health and memory could be seen as master metaphors for successful aging (Katz, 2012), cognitive decline and memory loss are associated with frailness and the “potential loss of successful selfhood” (Williams et al., 2011, p. 242). Because cognitive decline is, in addition, no longer viewed as an inevitable fate but as an avoidable disease, the maintenance of cognitive performance until old age might be increasingly seen as a matter of personal responsibility and individual efforts.

Analyzing Responsibility Ascriptions in German Dementia Discourses

Because assigning responsibility to individuals cannot be understood as per se problematic (Schweda & Pfaller, 2020), the analysis of notions of responsibility in the field of dementia prevention must specify who is actually addressed in which social role and on which normative and scientific basis as responsible for what. Although an increasing emphasis on individual risk management and personal dementia prevention might be observable in many countries, the analysis and evaluation of responsibility ascriptions in the field of dementia prevention and care must further reflect the specific institutional characteristics of different countries and the respective situatedness of different dementia discourses (Leibing, 2018) and health care systems (Kümpers et al., 2005). In Germany (and many other European countries), the forms of state intervention and the logic of health and social policies affecting care have changed in the last decades. Instead of collectivizing life risks and directly ensuring social security, they focus now on individual risk management, privatizing risk provisioning and encouraging self-care (Lessénich, 2015). Professionalization, including the increased academic qualification level of nursing care, and economizing trends such as cost containment, efficiency-oriented measures, provider competition, and consumer choice also took hold in the German care sector since the introduction of long-term care insurance in the mid-1990s (Auth, 2012; Pfau-Effinger, 2012). Care of the elderly is at the same time still strongly dependent on informal care by family members (Ehrlich & Kelle, 2019; Pfau-Effinger, 2012). Despite the neo-social reconfiguration of state intervention (Lessénich, 2015), German welfare policy is still characterized by relatively high public social spending and comprehensive social security (Hinrichs, 2017). Following Leibing’s (2018) conception of “situated prevention,” we seek to take into account these sociopolitical contexts to contribute to a profound understanding of the discourses on prevention, care, and treatment of dementia and the specific notions of responsibility ascriptions in the different fields.

Ascriptions of responsibility become ethically questionable if the subjects held liable do not have the freedom of and capacity for meaningful choice among different courses of action or if there is no causal relationship between the moral subject’s action and the outcome (Schicktanz, 2016; Schweda & Pfaller, 2020). In democratic societies, justifiable responsibility ascriptions should rely on norms that can be explicated, contested, and jointly agreed on in deliberative processes. In short, taking responsibility requires individual autonomy—not merely in the negative notions of private autonomy but also in the positive conceptions of social, ethical, moral, and political autonomy (Börner et al., 2020). With regard to an ethical evaluation of responsibility ascriptions in the context of prevention, it is, furthermore, relevant whether preventive measures have been proven effective, whether they have positive risk–benefit and cost–benefit ratios, how restrictive they are, and whether they have been agreed upon and implemented using legitimate decision-making procedures (Marchkmann, 2010).

To expose and evaluate the specific foundations and characteristics of responsibility ascriptions in the field of dementia prevention, we use an adapted relational conception of responsibility first introduced by Schicktanz and Schweda (2012) that includes the following relata: Someone (subject) is—in a particular time frame and a certain temporal direction—responsible for something/someone (object) vis-à-vis someone (norm-proofing instance) on the basis of specific normative standards and understandings of causality and with specific consequences. Analyzing discourses in the fields of medical science, nursing science, and media, we seek to expose the normative and epistemic foundations as well as the moral and social implications of responsibility ascriptions in current German dementia discourses.

Research Methods

Discourse Analytical Approach

In our empirical analysis, we use a discourse analytical approach, inspired by the work of Diaz-Bone (2006).
Following Foucault (1982), discourses are understood as systems of knowledge, which structure the field of the sayable. Discourses determine what can be said and what will be concealed, what is considered true and what is considered false. The aim of discourse analysis is not only to describe discourses in terms of content and topic but to reconstruct the deeper structure of the discursive formations (see Diaz-Bone, 2006). Employing a structural perspective,7 the discourse analysis hence aims to discover the rules of formation, which make statements, claims, and calls possible (and are at the same time always implied within them).

**Sampling**

The analysis seeks to reconstruct contemporary dementia discourses in Germany in the fields of medical science, nursing science, and media. Based on our research interest, the discourses to be analyzed were characterized in terms of their manifest content, and a provisional corpus of texts was determined.

For the field of medical science, widely distributed journals were chosen (see Table 1). We included the *Deutsches Ärzteblatt* (official body of the German Medical Association and distributed to all physicians in Germany) as well as the S3-Guideline Dementia and one exemplary high-circulation journal per relevant discipline (neurology, psychiatry, geriatrics, and internal medicine). For nursing science, widely distributed, practice-oriented journals; recommendations for action; and online resources were included in the analysis. The media discourse was analyzed based on a sample of two leading weekly magazines and their online sites, two leading German daily newspapers, and the *Apotheken Umschau*, a popular science magazine which has the highest circulation of all magazines in Germany. Using a keyword search (“Alzheimer’s disease,” “dementia diagnosis,” “dementia treatment,” “dementia prevention,” and “dementia care”), relevant articles about dementia were identified. We included texts from the last 6 years (2014–2019) in our corpus. Only articles relating directly to the respective topics were selected; about 130 texts were included in the analysis.8 Following the idea of theoretical sampling, the size of the sample was not finally determined at the beginning of the analysis; instead, texts were included in the analysis incrementally until theoretical saturation (data satisfaction) was reached (Glaser & Strauss, 2009).

**Coding and Analysis**

In preparation for the analysis, heuristic questions and main thematic categories were developed that analytically frame the access to the texts and sharpen theoretical sensitivity (Diaz-Bone, 2006). In accordance with our research interest, we looked for notions of aging, cognitive health and dementia, nursing approaches, and prevention strategies. Across these topics, we examined underlying normative and scientific foundations of responsibility ascriptions and reconstructed who is addressed in what role (subject) as responsible for what (object). In a preliminary analysis, the material was reviewed for main topics and roughly thematically coded with MAXQDA. Based on these sequences, thematic subcategories were formed inductively. First, in vivo codes (short quotes) were assigned to the text passages; in

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**Table 1. Sampling Current Dementia Discourses in Germany (2014–2019).**

| Discourse        | Journal/Newspaper/Guideline (English Translations by Authors) | Abbreviation |
|------------------|---------------------------------------------------------------|--------------|
| Medical science  | *Deutsches Ärzteblatt* [The German Physicians Journal]      | DA           |
|                  | *Der Nervenarzt* [The Neurologist]                           | NA           |
|                  | *Der Neurologe und Psychiater* [The Neurologist and Psychiatrist] | NP           |
|                  | *Der Internist* [The Internist]                               | INT          |
|                  | S3-Guideline Dementia                                        | S3           |
|                  | Zeitschrift für Gerontologie und Geriatrie [The Journal for Gerontology and Geriatrics] | GG           |
| Nursing science  | Heilberufe—das Pflegemagazin [Healing Professions—The Journal for Care] | HB           |
|                  | Pflegezeitschrift [The Care Journal]                         | PZ           |
|                  | Die Schwester/Der Pfleger [The Nurse]                        | SP           |
|                  | Zentrum für Qualität in der Pflege [Center for Quality in Care] | ZQP          |
|                  | MDS-Grundsatzstellungnahme [MDS Policy Comment on Dementia Care] | MDS          |
| Media            | Frankfurter Allgemeine Zeitung [Frankfurt General Newspaper], daily newspaper | FAZ          |
|                  | Süddeutsche Zeitung [South German Newspaper], daily newspaper | SZ           |
|                  | Der Spiegel, weekly magazine and online news                  | DS           |
|                  | Focus, weekly magazine and online news                        | FO           |
|                  | Apotheken Umschau [Pharmacy News], popular science magazine   | AU           |

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7The *Zeitschrift für Gerontologie und Geriatrie* [The Journal for Gerontology and Geriatrics] includes both medical and nursing science articles; articles were assigned according to their disciplinary orientation.
a second step, more abstract categories were developed and similar rationalities were combined into patterns. In the subsequent interpretative analysis, regularities, references, and coherent connections as well as oppositions and contradictions between categories and arguments were sought to reconstruct the structural logic of the different discourses (see Diaz-Bone, 2006). This way, it was possible to analyze which patterns are interlinked, that is, different notions of aging, concepts of illness and dementia, responsibility ascriptions, and prevention recommendations. Analyzing medical, nursing, and public dementia discourses separately, the analysis also aimed to make clear how expertise and knowledge are transferred between the different fields and to identify the intersections and special features of these special discourses.

**Results**

In this section, we present our main findings regarding each discourse, starting with medical science, followed by nursing science and media. In each subsection, we reconstruct how research on dementia is portrayed and describe what rationalities are implied in guidelines and dementia risk communication. Finally, we compare framing and responsibility ascriptions between the three examined discourses.

**From Treatment to Risk Reduction: New Conceptions of Dementia in Medical Science**

In medical science, dementia is no longer seen only as a disease of old age. As noted in the “Introduction” section, the focus has shifted to the early, long, symptom-free phase, to the treatment of risk factors, to health promotion, and to individual behavioral prevention. Understanding and diagnosing AD no longer focus on the clinical signs of cognitive decline but rather on neuropsychological changes in the brain. Whereas pathological change was once only a “post-mortem criterion,” it now also applies to “living patients” (DA 3). This paradigm shift is as such explicitly addressed in the examined journals. It is referred to as a fundamentally “new conception” of AD (DA 7) or as a “dramatic shift” in Alzheimer’s research (DA 3).

With this new focal point on the early phase of the disease, predictive and early diagnosis of dementia is becoming increasingly important (e.g., DA 15; DNP 4; NA 7). So far, predictive, biomarker-based dementia diagnosis in symptom-free patients has been discouraged due to a lack of effective treatment options (DA 7, 15; DNP 4; NA 7). However, an early differential diagnosis at the first signs of cognitive changes is now emphasized in the German medical discourse as critical for appropriate care and treatment (DA 2, 6; DNP 7; NA 6). This rationale for the importance of early differential diagnosis is based on two approaches to possible interventions: the elimination of reversible causes of dementia and the hope of delaying the course of the disease through individual lifestyle changes (DA 2, 7). The possibility of earlier diagnoses, it is also hoped, will support the development of pharmacological therapies for the phase of the neuropsychological disease development prior to the first appearance of clinical symptoms (DA 9; NA 3, 7).

The uncertainties and ethical challenges of current (early) dementia diagnosis and the limits of current treatment options are regularly debated in the medical discourse (DA 7, 15; DNP 4). The limited number of available therapeutic options is used to emphasize the relevance of primary prevention and treatment of risk factors (DA 12, 14; DNP 4; GG 3; INT 2; NA 4). The urgency of dementia prevention is rhetorically further framed by references to various other topics: the increasing number of illnesses as a result of demographic change (GG 3; INT 3; NA 2, 8), the burden on the health care system and economic follow-up costs (GG 3; INT 1, 2; NA 1, 4), and, less dominantly, the dementia-associated strains on patients and their relatives (INT 1; NA 1).

Medical intervention guidelines for clinical practice primarily recommend early (pharmaceutical) treatment of diabetes, hypertension, and obesity but also depression and hearing loss (DA 8, 10; INT 4; NA 1, 4). In addition to medical risk management, both environmental factors such as good education and individual lifestyle modifications such as healthy diet and cognitive, physical, and social activities are stressed (DA 8; DNP 5, 8; GG 3; NA 2, 4). The importance of preventive behavioral interventions which promote healthy aging is highlighted (GG 3). Primary prevention should start in young adulthood. The aim is to decelerate neurodegenerative processes as early as possible “before the actual relevance to everyday life” and to identify and implement “salutogenic resources” sustainably in one’s lifestyle (NA 8). Multimodal prevention approaches are preferred, and the weak evidence for individual measures is discussed (e.g., DNP 2; NA 8).

With the focus on individual lifestyle factors and primary prevention, personal responsibility is stressed increasingly. In particular, contributions focusing on concepts of “successful aging” (GG 3; NA 8) tend to understand patients as directly responsible for a healthy, proactive lifestyle and the prevention of health risks: “A high degree of personal responsibility is required in primary prevention, which ultimately each person must take for himself or herself” (NA 8). Appropriate lifestyle measures should slow down cognitive decline, prevent severe stages of dementia, and maintain “independence until death” (GG 3). Consequently, patients are not seen as passive objects but as “managers and shapers of their risk,” who can “actively and preventively do something” against dementia (NA 8).
This paradigmatic shift in dementia research corresponds with a change of the professional self-image in geriatrics and neurology from symptomatic or curative dementia therapy to primary and secondary prevention as well as health promotion. The professional reorientation also requires a change in understanding of the role of physicians. Physicians are no longer merely responsible for treating manifest diseases and passing on the treatment plan to the passive patient. Instead—against the background of the new understanding of dementia—risk management and support of lifestyle changes in the middle-age years are debated as additional responsibilities of medical professionals. Physicians should represent the role of advisors for “successful aging” for an informed, actively interested, and self-responsible patient (NA 8).

The changes in the medical understanding of dementia and the role of physicians also alter the conception of what it means to be a patient. It is no longer only those who turn to physicians with memory problems who are seen as patients. Rather, people are addressed as “persons at risk” or even “patients” long before symptoms like memory loss appear. As a result of the shift, also the line between cognitive health and disease is becoming increasingly blurred. Above all, patients are not (only) seen as passive symptom carriers but (also) positioned as persons at risk in middle age, who can—and should—reduce their dementia risk by pursuing an active and healthy lifestyle.

**Dignity, Autonomy, and Activation: Dementia Care in Nursing Science**

The nursing science discourse is characterized by a strong focus on the burdens associated with dementia for relatives, caregivers, affected persons, and society (e.g., MDS; PZ 4; SP 1). It is, for example, argued that in times of “mass aging,” the growing number of people with cognitive disabilities and impaired everyday skills will challenge the health care system (PZ 4). Not only the cognitive limitations in the stricter sense are seen as potential burdens for both professional caregivers and caring relatives. Also, and more specifically, the psychological and behavioral symptoms such as physical aggression, anxiety, or irritability, and personality changes are highlighted (MDS; PZ 4; SP 1, 6).

In the German nursing science, two separate discourses can be discerned that revolve around the need to develop innovative nursing approaches and to embed prevention and rehabilitation more firmly in the practice of nursing care. The first underlying rationale is that, in light of demographic change and the expected increase in dementia rates, the burden on the health care system and society should be reduced. For example, recommendations for action are contextualized with reference to cost studies, which point to the enormous economic burdens caused by dementia (MDS; PZ 4). Second, individual quality of life with dementia represents a central reference point of debate in nursing science. One quality-of-life discourse is oriented around the guiding principles of self-determination and self-reliance (MDS; PZ 1, 5; ZQS 1), another is characterized by references to human dignity, personal needs, and relationships (MDS; SP 4, 8).

Good dementia care in this sense means, as stated in The Nurse [Die Schwester/Der Pfleger], perceiving the person in need of care in their unique personality and strengthening their self-esteem and emotional well-being (SP 4). Nursing approaches such as “person-centered care” therefore aim at relationship building and successful communication between caregivers and patients and are oriented toward the needs and feelings of the persons in need of care (MDS; SP 1, 4). The reference to the value of human dignity thus primarily justifies nursing concepts that emphasize relationships, communication, closeness, and safety. In this context, nursing care approaches do not primarily aim to restore (cognitive) abilities or prevent further decline but are oriented toward the immediate well-being of the persons in need of care.

On the contrary—and oriented toward the ideal of personal autonomy—there are also nursing approaches which first of all intend to strengthen the daily living skills and personal responsibility of those in need of care. In this context, the entitlement of people with dementia to the greatest possible degree of self-determination is stressed; patronizing practices in care are problematized. Activating care aims at maintaining or improving “mobility and independence in everyday life,” which are considered important indicators of quality of life and subjective well-being (PZ 1). It is emphasized that even severely impaired patients have potentials for health promotion and the preservation of health resources. Specifically, care services should preserve the “functional performance of patients” (PZ 5), strengthen the “active participation” of people in need care (HB 2), or promote the “motivation and competence to carry out measures on their own terms” (HB 2). In this framework, a range of specific nursing interventions such as dancing, coordination exercises, and cognitive stimulation for the purpose of maintaining cognitive performance are recommended (GG 1; HB 1, 3; MDS; PZ 2, 5; ZQP 2, 3), despite low-quality evidence (GG 2, 5). “Permanent advancement” and specifically the combination of cognitive and physical training are expected to effectively delay mental deterioration and maintain or even restore everyday skills (HB 3). Conversely, a deterioration of cognitive abilities is associated with inactivity and the lack of “movement and environmental stimuli” (PZ 2). Nurses should not do anything for persons with dementia that they can still do themselves. For nurses, this means that they must shift
from an attitude of care toward an attitude of encouragement and support (PZ 2).

In this context, nurses are seemingly considered to be directly responsible for maintaining the cognitive health of persons in need of care. In some articles, the possible benefits of successful, activating care are seen to be substantial: “So one thing is clear: how good our mental performance is depends on how much we perform” (PZ 2). Assuming a straightforward causal relationship between cognitive activity and cognitive health, it seems to be a question of good care whether the patient’s abilities deteriorate or recover.

Risk, Prevention, and Responsibility: Dementia in the Media

While the importance of environmental protective factors and the unclear evidence for the success of individual measures of prevention are still regularly discussed in professional discourses, the media discourse is characterized by a stronger and partly exclusive focus on individual behavioral prevention.

One can reconstruct the following storylines that typically frame media coverage on dementia in Germany. First, media coverage on dementia is usually contextualized with references to demographic change and a prognosis of future dementia rates (e.g., AU 7; DS 1, 9; FAZ 4, 9; SZ 6). The estimations about rising case numbers and the prospect of rising costs are used to call attention to the issue. Second, the suffering associated with dementia and its psychological and behavioral symptoms are portrayed. As in the nursing science discourse, the burden for caregivers is also occasionally highlighted. Headlines like “Forgetful, Aggressive, Confused: Experts Warn About the ‘Dementia Republic of Germany’” (FO 5) convey degrading images of dementia and paint an alarming picture of the increase of cases in an aging population. However, other articles use more sophisticated and careful formulations; some voices also argue that dementia “doesn’t have to be a big deal” as most courses of the disease are mild (SZ 2). Third, the possibility of dementia risk reduction and the findings regarding the impact of individual lifestyle choices are presented as a glimmer of hope against the background of a lack of treatment options and the failure of recent drug trials (SZ 6; DS 2, 8; FO 9; FAZ 1, 5).

Thus, the reference to demographic change and limited treatment options is generally used to emphasize the relevance of risk reduction and dementia prevention. However, the actual presentation of scientific research and the understanding of individual responsibility differ greatly within the media discourse on dementia. On one hand, we found articles in the science sections of newspapers and weekly magazines, which closely reflect current medical debates and knowledge. In these articles, recent paradigmatic shifts in dementia and Alzheimer’s research are portrayed, the importance of cardiovascular risk factors is highlighted, and multimodal preventive strategies are discussed (SZ 3; DS 9; FAZ 1, 3; AU 5). Headlines like “What Is Good for the Heart Is Also Good for the Brain” (SZ 7) reflect the current medical focus on cardiovascular risk factors. In addition, the lack of evidence for single preventive efforts is portrayed (DS 7, 9; FAZ 5, 6), and the relevance of environmental factors like the influence of education on dementia risk is mentioned (DS 3, 9; FAZ 5; SZ 3). Above all, in light of limited treatment options and with reference to WHO recommendations or the Lancet Report, it is stressed that there are many risk factors and that risk reduction and prevention in middle age as well as early detection are crucial (DS 9; FAZ 5, 10; SZ 3).

On the contrary, we found articles in newspapers, weekly magazines, and popular science magazines that strongly focus on individual lifestyle measures. In this context, the readers are often addressed as being directly responsible for successful dementia prevention. Typical headlines such as “How to Reduce Your Risk of Alzheimer’s” (DS 2) or “Preventing Dementia: How to Strengthen the Self-Healing Powers of the Brain” (FO 4) convey the idea that successful dementia prevention is mostly a question of sufficient individual efforts and correct lifestyle choices. Insights from epidemiological and lifestyle studies are used as a basis for responsibilization of the individual, for example, for the moral call to lead an active and healthy life. The advice and the medical studies cited focus on a wide range of very specific measures like dancing (DS 5), playing video games like “Super Mario” (FO 3), or eating nuts and avocados (FO 7). Headlines like “Study Shows How Many Cups of Coffee You Have to Drink to Protect Yourself From Dementia” (FO 8) or “Food Against Dementia: 20 Foods That Help and 9 That Hurt” (FO 7) create the impression of conclusive and clearly measurable causal relationship between individual living habits and dementia. In addition to articles that focus on the impact of single interventions, readers are also provided with comprehensive lists of dementia prevention measures as “Seven Components that Protect Your Brain From Dementia” (FO 1, also FO 10, 11; AU 3, 4). In this context, uncertainties regarding the evidence for the effectiveness of individual prevention measures are not commonly mentioned.

It is further noticeable that readers are addressed directly as a potential risk group and asked to take dementia prevention into their own hands. Headlines like “How We Should Live to Protect Ourselves From Dementia” (FO 9) convey the moral responsibility to live health consciously to reduce the risk of dementia (also AU 4). Dementia prevention and an active, healthy lifestyle tend to be discussed as an individual duty. Young people are
prompted to prevent future cognitive decline (e.g., SZ 1), and older people are encouraged to face the cognitive decline with an active lifestyle. “The elderly can stay mentally fit even if they already have initial memory gaps. A healthy lifestyle is crucial for preventing dementia” (DS 10). A media report on activation measures offered in nursing homes exemplifies the strong focus on self-responsibility and self-help, concluding with the paradigmatic sentences: “The residents strain their brains, move around and meet like-minded people while playing. Instead of waiting for medication, they themselves take care of their brain health” (DS 9). In addition, readers are occasionally called to contribute, wherever possible, to the well-being of the community, as illustrated by the following example: “Whoever takes on a social volunteer service or a voluntary position links the strain on the brain with a meaningful and thus fulfilling activity—a strong mental protection” (FO 6).

Above all, the media discourse on dementia is focused on individual risk management. The burden the disease places on society and the lack of treatment options are used to emphasize the importance of dementia prevention through individual lifestyle changes.

Comparing the Framing of Dementia Prevention Between Medical Science, Nursing Science, and Media Discourses

Framing and responsibility ascriptions differ between the three examined discourses. Medical science debates are framed by the changing neuroscientific understanding of AD and the novel focus on the presymptomatic disease stage in middle age. The nursing science discourse is characterized by a strong emphasis on the burdens for caregivers and the health care system (see the similar results in the analysis for the German nursing science discourse in Panke-Kochinke et al., 2015). In German media, dementia is predominantly framed by demographic change and alarming future visions of dementia rates.

Recommendations about dementia risk reduction are no longer directed to older people exclusively but also address persons in middle age at risk for developing dementia. In the medical science discourse, both physicians and patients are addressed as being responsible for dementia prevention, albeit in (naturally) different ways. Physicians are seen as responsible not only for the correct diagnosis and treatment of advanced dementia but also for considering risk factors in middle age. The consequent implication is that patients and persons at risk are seen as responsible for behavioral prevention and dementia risk reduction. In the media, the main focus is on lifestyle changes and individual risk management (as also observed by Peel, 2014, for U.K. newspapers). Readers are—as also shown by Lawless et al. (2018) for English online dementia health information and Mohr et al. (2021) for online women’s brain health campaigns—positioned as being at risk and are directly addressed and called on to adopt a healthy and active lifestyle to strengthen their cognitive abilities and to reduce the future risk of dementia. Frequently used normative phrasings imply a moral obligation to engage in dementia prevention (see also Lawless et al., 2018). Nursing science focuses on well-being and rehabilitation of persons with advanced dementia. Professional caregivers are called on to restore or maintain the cognitive abilities of persons in need of care using specific mental and physical interventions. Some nursing science articles portray nurses as directly responsible for maintaining the cognitive health of persons in need of care.

While limited evidence of the actual success of prevention measures is regularly addressed in medical and nursing discourses, media coverage tends to highlight single studies and to overestimate the effectiveness of behavioral dementia prevention. Here, most clearly, dementia tends to be portrayed as a direct outcome of individual lifestyle choices; the preservation of cognitive abilities through old age implicitly seems to be a matter of personal responsibility. Table 2 summarizes these findings by using the different dimensions of responsibility to highlight the similarities and differences between the examined discourses.

Discussion

Contemporary discourses on successful aging and the trend toward behavioral prevention have been problematized as part of a general (self-)responsibilization of aging. Specifically, the focus on individual lifestyle choices has been criticized for masking the relevance of economic and social prerequisites for successful aging. The critique can be differentiated—as suggested by Schweda and Pfaller (2020)—along the following key points: overextension of effectiveness of preventive measures, privatization of life risks and individualization as in reducing complex social and medical issues to individual behaviors and lifestyle choices, ideologization (as in justifying welfare cuts by glorifying self-care), and stigmatization of old age frailty.

Overextension and Oversimplification

Our analysis of nursing science, medical science, and media discourses on dementia in Germany identifies some of these critical aspects in the different fields. Tendencies of overextension and specifically oversimplification and inadmissible generalization can be found partly in nursing science and more distinctly in media discourses. The fact that numerous findings on the influence
of individual prevention measures are contradictory or controversial and that results of single studies in many cases cannot be confirmed (see, for example, Kivimäki & Singh-Manoux, 2018) is often neglected within the examined discourses. Instead, a direct and strong causal relationship is often suggested between certain lifestyle choices or preventive measures and cognitive performance and personal dementia risk. The importance of cognitive training is, for instance, highlighted regularly, despite comparatively weak or even insufficient evidence (Butler et al., 2018). If the evidence of certain measures is partly missing or critically discussed, the underlying moral assumption seems to be that recommending a healthier lifestyle is nothing that harms—even if it would be ineffective for dementia prevention. Yet, oversimplification and misinterpretation of scientific findings on dementia prevention can create excessive responsibility demands and false expectations, and could, as Anstey and Peters (2018) argued, foster pessimism toward dementia prevention research.

**Individualization and Privatization**

In addition, the strong and partly exclusive focus on individual preventive measures might support an *individualization and privatization* of life risks. In German media, aging readers are called on to model their lifestyle along the normative guiding principles of “active aging” and to shape their lives in a healthy and socially responsible manner. The political, economic, and social prerequisites for active aging and dementia prevention tend to be neglected (see also Forlini & Hall, 2017). The comparatively large protective influence of education (Livingston et al., 2017) is discussed only occasionally in the examined discourses. This focus on individual lifestyle choices and the call for optimizing individually one’s health and to preserve it until old age reflect the logic of an increasing privatization of life risks. The management of life risks, which had been a task of direct political intervention in the “Keynesian welfare state,” is transferred to individual citizens (Börner et al., 2020; Rosa et al., 2017). In nursing science, too, successful prevention and rehabilitation seem to be understood foremost as a question of good nursing by individuals; external factors and structural preconditions as, for example, the substantial influence of the economic rationalization and rationing of health care on the quality of dementia care (Armstrong et al., 2016; Newerla, 2014) are rarely considered.

**Ideologization**

Against the background of the individual suffering and societal burden associated with dementia, individual risk reduction and behavioral prevention are discussed further.

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**Table 2. Framing and Responsibility Ascriptions in German Dementia Discourses.**

| Framing and Responsibility Ascriptions | Medical Science | Nursing Science | Media |
|----------------------------------------|----------------|----------------|-------|
| Framing | Biological definition of Alzheimer’s disease; focus on early disease stages and dementia risk reduction | Demographic change; dementia as a burden for caregivers and society | Demographic change and increasing dementia rates |
| Responsibility ascriptions | | | |
| Subject (Who is addressed as responsible?) | Physicians and persons at risk (as early as middle age) | Professional caregivers | Patients, persons at risk in middle age, and family members |
| Object (What is the object of responsibility?) | Cognitive health of patients and persons at risk | Well-being and cognitive abilities of persons in need of care | Personal cognitive health |
| Time frame and temporal direction (retrospective vs. prospective) | Risk management in middle age to reduce future dementia risk; treatment of present symptoms | Care and rehabilitation of (old age) persons living with dementia | Risk management in middle age to reduce future dementia risk |
| Epistemic foundations and understanding of causality (What is the causal relation between action and outcome?) | Discussion of evidence for effectiveness of dementia risk reduction; focus on multimodal preventive strategies | Reference to medical and nursing science studies; recommendations often based on weak evidence | Reference to scientific studies; strong assumptions about causal relationships between single lifestyle factors and dementia risk |
| Normative foundations (normative standards such as moral principles or legal norms) | Professional responsibility guided by the norms of beneficence and nonmaleficence | Professional responsibility to respect dignity and support autonomy of persons in need of care | Self-responsibility based on the duty to avoid harm for oneself and the society |
not only as an individual opportunity but implicitly also as a duty. Prevention strategies and an active lifestyle not only aim to improve individual health and extend autonomy in old age. They seemingly also—and this could be discussed as ideological embeddedness in the sociopolitical regime of the activating welfare state (Lessenich, 2015)—aim to relieve the (financial) burden on society. Aging people are addressed in their personal responsibility for preventing illness and proactively preserving their physical and mental abilities to sustain their living standards independently, to avoid need for help, and to contribute to the public good (van Dyk et al., 2013). In context of this framing, cognitive decline in old age and forgetting might even appear, as Williams et al. (2011) have argued, as a sign of personal failure. Those who remain healthy and cognitively fit demonstrate the willingness and ability to take care of themselves in a socially responsible manner. Conversely, cognitive decline threatens those capabilities necessary to age as an active citizen and tends to be associated in parts of German media with lacking preventive efforts. However, whereas the productivity-oriented active aging discourse is clearly linked to the idea of actively contributing to the common good even in old age (van Dyk et al., 2013), German dementia prevention discourses are still more centered on the personal well-being and the individual quality of life in old age.

**Stigmatization**

The (self-)responsibilization of cognitive aging and the fact that cognitive decline no longer appears as an inevitable fate but rather as a preventable disease could further lead to an increased stigmatization of both risky lifestyles and dementia itself. Our discourse analysis shows that the moral obligation to take individual responsibility for dementia prevention is more or less implicitly implied in German dementia discourses. If healthy aging and dementia prevention appear a question of individual efforts, there is a danger of associating dementia with a negligent lifestyle and blaming the individual for cognitive decline. The responsibility for cognitive health and the blame for cognitive decline in old age might be shifted onto those who do not follow health and prevention recommendations and thus fail or refuse to live their lives in a healthy, active, and socially acceptable manner (Forlini & Hall, 2017). In interaction with degrading and objectifying images of dementia (Harvey & Brookes, 2019; Low & Purwaningrum, 2020), the strong emphasis on individual responsibility might support “victim-blaming of those living with dementia and result in increased stigmatization” (Lawless et al., 2018, p. 1548; see also Harris et al., 2016; Mohr et al., 2021; Peel, 2014). The responsibilization of cognitive aging could hence contribute to new forms of ageisms which replace the earlier general angst of aging with a specific fear of frailty, inability, and loss of cognitive abilities (Holstein & Minkler, 2003), and reinforce a devaluation of those who, due to physical and cognitive decline, can no longer comply with the ideal of self-reliant, successful aging.

**Conclusion**

Our analysis of current German dementia discourses showed not only that the understanding of dementia and AD has changed in recent years. In addition, medical measures and media coverage of dementia have expanded their focus to younger people who do not or do not yet have any cognitive impairments. With new focus on risk reduction and the possibility of using biomarker-based diagnostics to detect pathological changes in the brain even before first symptoms of cognitive impairment become apparent, people in middle age who feel healthy may suddenly be classified as persons at risk—or even as presymptomatic Alzheimer’s patients if they show some pathological biomarkers (see Leibing, 2018).

In the discourses examined, prevention strategies focus on individual lifestyle choices in middle age. Protective factors active at the societal level, such as education and the influence of the health care system, are addressed only occasionally. Successful dementia prevention as well as successful aging are first and foremost conceived as a question of sufficient personal activity. In all examined discourses, the importance of physical, cognitive, and/or social activities for cognitively healthy aging is emphasized. Effective dementia prevention and healthy aging are linked to the successful mobilization of activity potentials, whereas progressive cognitive decline and the loss of everyday skills are associated with passivity and lack of exercise. In line with the privatization of life risks and a general (self-)responsibilization of aging, the preservation of cognitive health tends to be discussed foremost as a question of individual lifestyle choices and personal responsibility.

Further research is required to understand and reflect on the practical implications of the rapid innovations in medical science regarding dementia diagnosis, prognosis and risk reduction, and the associated public communication in different institutional contexts. Although the results of our study can be situated within international studies on dementia risk communication (e.g., Lawless et al., 2018; Mohr et al., 2021; Peel, 2014; Robillard & Feng, 2017), an in-depth comparison of dementia discourses would require a comparative analysis of cultures or national institutional contexts. Another important future line of research would be to analyze more in detail the underlying body concepts. Leibing (2018) argues that
the lifestyle turn in dementia research has changed the focus from the brain to the heart, or at least from the brain to brain–heart interactions. Others might see the current focus on biological and genetics issues as a form of (bio-) mechanization of the aging body. This line of thinking often conflicts with phenomenological and social views of the body (Schicktanz, 2007).

As our analysis is limited to the discursive level of social reality, we could only describe normative models of healthy cognitive aging as well as scientific and public conceptions of dementia risk management and prevention. The presented discourse analytical examination of medical knowledge and public perceptions of dementia gives insight into contemporary scientific knowledge and political rationalities but does not provide an understanding of what the people who are subjected to these regimes actually think and do (Börner et al., 2020; Bröckling, 2016). The sociological discussion and ethical evaluation of responsibility ascriptions in the field of dementia prevention therefore cannot solely rely on the reconstruction of the normative and scientific foundations of dementia discourses. Further empirical studies are required to provide an understanding of how physicians, nurses, persons-at-risk, and patients perceive dementia risk communication and adopt those responsibility ascriptions in everyday life.

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Notes
1. Original quotes translated by the authors.
2. Dementia is a general term to describe clinical syndromes characterized by the deterioration of cognitive functions (thinking, remembering, orientation, reasoning) and behavioral abilities severe enough to interfere with everyday activities. Dementia includes subtypes as frontotemporal dementia, Parkinson, Lewis body, cardiovascular dementia, and Alzheimer’s disease (AD). AD is the most common underlying pathology of dementia, characterized by pathological accumulation of certain proteins (amyloid and tau) and neurodegeneration in the brain. In current research contexts, there is an observable shift from an understanding of AD as a syndromal, clinical entity to a continuum based on biopathological mechanisms that include also presymptomatic and preclinical stages (Jack et al., 2018). However, in various debates, the terms are used interchangeably, especially in the public and in media discourses in Germany. Aiming to explore the social and moral implications of the changing understanding of AD, we use the term dementia as an umbrella term for the different types of dementia syndromes and pathologies, including AD. When we use the term cognitive decline, we refer not only to manifest dementia but also to mild cognitive impairment and age-related memory loss.
3. Discourses are understood as ordered systems of statements, which structure the field of the sayable and shape the thinking, speaking, and acting of people (Diaz-Bone, 2006; see also our research methods section). Conceptualizing nursing and medical knowledge and public communication on dementia as three different special discourses, we aim to expose the specific logics of knowledge production in these different fields and compare the respective patterns of communication on prevention, care, and treatment of dementia.
4. The term (self-)responsibilization describes the transfer of responsibilities from the state to individuals (Peeters, 2019).
5. Following newer evidence, the Lancet Commission on dementia prevention, intervention, and care added three more risk factors for dementia in 2020, arguing that the 12 modifiable risk factors account for around 40% of worldwide dementias (Livingston et al., 2020).
6. The subject refers to the agent who is considered responsible. Moral objects can include not only persons but also animals or plants, and abstract concepts such as peace or health. The instance is the norm-proofing authority that decides whether a responsibility has been met or not (e.g., courts, social peer groups, individual conscience, or God). Standards refer to the moral principles or legal norms, which underlie responsibility ascriptions (e.g., saving life, curing diseases, respecting others). Causality describes the assumed causal relationship between a moral agent’s action and an event (such as evidence for the effectiveness of certain actions or measures or risk–benefit and
cost–benefit ratios). The time frame refers to a period in which the moral subject is addressed as being responsible. The temporal direction indicates whether responsibility is understood retrospectively as with guilt in jurisprudence or prospectively in the sense of being responsible for future events or developments. Consequences include actions or judgments that are supposed to take place if a subject has or has not acted in a responsible way (Schicktanz & Schweda, 2012).

7. Diaz-Bone’s poststructural, Foucauldian-inspired discourse analysis aims at the reconstruction of basic discourse structures and is based on the initial assumption of a coherent discursive practice that can be reconstructed from a corpus. In this context, poststructuralism is not conceived as a means for overcoming of structuralism but as a theoretical development from structuralism, as an extension of the basic positions of structuralism (see Diaz-Bone, 2006).

8. The full list of all included articles and guidelines can be found in the supplementary material.

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