

NIKLAS PETERSEN, M.A.

„Preserving Cognitive Functions!“ Prevention and Care in German Public and Professional Discourses on Dementia

CREGÉS Conference
April 28, 2022

Research Project

›Practices of (De-)Activation.
Prevention, Care and Treatment
of Cognitive Decline in Old Age

2019 – 2023

Supervision: Prof. Dr. Silke Schicktanz

Department of Medical Ethics
and History of Medicine,
University Medical Center Göttingen,
Germany

The project examines discourses and practices of dementia prevention and care in German nursing homes in context of

- activating social and health policy,
- the medicalization of aging, and
- the economization of health care.

The analysis also seeks to understand

- how professional caregivers interpret knowledge about dementia,
- and how they cope with the guiding principles of dementia prevention, treatment and care in daily routine.

Overview

- I. Background
- II. Methodological Approach
- III. Results
- IV. Discussion

Overview

I. Background

II. Methodological Approach

III. Results

IV. Discussion

“New Dementia”

- Very limited progress in the curative treatment of dementia despite massive research efforts
- New biological definition of Alzheimer's disease (Jack et al. 2018)
- Increasing focus on dementia prevention as well as early detection and prediction (Leibing 2018)

“New Dementia”

- Very limited progress in the curative treatment of dementia despite massive research efforts
- New biological definition of Alzheimer's disease (Jack et al. 2018)
- Increasing focus on dementia prevention as well as early detection and prediction (Leibing 2018)

Dementia Prevention

- 40% dementia cases could be prevented if 12 risk factors were better managed (Livingstone et al. 2020)
- Health programs and campaigns encourage older adults to engage in mental, physical and social activities to prevent cognitive decline (Forlini et al. 2017).

Successful Aging and Prevention

- Geriatric activity theories emphasize the plasticity of aging processes and highlight the activity and productivity potentials of aging persons (Martinson & Berridge, 2015).
- Prevention and activating care as new objectives of German care policy (German Prevention Act, 2015)

Successful Aging and Prevention

- Geriatric activity theories emphasize the plasticity of aging processes and highlight the activity and productivity potentials of aging persons (Martinson & Berridge, 2015)
- Prevention and activating care as new objectives of German care policy (German Prevention Act, 2015)

Economization of Care in Germany

- 1990s: Reform of nursing care insurance:
 - efficiency enhancement
 - cost containment
 - competitive measures
- Despite a professionalization of care work, ongoing staff reduction and deteriorating working conditions:
 - atypical employment
 - falling wages
 - rationing and rationalization of nursing care (Auth 2013)

Overview

I. Background

II. Methodological Approach

III. Results

IV. Discussion

Methodological Approach

The project combines a

- examination scientific and public knowledge about dementia,
- a political-economic analysis of contemporary health care, and
- a practice-theoretical reconstruction of orientations and practices of professional caregivers in German nursing homes.

1. Discourse Analysis

Examination of German dementia discourses based on an analysis of

- medical science journals,
- nursing science journals, and
- newspapers and patient magazines

Deutsches
Arzteblatt

Der Nervenarzt

PFLEGE
ZEITSCHRIFT 12 | 2018

DIE SCHWESTER
DER PFLEGER

Süddeutsche Zeitung

DER SPIEGEL

Frankfurter Allgemeine
ZEITUNG FÜR DEUTSCHLAND

APOTHEKERN
Umschau

2. Problem-Centered Interviews

examination of orientations and everyday practices in six German nursing homes.

Overview

- I. Background
- II. Methodological Approach
- III. Results**
- IV. Discussion

I. Medical Science

“Dramatic shift” in Alzheimer’s research:

- Focus on early disease stage and prevention is framed by references to the lack of treatment options, the demographic change and rising dementia rates, and the burden for the health care system.
- Change of the professional self-image in geriatrics and neurology: Physicians as advisors for successful aging
- Patients as persons at-risk, long before symptoms appear

The aim is to decelerate neurodegenerative processes as early as possible “before the actual relevance to everyday life” and to implement “salutogenetic resources” in one’s lifestyle and maintain “independence until death” (GG 3).

“A high degree of personal responsibility is required in primary prevention, which ultimately each person must take for himself or herself.”

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).

II. Nursing Science

- Strong focus on the burdens associated with dementia
- Three separate rationales for prevention and innovative nursing approach in dementia care:
 - *Economic discourse*: reducing the burden on the health care system
 - *Quality of live discourse I*: strengthen patients' self-responsibility and daily living skills
 - *Quality of live discourse II*: focus on human dignity, personal needs, and relationships

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)

Care 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).

“So one thing is clear: how good our mental performance is depends on how much we perform” (PZ 2).

II. Nursing Science

- Strong focus on the burdens associated with dementia
- Three separate rationales for prevention and innovative nursing approach in dementia care:
 - *Economic discourse*: reducing the burden on the health care system
 - *Quality of live discourse I*: strengthen patients' self-responsibility and daily living skills
 - *Quality of live discourse II*: focus on human dignity, personal needs, and relationships

“I question how far you can really stop dementia. It is so often said now that people with cognitive impairments need to do memory training.

I myself have a father who is getting dementia. My mother thinks she always must play with him to train his mind. But my father didn't play his whole life, he didn't play board games or card games, he hated them.

Should this man now play cards, just because he's old and has cognitive limitation? I think that's really bad. I don't think you should do that in the nursing homes either.” (Nurse 1)

III. Public Media

- Reference to demographic change, alarming pictures of rising dementia rates and limited treatment options to emphasize the relevance dementia prevention
- Strong and partly exclusive focus on individual behavioral prevention
- Uncertainties regarding the evidence for the effectiveness of individual prevention measures and the importance of environmental factors are not commonly mentioned.

“Forgetful, Aggressive, Confused: Experts Warn About the ‘Dementia Republic of Germany’” (FO5)

“How to Reduce Your Risk of Alzheimer’s”

“The elderly can stay mentally fit even if they already have initial memory gaps. A healthy lifestyle is crucial for preventing dementia” (DS 10).

“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).

Overview

- I. Background
- II. Methodological Approach
- III. Results
- IV. Discussion**

Discussion

Dementia prevention as an individual choice and responsibility:

- *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*, and
- *stigmatization* of old age frailty?

(see Schweda & Pfaller 2020)

Research Article

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

Niklas Petersen¹  and Silke Schicktanz¹

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

Qualitative Health Research
2021, Vol. 31(11) 2005–2018
© The Author(s) 2021



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/10497323211014844
journals.sagepub.com/home/qrh



Literature

Auth, D. (2012). Ökonomisierung von Pflege in Großbritannien, Schweden und Deutschland [Economization of long-term care in Great Britain, Sweden and Germany]. *Zeitschrift für Gerontologie und Geriatrie [Journal for Gerontology and Geriatrics]*, 45(7), 618–623. <https://doi.org/10.1007%2Fs00391-012-0389-0>

Jack, C. R., Bennett, D. A., Blennow, K., Carrillo, M. C., Dunn, B., Haeberlein, S. B., . . . Sperling, R. (2018). NIA-AA research framework: Toward a biological definition of Alzheimer’s disease. *Alzheimer’s & Dementia*, 14(4), 535–562. <https://doi.org/10.1016/j.jalz.2018.02.018>

Leibing, A. (2018). Situated prevention: Framing the “New Dementia.” *The Journal of Law, Medicine & Ethics*, 46(3), 704–716. <https://doi.org/10.1177/1073110518804232>

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., . . . Mukadem, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, 396(10248), 413–446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

Forlini, C., & Hall, W. (2017). A prospectus for ethical analysis of ageing individuals’ responsibility to prevent cognitive decline. *Bioethics*, 31(9), 656–664. <https://doi.org/10.1111/bioe.12387>

Martinson, M., & Berridge, C. (2015). Successful aging and its discontents: A systematic review of the social gerontology literature. *The Gerontologist*, 55(1), 58–69. <https://doi/10.1093/geront/gnu037>

Schweda, M., & Pfaller, L. (2020). Responsibilization of aging? An ethical analysis of the moral economy of prevention. In A. Leibing & S. Schicktanz (Eds.), *Preventing dementia: Critical perspectives on a new paradigm of preparing* (pp. 192–213). Berghahn.