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Putting primary prevention of dementia on everybody's agenda

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ABSTRACT

Many publications on dementia start by outlining the current estimated number of people with dementia and how that figure is going to double (in Western societies) or even quadruple (in developing countries) in the coming decades as a result of increasing life expectancy (in itself a good development). Dementia is therefore a huge challenge to society, both in terms of providing good care for persons living with dementia and their family caregivers, as well as in searching for curative solutions. Both these challenges are complex. Fortunately, recent research indicates primary prevention to be a promising additional strategy in the dementia quest. Now that epidemiological research robustly shows the link between lifestyle and risk of dementia, new challenges emerge, such as how to increase public awareness about brain health, how to develop and implement strategies to promote brain healthy lifestyles and how to avoid increasing health inequalities. Interdem, the pan-European network of researchers on Psychosocial Interventions in Dementia, strongly welcomes this new strategy and consequently established a taskforce on primary prevention. In this position paper, we outline what we see as main building blocks of primary prevention of dementia.

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Introduction

Many publications on dementia start by outlining the current estimated number of people with dementia and how that figure is going to double (in Western societies) or even quadruple (in developing countries) in the coming decades as a result of increasing life expectancy. On the other hand, recent estimates from several population-based prospective studies indicate that the age-specific incidence of dementia is declining in high-income countries (Stephan et al., 2018). However, these studies unfortunately offer no signs yet of 'flattening the curve'. Dementia is therefore a huge challenge to society, both in terms of providing good care for persons living with dementia and their family caregivers, as well as in searching for curative solutions. Both these challenges are complex.

A new challenge emerges

Fortunately, recent research indicates primary prevention to be a promising additional strategy in dealing with dementia. Recent epidemiological research highlights that modifiable lifestyle factors can be changed at middle age (40 to 75 years old) to substantially decrease the risk of dementia in later years. This possibility implies that, beyond providing good care to those who have dementia (and

their family caregivers) and conducting fundamental research to find a cure for future generations, we now also have the opportunity to substantially reduce the number of future cases of dementia by promoting brain-healthy lifestyles and environments.

Just as providing good care and finding curative solutions, primary prevention will not be easy and demand great effort, finding the right answers to issues such as how to increase public awareness about brain health, how to develop and implement strategies to promote brain healthy lifestyles, how to avoid increasing health inequalities and how to establish brain-healthy physical and social environments.

Moreover, this calls for a long-term perspective, as the pre-clinical stage of dementia can take up to 15–20 years. How to motivate people to invest in a brain-healthy lifestyle now, when the benefits are decades away? This is very similar to what the Club of Rome wrote in their 1972 report on climate change: 'The majority of the world's people are concerned with matters that affect only family or friends over a short period of time' (Meadows, 1972, p. 19).

Interdem, the pan-European network of researchers on Psychosocial Interventions in Dementia, strongly welcomes this new strategy and consequently established a taskforce on primary prevention. In this position paper,

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we outline what we see as main aspects of primary prevention of dementia, and what research and arguments supports this.

We call upon all dementia actors (research, policy, practice) to build liaisons with public health actors to develop campaigns that promote awareness about brain health. This goal is a fundamentally social endeavour, as somebody's lifestyle is more the result of the social environment than pure individual lifestyle choices. Moreover, it is a social endeavour as a result of the challenge to reach high risk group (e.g. people in poverty, persons with low health literacy, persons with non-Western ethnicity, ...) with non-traditional public health campaigns. Finally, it is a social endeavour as promoting brain health at all costs needs to avoid increasing the stigma on dementia.

Modifiable lifestyle factors

Given the complex nature of dementia and the broad range of exposure to a variety of risk and protective factors throughout the lifespan, a life-course approach to prevent dementia should be taken into account.

During the last decades, a rapidly increasing amount of epidemiological evidence established a consensus that modifiable risk and protective factors are associated with the onset of cognitive decline and dementia. Several international actors have recently underlined the importance and potential of dementia risk reduction within their reports (e.g. Leshner, 2017; Livingston et al., 2017; World Health Organization, 2019) and they have all concluded that the time is ripe to act.

The broad range of modifiable risk and protective factors includes environmental, physical, social, cognitive and lifestyle factors. For lifestyle factors, most evidence points towards midlife (40–75 years) as being a critical period where lifestyle changes have an effect on late-life dementia risk. Even in individuals with a low or intermediate genetic risk, a healthier lifestyle is related to lower dementia risk compared to people with a less healthy lifestyle. Several of these risk factors have been included in validated dementia risk scores, such as the Australian National University Alzheimer's Disease Risk Index (ANU-ADRI), the Cardiovascular Risk Factors, Aging and Dementia (CAIDE) score and the 'Lifestyle for BRAin health' (LIBRA) score. LIBRA is the only well-validated risk score consisting of solely modifiable risk and protective factors that can be targeted by lifestyle interventions and prevention strategies in primary care (see Table 1) (Deckers et al., 2015; Schiepers et al., 2018).

Available knowledge

Uptake of public health actions on dementia prevention have so far been slow, partly due to the conceived lack of causal evidence for many risk factors (Plassman, Williams, Burke, Holsinger, & Benjamin, 2010). Though many dementia risk factors can be treated, previous trials showed mixed results that this translates to delay of dementia onset (Andrieu, Coley, Lovestone, Aisen, & Vellas, 2015), partly because damage might have already occurred in the form

Table 1. Dementia risk scores and their components.

ANU-ADRI	CAIDE	LIBRA
Age	Age	Coronary heart disease
Sex	Sex	Diabetes
Education	Education	Hypercholesterolemia
Body mass index	Body mass index	Hypertension
Diabetes	Systolic blood pressure	Depression
Depression	Total cholesterol	Obesity
Serum cholesterol	Physical activity	Smoking
Traumatic brain injury		Physical inactivity
Smoking		Renal disease
Alcohol intake		Low-to-moderate alcohol use
Social engagement		High cognitive activity
Physical activity		Healthy/Mediterranean diet
Cognitive activity		
Fish intake		
Pesticide exposure		

of cerebral small vessel disease or neurodegeneration. The window for prevention might be further narrowed by the pragmatic approach taken by many trials such as selection of specific age groups or high-risk populations (e.g. based on genotype or early symptoms), often selecting on irreversible factors. Unselective randomised controlled trials including a broad age range and following individuals for a sufficient time to study accelerative cognitive decline or dementia onset are needed to validate observational evidence, but such trials are notoriously difficult to achieve (Friedland & Nandi, 2012). Well-conducted epidemiological studies comparing exposed and unexposed (or never exposed) individuals on future dementia risk with adequate follow-up and control of confounders have thus be given more weight in recent recommendations (e.g. Leshner, 2017; Livingston et al., 2017; World Health Organization, 2019).

Indeed, many risk factors suggest consistency (e.g. in meta-analysis), biological plausibility (e.g. associations with cerebral blood flow, brain ischaemia, oxidative stress, neurotrophic factors, inflammation), analogy (similar risk and mechanisms in peripheral tissue/organs) and dose-response associations (Deckers et al., 2015). Rather than leaving the public uninformed, recommendations for dementia prevention should take into account the strength of the evidence (Anstey, 2019).

Public (un)awareness

A growing scientific consensus about lifestyle and dementia risk does not necessarily translate into a broad public awareness. And such awareness is key to promoting brain healthy lifestyle. Unfortunately, creating public awareness has often proved to be tedious and slow. For instance, scholarly consensus on smoking and lung cancer took several decades to ooze into the public's mind (to a large extent the result of the 'Merchants of doubt') (Oreskes & Conway, 2010).

Given that the research identifying modifiable lifestyle risk factors for dementia is very recent, it is no wonder that currently citizens are mostly unaware about them. Thinking about dementia in terms of primary prevention is a relative novelty. Still the lack of public awareness is worrying:

'Clearly the messages on the importance of risk reduction highlighted recently by a WHO report are not getting through. People don't know what to do. We need to do more to spread this message at every level' (Alzheimer's Disease International, 2019, p. 11).

In the context of a public health campaign on lifestyle and dementia, a baseline survey was held in both Flanders and the Netherlands. In Flanders, only 34.8% of citizens (40–75 years old, $N=1003$) think there is something you can do in your lifestyle to influence risk on dementia. In the Netherlands, this perception was 44% ($N=577$). That is very similar to the Alzheimer research UK survey of 2354 adults aged 15 years+ without a dementia diagnosis, which also found only 34% of people believe it is possible to reduce the risk of dementia, compared with 77% for heart disease and 81% for diabetes (Stevens, 2019, p. 26).

The good news is that in both the Flemish and Dutch survey, 70% of the respondents indicated interest in receiving more information about brain health. Lack of knowledge was the main barrier for people not to engage in a brain-healthy lifestyle (Heger et al., 2019). Increasing public awareness is consequently a first target for any dementia prevention strategy. This goal seems feasible. A modest low-budget campaign that ran from summer 2018 to spring 2019 in Flanders managed to increase awareness by 10%. The campaign consisted of the distribution of 40,000 'vaccine boxes' with leaflets about the link between brain-healthy lifestyle and dementia at railway stations, markets and pharmacies on both World Alzheimer day (21st of September 2018), as well as the regional week of care (March 2019), effect of which was multiplied by an active campaign in news and social media. See the Taskforce section on www.interdem.org for more information.

A challenge for research and practice

Given a scholarly consensus on lifestyle and dementia risk in the context of public unawareness, a new set of challenges arises for both research and practice. Challenges for research lie in the methodological and interdisciplinary nature of the studies needed. Most dementia research is interdisciplinary, but public health researchers have not yet been included in the discourse so far. They are key partners to change.

Challenges for practice relate to the delivery of personalized/tailored preventive measures to young and middle aged people, preferably to those most at risk, who need to get informed and then motivated to engage in long-lasting lifestyle changes. Equally, there are the environmental risk factors that need to be addressed. A range of stakeholders are involved in the domain of prevention, such as middle aged and senior citizens and their representatives, professionals and organisations in the social, care, public planning and public health domain, educational organisations, employers and other partners in the private domain. These stakeholders are already connected in different networks and coalitions. This network may help getting access to these stakeholders, but it may also mean that the topic of dementia prevention has to compete with more

readily established prevention themes such as cardiovascular disease and cancer. This diversity and the complex nature of dementia prevention will make implementation of interventions complex and challenging. Establishing a collaboration with the public health domain is therefore essential.

Successive steps to be made in practice are monitoring and increasing public and political awareness, targeting environmental risk factors (e.g. at the workplace, Hussenoeder, Riedel-Heller, Conrad, & Rodriguez, 2019) and high-risk groups, framing an appealing public health message, cost-effective measures to reach a large audience, e.g. through e-health applications, as well as facilitating access to effective personalized/tailored preventive measures for middle aged people that have a lasting impact and do not increase health inequalities nor the stigma around dementia.

Brain health from a social health perspective

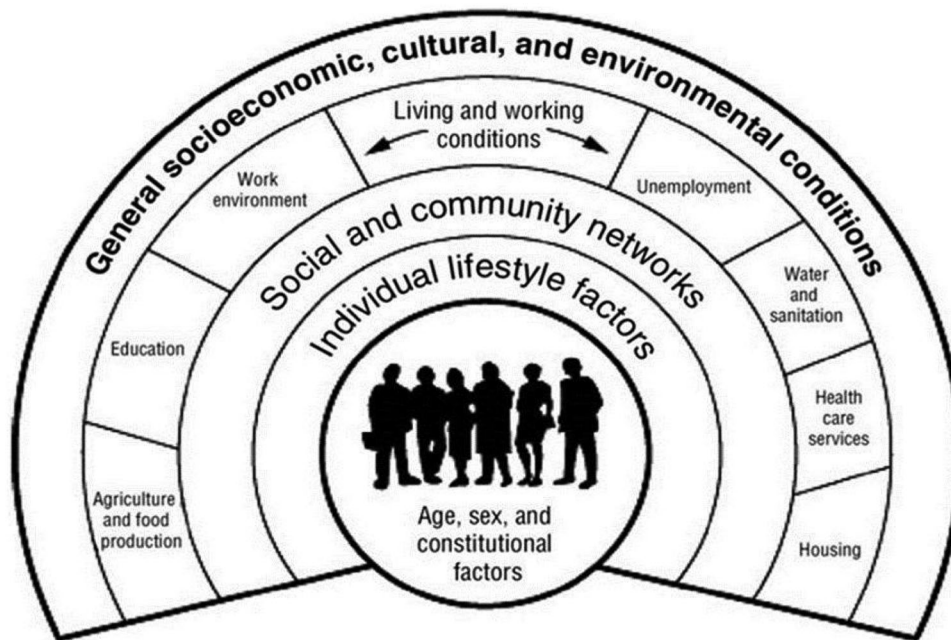
A recent re-definition of health as 'the ability to adapt and to self-manage, in the face of social, physical and emotional challenges' (Huber et al., 2011, 2016), is a critical starting point for realising and optimising prevention of dementia. This definition of health aligns with a broad notion of health promotion and prevention that considers the individual's health status as ever changing in the context of their life stages and also embraces different levels of prevention. It offers a framework to integrate biomedical and psychosocial approaches and allows to focus on both capacities and limitations (Vernooij-Dassen, 2020).

Such approaches to health acknowledge the importance of dementia prevention as a dynamic process that involves the interactions between the individual's physical, mental and social gradients of health and their ability to adapt and manage despite the challenges they experience due to varying aspects of health and life stage events. They also point to the influence society and social networks have on capacities. Social circumstances might allow or stimulate to use capacities or prevent its use (Vernooij-Dassen & Jeon, 2016).

Social health in terms of individuals' ability and opportunities to engage and interact with others, is also one of the factors influencing the prevention of dementia. Epidemiological research indicated that social factors constituting the structural base for social interactions were related to cognition (Bellou et al., 2017; Fratiglioni, Winblad, & von Strauss, 2007).

Multilevel approach, micro, meso and macro

Working on brain health from a social health perspective is in line with the Dahlgren-Whitehead 'rainbow model', first published in 1991 but since a key model in public health (Dahlgren & Whitehead, 1991). It distinguishes between factors on a micro- (e.g. differences in risk factors exposure, health literacy, motivation), meso- (e.g. social factors, the built environment), and macro-level (e.g. access to health care, income distribution, wider political forces). On each of these levels, work can be done to promote brain health and reduce risk on dementia.



Simplifying and refining the risk model

Reduce smoking to limit lung cancers was and is a very easy message, given the single cause and the high causality smoking has in relation to lung cancer. However, even after decades of health campaigns and anti-smoking policies, still about 20% of adults smoke. Public awareness does not guarantee lifestyle change.

In terms of the risk and protective factors for dementia, the message is less easy as there is not a single cause but a whole basket of factors, and the causality is weaker than between smoking and lung cancer. In order to design appropriate and effective health campaigns, it is essential to boil down all risk and protective factors to a simple message, which is easy to communicate, while at the same time not negating the complexities, uncertainties, and unknown factors in research.

In the campaigns in the Netherlands and Flanders, this approach resulted in three messages: (i) what is good for the heart, is good for the brain¹; (ii) stay mentally active; (iii) stay socially active. Still, this translation resulted in discussions on what 'staying mentally active' implied, and the need to highlight that playing sudoku's and crosswords regularly was not enough.

Avoiding to 'blame the victim'

Current awareness about the modifiable lifestyle factors that reduce the risk on dementia is low and should be increased. However, this change in awareness should be achieved differently from the approach taken over the past decade to dissuade people from smoking. That strategy was heavily based on fear (cigarette boxes became a catalogue of medical diseases) and stigmatisation of smokers, banning them from many places.

For several reasons, we should seek other strategies to work on prevention of dementia than relying on fear and stigma. For one, such strategy would add to the stigma dementia currently already has and thus impact on the quality of life of the current generation of persons living

with dementia and their family. Secondly, contrary to the link between smoking and cancer, the link between lifestyle and dementia is relatively new. Given that dementia is a process 'in slow motion' and the preclinical phase easily takes up to 20 years, there will be at least one generation of persons with dementia who could not have been aware of the link with lifestyle.

Many public health campaigns focus on individuals, persuading them to give up smoking, to stop drinking too much alcohol, to avoid drinking while driving, ... and forget all too often that healthy lifestyle is a multicomponent domain where individual, societal and environmental factors interact. The message consequently is to empower people while at the same time working towards changes at societal level.

Health gradient as an extra challenge

Like many things in society, life expectancy and health are not equally distributed, and not only on a global scale between developing/developed countries, but even within Western societies. People with low education have a life expectancy that is several years lower than people with high education. In terms of healthy life expectancy, the difference is even more than a decade.

Epidemiological research also indicated that the risk for dementia shows inequality. In Western countries, people living in poverty and immigrants with non-Western ethnic background have a substantially higher risk (Parlevliet et al., 2016).

Additionally, evaluation studies of public health campaigns indicate that exactly these groups with a higher risk are much harder to reach through generic public health campaigns. The challenge consequently is to design dementia risk reduction campaigns in such a way that the higher risk groups, at the same time being the harder to reach groups, do not fall behind. Otherwise, dementia risk reduction work could increase social inequality and the health gradient. In order to address this challenge, the

concept of proportional universalism is useful, but at the same time challenging to implement and translate into action. Key is to aim public health campaigns at the general public, but invest more in (different campaign formats) spreading the message among high-risk groups and hard-to-reach groups.

Conclusion

It is now time to translate the wealth of the research of the past decade into action and build a brain-healthy society. We need to build bridges between the groups that focus on good quality care, the researchers involved in finding a medical solution, and those groups researching and organising public health campaigns in other health domains. It is like Robert Putnam wrote in his seminal work on social capital: bonding social capital (ties within a group or community) is good for 'getting by' and bridging social capital (ties between groups and communities) is crucial for 'getting ahead' (Putnam, 2000). Such bridges have over the past decades helped lowering the number of lung cancers through reducing smoking, let's make it work for dementia as well.

Note

1. This part of the message seems to be gaining popularity, and can e.g. be found in the recent report of the Global Council on Brain Health (2020, The brain-heart connection) and Giovannoni (2020).

Disclosure statement

No potential conflict of interest was reported by the authors.

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