

Meaningful communication on dementia risk reduction: An ethical analysis of the views and perspectives of migrant communities and those economically disadvantaged

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Background

- About 45% **dementia cases are preventable** by addressing 14 modifiable risk factors.
- **Public health campaigns should raise awareness** about dementia risk reduction^{1,2}.
- Alongside increasing popularity, campaigns have been met with **ethical scrutiny**^{3,4}:
 - Medicalize everyday activities during midlife
 - Place high responsibility on individuals,
 - Address mainly advantaged groups, while ignoring socially disadvantaged populations
- **Research involving these target groups** can identify context sensitive perceptions and priorities on healthy ageing and dementia risk reduction.
- **Meaningful communication** with and for disadvantaged groups serves as one critical tool to address key ethical questions and develop more ethical public health campaigns.⁵

Objective

This study aims to provide **ethical guidance for responsible communication** on dementia risk reduction by investigating the views and perspectives of migrant communities and those economically disadvantaged, often also showing lower health literacy skills.

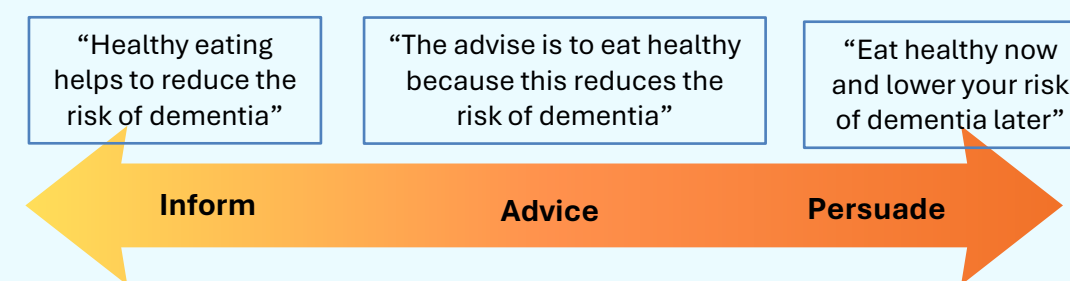
- Do campaigns on dementia risk reduction **add upon or align with** naive views on aging?
- Does the term of **‘brain health’** offers a valuable **positive linguistic tool** for communication
- What **level of directiveness** is most appreciated? Why? Informative, advisory, or persuasive?

Methods

An **empirical-ethical analysis** using focus-groups (n = 8) including 38 participants (P) who are economically disadvantaged, have a migration background and/or limited health literacy. The study is located in the Netherlands, migrant participants were mostly from Morocco and other Arab speaking countries.

Findings were analysed using **Guttman's theory on public health communication ethics**³ and **Oxman's spectrum on justified health risk communication**⁴.

Focus-group settings	N Focus-group	N Participants	Variable	n = 38*
Workplace (re)integration	4	14	Mean age (SD)	55.9 (11.9)
Learning Plaza (literacy support)	1	6	Female Gender,	25 (67.6%)
Migrant women's organisation	2	10	Educ. Level n%	
Salvation Army meeting point	1	8	Low	32 (86.5%)
			Middle/ High	5 (13.5%)



Framings of dementia risk reduction messages, inspired by Oxman et al's communication continuum.

Results

- **Perceptions of ageing:** Participants were concerned about aging, and associated it with physical decline and general uncertainty. They recognized and shared concerns about dementia when explicitly asked about. Dementia was clearly distinguished from normal ageing. There was uncertainty and skepticism about the extent to which dementia risk can be modified. 'Hoping for the best' was a frequently mentioned approach to prepare.
- **Terminology:** The term "dementia" (Dutch: *dementie*) evoked strong negative emotional responses (e.g., fear, dependency, death), whereas the allegedly positive term "brain health" (Dutch: *hersengezondheid*) functioned partly as a broad umbrella term, denoting a great variety of topics, while it was not understood by others and in general was not self-explanatory.
- **Messaging:** Participants expressed a clear preference for advisory and persuasive messaging over informative messaging. Informative messaging was perceived as top-down or even pressuring. Advice can be ignored, if disliked and persuasions are clear and graspable.

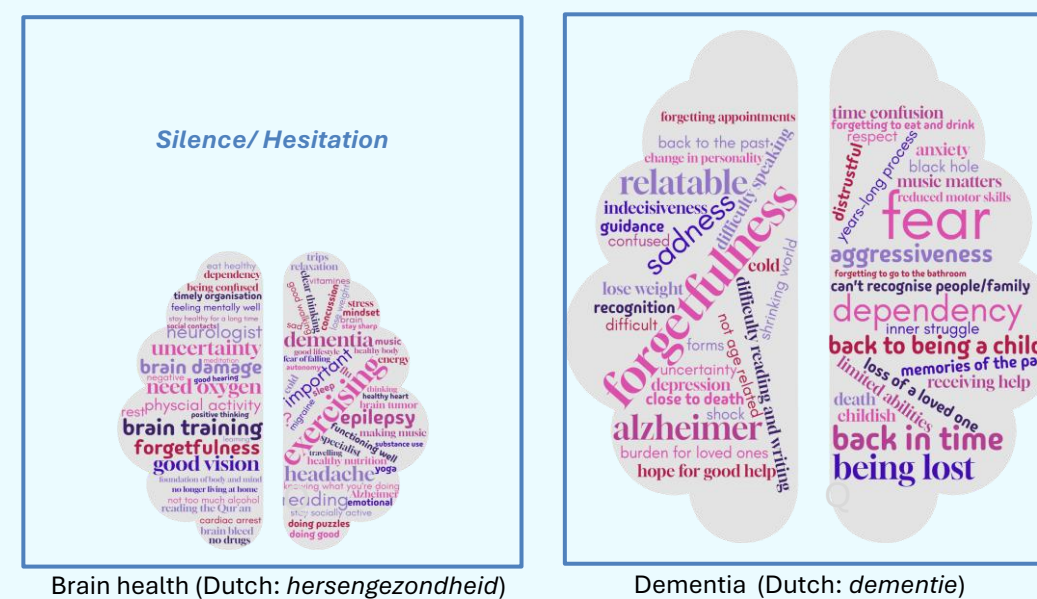


Figure 2. Word clouds illustrating reported associations with key terminologies.

Discussion

- Investigating options and requirements for **meaningful communication** on dementia risk reduction is **an important element** of understanding the needs of stakeholders .
- Ethical questions and concerns regarding public health campaigns on dementia risk reduction are only partly confirmed and in need of reconsideration.
- Explicit worries about aging mainly concern physical decline, the **forecast of cognitive decline** is not mentioned spontaneously but **emphatically confirmed** if highlighted .
- Framing **dementia risk reduction** not as an isolated goal **but as an extension of physical well-being** allows for meaningful non-stigmatizing engagement,
- Concerns about undue medicalization are less urgent if meaningful options are available
- The disease-centered term *dementia* triggers expected negative emotional reactions.
- The **allegedly positive alternative term *brain health*** however remains abstract, is **not or misunderstood**
- The Dutch context and the translation into *hersengezondheid* – a linguistically unusually complex term- **further complicates** the observation
- Further research needs to **identify context-sensitive, meaningful and correct wording**
- Public health messages that depend on long-term and population-based observational data **justify informative messages** but not also pressuring individual persuasions.
- Scientific evidence on modifiable risk factors and dementia risk reduction do depend on group-based findings which are long-term and not acute.
- Participants' preference for advisory and persuasive messages challenges** ethically justified messaging as due caution doesn't align well with perceived meaningfulness.

Conclusion

- Engaging stakeholders helps investigating ethical questions on dementia risk reduction public health campaigns
- Context-sensitive communication can address key issues but also requires navigating conceptual, ethical and linguistic challenges.
- Embedding cognitive health in physical health facilitates non-stigmatizing and anxiety-arousing communication and awareness
- Enabling conditions are crucial for informed and aware stakeholders to avoid undue responsabilization and bring about sustainable change