

Exploring Perceptions and Communication Needs regarding Dementia Risk and Prevention among Dutch Citizens: a focus group study

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Abstract

Background

Communication of dementia risk could enable those at risk to make informed decisions regarding preventative actions. However, it is not yet known whether citizens want to be informed about their (potentially modifiable) risk, what information they would like to receive and through which channel. Therefore, the aim of this study is to explore perceptions and communication needs of Dutch citizens regarding dementia risk and prevention.

Methods

Eleven focus groups were conducted with participants with varying levels of functional health literacy (FHL) recruited in diverse settings, including a reintegration support organization and an organization of women with a migration background. Focus groups were audio-recorded, transcribed and thematically analyzed independently by two researchers.

Results

A total of 58 participants were included. FHL varied widely (mean = 2.4, SD = 0.9). Core findings were: 1) Citizens generally preferred population-level dementia risk information over potential individual risk estimates of developing dementia; 2) Citizens had varying views on whether dementia was part of normal ageing and could potentially be prevented; 3) Views on brain health and dementia were shaped by personal beliefs, culture and spirituality, with optimism and faith seen as protecting factors; 4) Citizens generally preferred face-to-face communication when receiving information (e.g. via their general practitioner), yet they also suggested leaflets, brochures, community meetings and TV infomercials as potential information channels.

Conclusions

Perceptions and communication needs regarding dementia risk and prevention varied among Dutch citizens. Tailored communication strategies in public health campaigns and other prevention initiatives are therefore warranted. For example, accessible and simplified (culturally sensitive) messaging may be more appropriate for some groups, whereas others may benefit from more detailed risk information.

Introduction

The number of people living with dementia is expected to increase due to an ageing population and improved diagnostic methods (1–3). There are currently 57 million people with dementia worldwide, and this number is expected to increase to more than 155 million by 2050 (3, 4). Although medical

treatments are being developed, their effectiveness is limited to slowing the progression of cognitive decline that is characteristic of dementia (5). At present, there are no treatments available that can cure the underlying condition(s) or reverse the progression of dementia. Therefore, research focuses on the identification of risk factors for developing dementia and the development of effective dementia prevention interventions (6, 7).

Nearly 45% of all dementia cases could potentially be delayed or prevented by addressing 14 modifiable risk factors, as reported by Livingston et al. (8). As a result, there is a stronger emphasis in public health on encouraging citizens to maintain their cognitive health and reduce their risk of developing dementia. At the societal level, strategies promoting social participation and fostering active communities may contribute to reduced dementia risk and delay cognitive decline (9, 10). On an individual level, maintaining an active lifestyle and engaging in cognitive activities are associated with reducing the risk of dementia (11, 12). For effective reduction of dementia risk, it is thus essential to actively involve citizens, inform people about modifiable risk factors and their dementia risk, and foster the actual uptake of actions that could reduce risks.

People are more likely to adopt healthy behaviours when they perceive a potential threat to their health (13, 14). Meaningful lifestyle modification to reduce dementia risk thus starts with awareness, i.e., sufficient knowledge about dementia and related risk factors and adequate perception of their risk (15, 16). Limited functional health literacy, which is a lower capacity to access, understand and apply health-related information in order to make informed health-related decisions in everyday life (17), might hinder people's awareness and their ability to engage in dementia risk reduction behaviours (18, 19). This is unfortunate, since studies suggest that low health literacy is associated with an increased risk of developing dementia and it may foreshadow cognitive impairment (20). Health literacy levels also tend to be lower in people with a migration background (21) and those with a lower socioeconomic position (SEP) (22). These findings are concerning as dementia risk factors tend to cluster within people with a migrant background and/or lower SEP due to multiple factors, including less access to health resources and proper medical care, poor health behaviors and health outcomes (23, 24), thereby increasing their risk of developing dementia (8, 24). In the Netherlands, people with a migration background and a lower SEP exhibit a three to four times higher prevalence of dementia and mild cognitive impairment (MCI) compared to native-born populations in the Netherlands (25). In addition to addressing these factors, raising awareness and educating people with regard to dementia risk and prevention can support people in changing behaviours that might impact their dementia risk (26). Meaningful communication about dementia risk and prevention can help to raise awareness.

Yet, communicating about dementia risk and prevention in the public health context is challenging, for example, due to variation in public knowledge and perceptions of dementia (27, 28). Furthermore, individual needs and preferences for receiving information about dementia, dementia risk and prevention might also differ. Earlier studies examining knowledge and perceptions among Dutch citizens included large proportions of highly educated citizens and did not take health literacy levels into account (15, 29). Previous studies on communication about dementia risk have predominantly focused on risk

communication (needs) within trials or memory clinics (30–32). Consequently, it is not yet known whether citizens wish to be informed about dementia risk and prevention, what information they need, and which communication channels they prefer. Therefore, the aim of this qualitative study is to explore perceptions and communication needs regarding dementia risk and prevention among a diverse population of Dutch citizens, varying in health literacy.

Methods

Design

This qualitative study was conducted as part of the Netherlands Dementia Prevention Initiative (NDPI), a national consortium of eleven partners, including Amsterdam UMC. The NDPI aims to develop and investigate the effectiveness of (lifestyle) interventions for the primary prevention of dementia in citizens at increased risk of dementia, including those with a low SEP and/or migration background.

For this study, to explore perceptions and communication preferences about dementia risk and prevention among Dutch citizens, a qualitative design was used involving focus groups. Therefore, the Consolidated Criteria for Reporting Qualitative research (COREQ) were applied to report on this study (33).

Sample and Recruitment

Dutch-speaking citizens aged 18 years or older were included. We aimed to recruit a diverse group of citizens with varying FHL levels, specifically by recruiting in settings with a relatively higher representation of those with a lower SEP and/or a migration background. For that reason, various recruitment methods were used, and multiple organizations were contacted for participation. Participants of the focus group organized at Setting 1 (Table 1) were recruited through social media announcements (e.g., through LinkedIn posts and newsletters by the Dutch Alzheimer association and the Dutch Brain association). For this initial focus group activity, three consecutive sessions were scheduled, and participants were free to attend one, two, or all of them. They received a 20-euro voucher for each session they participated in.

After this initial focus group activity, we set out to recruit more participants with low to medium health literacy levels, by active outreach to a variety of settings, i.e., organisations, associations and other organized local groups and community centres. The researchers contacted and visited many settings, sometimes on multiple occasions, to explain the research and build trust. This is in particular done for setting 4–6 (Table 1). A setting contact person with interest in our research would help to connect with potential participants and identify the most optimal procedure to conduct a focus group at their specific setting. The contact person at the setting announced the focus group through their regular communication channels. If possible, potential participants received study information beforehand. However, sometimes it was not possible to inform all, since it was not known beforehand who would

attend the focus group. At the start of the focus group meeting, potential participants were therefore given written and verbal study information (once more), and were allowed time for questions, to help people decide whether they would like to take part.

In addition to the focus group conducted at Setting 1, we eventually conducted focus groups at five different settings (Table 1). At most of these settings, we conducted multiple focus groups, each with different participants. These focus groups consisted of a session of approximately one hour, and participants received a 20-euro voucher for their participation. All focus group data were collected between December 2023 and July 2024.

Table 1
Descriptions of the focus group settings.

Setting	Description of the setting	Number of focus groups	City, Province
1	Participants recruited via social media and newsletter announcements were invited to an academic hospital.	1 (divided over three consecutive sessions)	Noord-Holland
2	An organisation that supports residents of different municipalities with employment, financial matters, and integration, e.g., by helping people to improve their language or digital skills.	4	Noord-Holland
3	A Dutch Language ambassadors initiative, a volunteer driven entity to raise awareness, practice the Dutch language, and engage in local community work.	1	Noord-Holland
4	A meeting place of the Salvation Army Netherlands, designed to facilitate low-threshold social interaction and provide affordable meals.	1	Limburg
5	An International Women’s group, an intercultural community where women from diverse ethnic backgrounds meet to foster social cohesion and empowerment.	2	Limburg
6	Residential care organization that offers housing, community sense, and (optional) care services, where we invited residents (N = 6), and employees (N = 4) to join.	2	Zuid-Holland

Procedures and Measures

After providing informed consent, participants first completed a short questionnaire assessing their age, gender, level of education and FHL. Education is categorized as low, medium and high according to Dutch national guidelines (34). For FHL, we used a validated Dutch FHL (sub)scale (35), consisting of five items rated on a 4-point Likert scale, ranging from 1 = never, 2 = rarely, 3 = sometimes to 4 = often. Higher score indicates lower FHL. Participants were categorized based on the rounded average of the

five items. An example question is: "How often do you find that the content of the leaflets you receive from the hospital/general practitioner is too difficult to understand?". If participants needed help completing the questionnaire, the facilitating researcher or the setting contact person provided assistance by reading the questions aloud. Next, the facilitating researcher explained the focus group procedures, started the audio recording, and began the focus group discussion. One or two facilitators were present for each focus group. In total, five facilitators were involved: four women (EK, DH, LNCV and DP) and one man (AR).

Facilitators used a topic guide (Supplementary Tables 1 and 2) to guide the sessions, with the main topics being participants' perspectives on ageing, brain health, dementia, and dementia prevention, as well as their communication needs and preferences regarding dementia risk and prevention. The focus groups were initially set up as a series of three sessions (Supplementary Table 1), and at setting 1 we completed one focus group series. Yet, this strategy was adjusted after the first series, as it became apparent that organizing and/or participating in multiple sessions was more burdensome than expected and represented too great a commitment in terms of logistics and time for our intended target group at the various settings. To better align with participants' needs, we decided to adapt our procedure by: i) conducting a single session instead of a series of three, ii) aligning the session with existing meetings at the various settings to reduce participation burden, and iii) shortening our topic list (Supplementary Table 2), so that it fitted into one session. All sessions were audio-recorded using a Philips digital audio recorder. An external professional (VerTaaldden, Maarssen, The Netherlands) transcribed the audio recordings verbatim. A researcher (SA) checked all transcripts while listening to the audio recordings. Paper and pencils were used to visually capture input from all participants and elaborate on certain topics. All notes taken during the focus groups were also included as data.

Data Analysis

Two researchers (SA, EA) conducted a thematic analysis using MAXQDA software. The framework proposed by Naeem (2023) served as a guiding reference for the interpretation of the data and the conceptualization of its meaning (36). This framework consists of a systematic six-step thematic analysis process, including: selection of quotations, selection of keywords, coding, theme development, conceptualization through interpretation of keywords, codes, and themes, and as a last step, the development of a conceptual model (36).

First, both researchers carefully read all transcripts. Second, key terms were identified; repeated elements were grouped together to arrange these patterns into grouped key terms. Third, systematic coding took place so that the patterns could be identified as codes. The researchers (SA, EA) performed this coding independently, after which consensus meetings were held by the researchers to discuss findings and resolve discrepancies. As a next step, part of the research team (SA, EA, LNCV, ES) collaboratively reviewed the codes and formulated four overarching themes. Finally, the conceptualization process began where the research team (SA, EA, LNCV, ES) would interpret, (critically) reflect on, and try to cover the essence of each theme, after which one round with other co-authors (DP

and DH) followed, resulting in the final themes as presented in this manuscript. The research team (SA, EA, LNCV, ES) selected illustrative quotes to support the identified themes.

Results

Sociodemographic characteristics and perceptions of dementia

Across the eleven focus groups, organized at six settings, 58 participants were included, with a mean age of 61 years (range of 28–96 years old) (Table 2). The majority of participants were women (74%), with 62% having low and 14% having medium education levels. FHL varied widely, with a substantial proportion of participants reporting difficulties understanding healthcare brochures and/or leaflets, as 28% reported difficulties ‘sometimes’ and 16% ‘often’.

To appreciate participants’ initial thoughts on the topics at hand, we started each focus group with an exploration of their associations with the terms ‘brain health’ and ‘dementia’ (Fig. 1A and 1B). Participants generally associated ‘brain health’ with overall health and well-being, including factors such as sport, healthy nutrition, or social contact (Fig. 1A). Other participants associated ‘brain health’ with specific neurological conditions, like brain bleeding. Participants associated ‘dementia’ with symptoms commonly seen in its later stages, such as memory loss, dependency, confusion and the inability to recognize family members (Fig. 1B). Dementia was seen as a physical and visible condition with clear progression. Furthermore, the term ‘Alzheimer’ was often associated with ‘dementia’. When comparing responses to both terms, researchers observed that participants appeared more uncertain when asked about their associations with the term ‘brain health’, as they more often did not give an answer and/or took more time to gather their thoughts before explaining what ‘brain health’ meant to participants (illustrated question marks in Fig. 1A). To the term ‘dementia’ participants responded more quickly and had more associations to share.

Table 2: Sample characteristics.

Age, M (SD)	Total sample	Setting 1 ^A	Setting 2	Setting 3	Setting 4	Setting 5	Setting 6
	(N = 58)	(N = 10)	(N = 14)	(N = 6)	(N = 8)	(N = 10)	(N = 10)
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
	61.4 (15.0)	69.9 (8.3)	48.15 (9.7)	67.67 (9.3)	61 (10.4)	54.8 (10.5)	73.2 (15.0)
Range (min-max)	28–96	56–84	28–62	57–77	46–73	38–72	53–96
Gender							
Female	43 (74)	8 (80)	7 (50)	4 (67)	4 (50)	10 (100)	10 (100)
Male	14 (24)	2 (20)	6 (42)	2 (33)	4 (50)	-	-
Non-binary	1 (2)	-	1 (3)	-	-	-	-
Education level^A							
Low	36 (62)	-	10 (71)	4 (66)	4 (50)	5 (50)	3 (30)
Medium	8 (14)	-	3 (21)	1 (17)	3 (37)	4 (40)	6 (60)
High	13 (22)	10 (100)		1 (17)	1 (13)	1 (10)	1 (10)
Missing	1 (2)	-	1 (8)	-	-		
Functional Health-Literacy (FHL)							
Mean (SD)	2.4 (0.9)						
Range (min – max)	1–4						
Rounded average FHL score of 1 (Never)	13 (22)						
Rounded average FHL score of 2 (Rarely)	19 (33)						
Rounded average FHL score of 3 (Sometimes)	16 (28)						
Rounded average FHL score of 4 (Often)	9 (16)						
Missing	1 (2)						

^A According to Dutch national guidelines of the Central Bureau of Statistics.

Theme 1: Strong opinions on receiving information about their dementia risk

When asked, “What if there was information about your individual dementia risk estimate... Would you want to receive this percentage?”, participants provided a range of strong and differing opinions. Some participants expressed a desire to know their individual risk estimate (e.g. a percentage) for developing dementia, if such information was available. They demonstrated enthusiasm and curiosity and indicated a willingness to take preventive measures if they turned out to have a high dementia risk. Additionally, they highlighted the importance of preparing for a future with dementia, such as organizing healthcare plans or creating family photo albums to help retain memory and recognize loved ones. Participants noted: *“How are you going to handle care? Leaving a letter for your children, saying, ‘If I no longer have control, this is how I would like my life to be managed.’”* – [Setting 5], or *“Yes, organizing things is one, but also creating memories in a book. I’ve been thinking about it for a long time but haven’t started yet. I really missed that with my mother; luckily, I could still remember everything, so I could tell it all. But, you know, my children, for example, know about their birth, but there are no grandparents anymore to tell them anything. So sometimes I think I would make some sort of picture book with stories about how things were. And then, I think, prepare for that together.”* – [Setting 5].

Some participants stated that they would only want to know their risk of developing dementia if treatment options were available. The absence of medication diminished the perceived value of knowing a risk estimate. One participant stated: *“No, I would not like to know more about dementia risk and prevention. Because if there is no treatment, why would I want to know?!”* – [Setting 4].

Other participants expressed that they did not wish to know their individual dementia risk estimate, regardless of whether there are treatment options available or not, because such knowledge might cause a sense of helplessness and stress. As one participant noted: *“If I have to think about when I get dementia every day, it will only make me stressed.”* – [Setting 2].

Participants were also asked whether, regardless of their personal interest in knowing their individual risk of developing dementia, they would want to receive general dementia risk information, that is information about dementia risk and risk factors at the population level. Almost all participants expressed a desire for such information, as it was seen as more accessible, less frightening and useful for discussions about the future dementia risk of (older) family members.

Theme 2: Variation in views on dementia as an illness that could potentially be prevented.

Participants differed in their views on whether dementia is part of normal ageing and whether dementia could potentially be prevented. Most (yet not all) participants acknowledged that dementia is not a normal part of aging and that lifestyle choices, such as eating healthy, staying physically active,

engaging in social interactions and stimulating the mind, contribute to healthy aging. However, participants were uncertain about how these factors could influence the development of dementia. Participants expressed skepticism about the idea that lifestyle changes could significantly reduce the risk of developing dementia. One participant explained: *"I think it is like an illness that you either get or do not get. One person gets cancer, just to give an example, and another does not. I think it is similar to dementia or Alzheimer's, in that some people develop it and others do not."* – [Setting 6]. Others also provided counterexamples, such as relatives who lived a very healthy lifestyle yet still developed dementia later in life. One participant noted: *"So I believe there is no guarantee. Guarantees don't exist, fate is so unpredictable, it happens to you, it's something you deserve, or it's genetically determined. But yes, you can reduce the risk, you can lessen it by, as I said, nutrition and care, meditation, yoga, and everything you can do. Optimism, music, love, all those good things. You might be able to counter it and reduce the risk, but a guarantee doesn't exist."* – [Setting 1].

Moreover, participants who acknowledged that individual health behaviors could potentially help delay the onset of dementia were not always motivated to adopt other or additional health behaviors. One participant noted: *"Or if you're too focused on your health, then, well, you're preoccupied with that. But then you forget to do the things that could help you forget about dementia and just live your life."* – [Setting 1].

Furthermore, participants believed that genetic predisposition plays a significant role in developing dementia during one's lifetime, influencing preventability. One participant explained: *"Well, if you have depression at a relatively young age, or what is it called, dementia, then I do think that it is hereditary. But if it happens at a much later age, then you have had a very good life. And then, gradually, your brain starts to deteriorate."* – [Setting 3]. In addition, some participants questioned whether citizens themselves or public authorities are responsible for reducing the risk of developing dementia. One participant noted: *"People at Tata Steel [a steel factory responsible for much pollution EA] or in Groningen [a Dutch province suffering from earthquakes due to gas extraction from the soil, EA], may get dementia because of environmental factors."* – [Setting 1].

Theme 3: Influence of personal life attitudes and beliefs on participants' views on brain health and dementia prevention.

Participants' views on whether dementia was part of normal aging or could potentially be prevented appeared to be influenced by personal life attitudes, religious or spiritual beliefs, and cultural background. This, in turn, can have an influence on the needs participants have for information about dementia risk and prevention.

Personal life attitudes, such as optimism and acceptance, were viewed as protective factors for dementia. Participants described maintaining a positive outlook, emotional balance and inner peace as ways to 'keep the brain healthy' or 'prevent dementia'. One participant stated: *"It is more beneficial to your health to eat a whole pie, and not worry about it, than eat a tiny piece, with an overwhelming sense of guilt."* – [Setting 1]. Optimism was particularly seen as a source of resilience and brain health among older participants: *"And yes, that's also a very good point. Being optimistic, just staying positive. No, but*

apparently, the older you get, and you say you're happier now, optimism seems to increase as we age, so that's a very healthy thing for our brains. That makes you happy again." – [Setting 6].

In multiple focus groups, participants mentioned religion or spirituality as an important factor in maintaining brain health. Specific examples included engaging in prayer or reading the Quran. These practices were perceived as providing mental stimulation and grounding. They stated: *"What we also say is reading the Quran. We say that for our brains, it's always good to read the Quran."* – [Setting 5].

For some participants, religion or spirituality influenced whether they wanted to initiate behavioral change to prevent dementia, or if they perceived a condition like dementia as inevitable. One participant stated: *'But yeah... [...] Whatever God gives, I will accept.'* – [Setting 3]. Cultural norms appeared to influence how information provision about dementia risk and prevention would be valued and perceived. Participants noted that the topic of dementia is often avoided or is stigmatized. In some focus groups, participants mentioned that dementia is considered taboo in their communities. Cognitive decline might be viewed as a moral or spiritual failure, or, although a normal part of aging, not to be discussed in public. One participant remarked: *"In our community, people don't believe dementia is real."* – [Setting 5]. Others pointed out that fear, shame, or the feeling of being a burden prevented participants from discussing their symptoms or reaching out to loved ones for help or support.

Theme 4. Preference for in-person information provision about dementia risk and prevention

When asked about their preferred sources and channels for receiving information on dementia risk and prevention, participants consistently preferred face-to-face communication (e.g. discussions with their health care professionals) over other methods (e.g. television infomercials). They perceived personal contact with healthcare professionals as reliable and reassuring, especially when these professionals were general practitioners or practitioner nurses. One participant stated: *"I think that when you reach a certain age, it should be a topic to discuss with your doctor. I also believe that the doctor should bring it up at a certain age."* – [Setting 3].

Other suggested ways of face-to-face communication included: community meetings and informational evenings, held in neighborhood centers. Many participants highlighted that verbal information provides room for immediate clarification, which is particularly important when discussing sensitive and complex topics such as decline in brain health and dementia risk. Participants also expressed a need for empathetic human interaction because of the emotional load of the topic. Participants often shared that receiving this information from a familiar and respected person would grant them a greater sense of safety and engagement.

In addition to face-to-face communication, printed materials like brochures and flyers were frequently seen as supplemental channels of information regarding dementia risk and prevention. Printed materials were particularly seen as useful for older citizens with lower levels of digital literacy. Participants

recommended distributing these materials via easy-to-access locations, such as the health care specialists' offices, libraries, hospitals, community centers, and places of worship.

Television was also suggested as a communication channel, through engaging and easy-to-understand campaign ads, evening talk shows on dementia, or documentaries about dementia risk and prevention. However, some participants were tired of television infomercials presenting health risk information. They had encountered infomercials so frequently that they were no longer engaged with them. The internet was also recommended, although some participants were hesitant to use online information since it could cause anxiety and uncertainty regarding the trustworthiness of the information. One participant noted: *"People get their information from Google, which is not always as reliable."* – [Setting 5]. Perceived trustworthiness of the information played a crucial role in preferences for certain information channels. One participant stated: *"No, I wouldn't want to see anything in commercials. But I do think that if you want to search for something on the internet, you can easily find the 'Hersenstichting' (Brain Foundation'). And if you type in Alzheimer's, a lot of information comes up. It would be nice if this were linked to one portal or something, so that you can quickly find what you're looking for. And then, for example, also information on what you can do yourself."* – [Setting 1].

Finally, family members were mentioned as an important source of information. Many older participants stated that they relied on their children or younger relatives to interpret and explain health information. Due to language barriers and taboos, the role of younger family members as mediators was particularly crucial in multilingual and migrant communities. As a participant stated: *"It's clear that there's a taboo about dementia in the older generation, but if there's more discussion about it, more conversations with our children, then they might recognize the symptoms and think: 'My mother or father is acting strange' and realize it can happen."* – [Setting 5].

Participants noted that information provision should not focus only on older adults but should also include younger family members. Moreover, information on dementia risk and prevention should preferably be available in multiple languages. This strategy could encourage intergenerational dialogue about dementia risk and prevention and provide more equal access to dementia prevention strategies throughout the general population.

Discussion

This focus group study explored perceptions and communication needs regarding dementia risk and prevention among a diverse population of Dutch citizens, with varying health literacy levels. Four recurring themes emerged. First, in general, many citizens preferred population-level dementia risk information above knowing their own, individual risk estimation (e.g. percentage) of developing dementia, especially in the absence of treatment options. Second, participants differed in their views on whether dementia was part of normal ageing and could potentially be prevented. While many participants had a general understanding of factors that contribute to overall health, they were uncertain or skeptical about whether and how these factors could influence brain health or reduce the risk of

developing dementia. Third, personal life attitudes, religious or spiritual beliefs and cultural norms influenced participants' views on whether dementia was part of normal ageing and could potentially be prevented. Fourth, citizens generally prefer face-to-face communication when receiving information about dementia risk and prevention. Proposed information sources were general practitioners and/or other trustworthy parties such as family members.

In this study, participants expressed clear preferences regarding dementia risk communication. Participants showed hesitations toward receiving information about their specific, individual dementia risk, i.e. explicit percentages. On the other hand, many showed interest in receiving population-level dementia risk estimates, and information about risk factors. This preference for population-level risk information seems to result from concerns about psychological discomfort, feelings of helplessness, and the current lack of effective treatments. These findings are in line with results of a study by Claus et al. (2025), where citizens were reluctant to engage with information on dementia risk and prevention due to fear, emotional burden and skepticism about the effectiveness of preventive measures (37). This is in contrast with findings in the field of oncology, where Vromans et al. (2022) found that, among 174 cancer survivors, 55% preferred personalized information over generic statistical information (38). Reasons for preferring personalized cancer statistics included a desire to feel more in control and to make better-informed treatment decisions (38). Since there is currently no available treatment for dementia, this may explain the differing results observed in our study. Overall, these results suggest a need for developing communication strategies that consider citizens' preferred level of detail and personalization in dementia risk information.

Some of our participants expressed doubt about the extent to which their individual actions could influence the likelihood of developing dementia later in life. Dementia was seen by some as part of normal aging, and a proportion of participants also tended to believe that genetic predisposition played a more significant role in the development of dementia than modifiable risk factors. These findings highlight the need for information that is in line with what people already value and for future interventions and public health campaigns to not only provide information about modifiable risk factors, but also address unmodifiable factors, uncertainties (what we do not know yet), and people's perceived lack of control over their risk, even when it comes to potentially modifiable factors.

Findings of this study further demonstrate that the perception of dementia as a condition that can be prevented is shaped by personal life attitudes, religious or spiritual beliefs and cultural norms. Especially interesting are our findings that citizens mentioned an optimistic mindset, acceptance and spiritual activities as protective factors against the development of dementia. However, these factors are not consistently supported by current scientific evidence on modifiable risk factors, such as those included in the LIBRA index or identified by Livingstone et al. (2024)(8, 39). While these beliefs may shape how citizens engage with dementia prevention, they should not be directly translated into intervention targets. Instead, they may be used as entry points to communicate evidence-based modifiable risk factors more effectively.

Moreover, cultural influences appear to shape how dementia symptoms are perceived within different communities, with some participants interpreting symptoms in terms of spiritual causes. Additionally, some communities avoid discussing dementia due to stigma and feelings of shame, and previous studies highlighted a need for better access to information about dementia (e.g. in different languages and formats) to overcome these barriers (40–42). Development of co-designed, culturally-sensitive communication materials involves considering the delivery mode, imagery, and tone of the resource; ensuring cultural appropriateness; anticipating end-user needs; and addressing linguistic challenges across multiple languages are essential aspects in dementia risk and prevention communication (43). Moreover, influencing social-structural determinants of health behavior, for example by influencing injunctive and descriptive norms and stimulating local, social support for dementia prevention behavior, is important to reduce dementia risk, especially in those populations that are currently underrepresented in dementia prevention research (44).

Furthermore, among potential information channels and sources, participants highlighted a strong preference for face-to-face communication with health care professionals, especially those working in primary care, for information provision about dementia risk and prevention. This finding emphasizes the need for trust and human connection in the communication of dementia risk and prevention. This aligns with a study demonstrating that for complicated or emotional health issues, interpersonal communication is more successful than mass media alone due to higher trust and reduced suspicion of motives (45). Interpersonal risk communication might especially be relevant for older citizens and those with lower levels of health literacy, since they may face greater challenges interpreting health information, as highlighted in a study on effective health communication during the COVID-19 pandemic (46).

In addition, participants suggested using printed materials and TV programming as approaches supplementary to face-to-face communication, which emphasizes the need for a multi-channel approach to reach different populations. Research in health communication has demonstrated that TV infomercials can effectively raise awareness about cancer and its conditions (47, 48). This approach may also have potential in increasing public understanding of dementia risk and prevention strategies.

At last, participants identified the potential role of (younger) family members as intermediaries for translating health information. This highlights the potential of intergenerational communication in disseminating information about dementia risk reduction, especially among citizens with a migration background. Public health campaigns that engage (younger) family members as communicators, and to also engage in healthier behaviors themselves (49, 50), may enhance the effectiveness and reach of messages on dementia risk and prevention (51, 52).

A key strength of this study is the involvement of citizens who are often underrepresented in dementia prevention research (53, 54). This includes citizens from migrant and non-migrant communities, with varying levels of health literacy, and from diverse socioeconomic positions. Citizens were recruited by

using meaningful engagement strategies in order to create face-to-face contact between researchers and citizens and build a relationship and trust.

A limitation of this study is that the initial design of three consecutive focus groups had to be modified. The original design involving three consecutive sessions per focus group as conducted at setting 1 appeared unfeasible in other community settings. Our findings would have been more generalizable if each focus group had followed the exact same topic guide. The variation in number of sessions may explain why participants at setting 1 provided more responses to the topics discussed during the sessions compared to participants from the other settings; they had more time to reflect on the topics and become familiar with other participants and facilitators. However, these participants also reported higher levels of health literacy. It therefore remains unclear whether the observed differences are due to the multi-session format, the participants' higher health literacy levels or a combination of both. Moreover, this limitation may operate the other way around as well, where a shorter time available per focus group and/or lower levels of participants' health literacy at the other settings may have influenced the generalizability of the findings. This study did not systematically compare responses from participants with high health literacy to those with lower health literacy.

As a next step, the findings of this study are being validated on a larger scale, while also examining differences between participants based on characteristics such as their health literacy. To enable large-scale participation among underrepresented groups, including those with lower levels of health literacy, lower socioeconomic position and/or a migration background, a co-designed booklet has been developed. This booklet contains a limited number of easy-to-understand items, along with accessible information about dementia and dementia risk. This approach ensures that those with lower literacy can also participate meaningfully. For future research, examining how various strategies for dementia risk communication affect citizens' motivation for risk reduction could provide valuable insights for creating more effective public health campaigns. Furthermore, longitudinal studies exploring how risk perceptions and information needs evolve over a lifetime are crucial for developing age-appropriate dementia risk communication strategies.

Conclusions

This study highlights the diverse communication needs and preferences of citizens regarding dementia risk and prevention. It underscores the need for tailored approaches that align with individual preferences and personal beliefs of citizens when it comes to dementia risk and prevention, with a general preference for face-to-face communication, for example, with the general practitioner. More research is needed in larger samples of citizens, especially in often underrepresented groups who are at high risk of developing dementia, to investigate their communication needs and motivation for lifestyle change for dementia risk reduction.

Abbreviations

COREQ
Consolidated Criteria for Reporting Qualitative research
FHL
Functional Health-Literacy
MCI
Mild Cognitive Impairment
NDPI
Netherlands Dementia Prevention Initiative
SD
Standard Deviation
SEP
Socioeconomic Position

Declarations

Ethics approval and consent to participate.

The Medical Ethical Committee of Amsterdam UMC declared this study as not subject to the human subject act (non-WMO) (METC no. 2023.0542). All participants provided informed consent prior to participation. The study complies with ethical standards of the Helsinki Declaration.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

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Authors' contributions

EK, DP, DH, EMAS and LNCV contributed to the study conception and design and material preparation. EK, DP, DH, AR and LNCV contributed to data collection. Analyses were performed by SA and EA. The

first draft of the manuscript was written by SA and EA. All authors commented on previous versions of the manuscript. All authors read and approved of the final manuscript.

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Figures

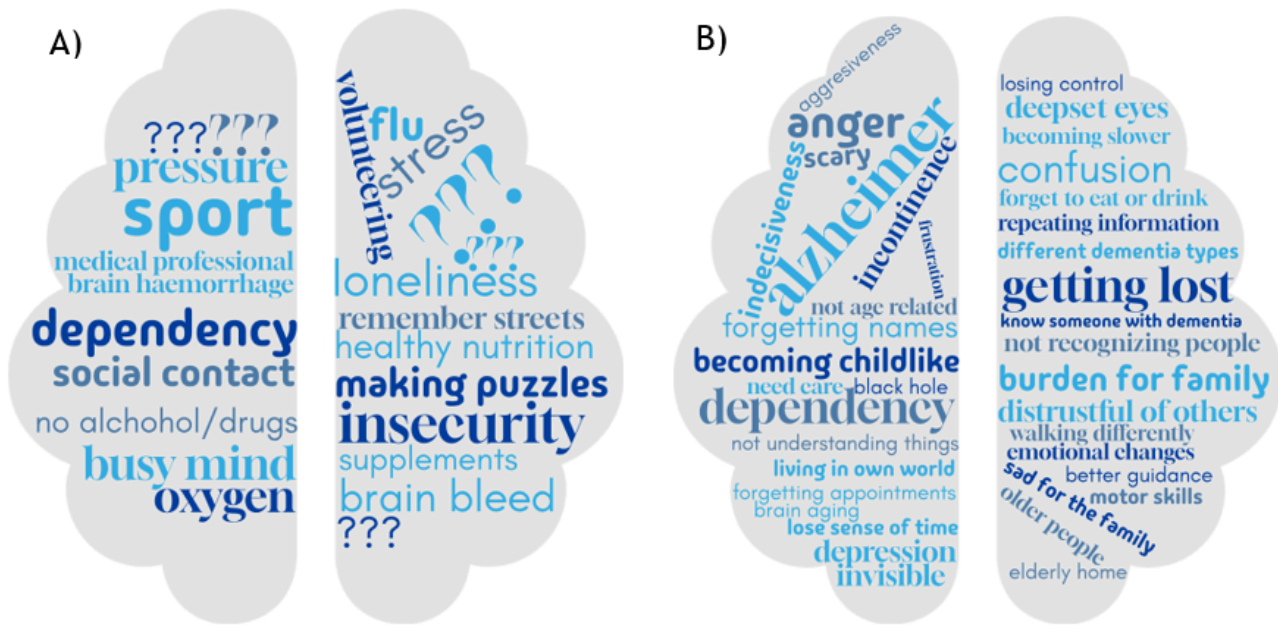


Figure 1

A) Word cloud of participants' associations with the term 'brain health'. Question marks demonstrate that (some) participants hesitated to answer. B) Word cloud of participants' associations with the term 'dementia'.

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