



Research Article

Personal and Family Perspectives Regarding Neurodegenerative Disorder Risk

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Abstract

Background: It remains unclear how awareness-of and planning-for eventual neurodegenerative disorder (NDD) diagnosis and care is influenced by age, gender, and culture across worldwide societies. **Methods:** 100 participants from eight countries were surveyed targeting 1) opinions about how knowledge of being at risk for an NDD might impact quality-of-life, and 2) how knowing the NDD risk of a parent might impact the participant. **Results:** Participants showed strong agreement in their feelings and interest in knowing the NDD risk for both their parents and themselves, but age, gender, and country differences were observed. Openness to assessment of NDD risk for oneself was influenced by age, interest in investigating NDD mitigation strategies were greater in women, willingness to pay out-of-pocket to establish NDD risk differed across countries, and wanting to know a parent's NDD risk was subdued in Germany and Japan. Despite potential anxiety associated with NDD risk disclosure, benefits toward future planning were the primary driver in participants interested in knowing the risk of NDD in themselves or their parents. **Discussion:** Societal communication strategies aimed at public health NDD informational and screening initiatives should be sensitive toward considering population characteristics of age, gender, and country of residence. Younger adults and especially women should be targeted with educational messaging about managing NDD risk.

Keywords: Neurodegenerative disorder risk; Prodromal disclosure; Dementia; Mild cognitive impairment; Healthcare management

Background

By 2050, the number of people living with dementia worldwide is projected to increase from approximately 60 million to over 150 million (Shannon et al., 2026). Mild cognitive impairment (MCI) represents a prodromal stage between normal cognitive function and dementia, which affects 15% of those over 50 years of age and as many as 22% of those over 70 years (Campbell et al., 2013; Bai et al., 2022). Many livings with MCI and dementia remain undiagnosed (Mattke et al., 2023; Prince et al., 2011). Even in higher-income countries like Germany, life expectancy is less than 10 years once MCI begins (Martins et al., 2022). Studies done in the United States have also shown demographic differences in morbidity and mortality with women living on average 4.2 years with MCI and 3.2 years with dementia, compared to 3.5 and 1.8 years for men (Hale et al., 2020).

Care of people living with cognitive impairment requires significant resources. Two or more caregivers are typically required to assist people living with dementia who reside in their own homes (Gamble et al., 2022). Residential long-term care facilities are most often required for people with moderate or severe dementia, and especially those showing symptoms of agitation, distress or delusions (Exarchos et al., 2025; Toccaceli et al., 2023). Annual institutional dementia care costs in Australia, Canada, France, Japan, Italy, United Kingdom, and United States range from \$22,000 to well over \$100,000 depending in part on the Alzheimer's dementia stage. Meanwhile over half of total societal cost of dementia is borne by unpaid caregivers and families, representing substantial covert and difficult to estimate opportunity and quality of life costs (Gnanamanickam et al., 2018; Canadian Centre for Economic Analysis, 2023; Rapp et al., 2018; Ishihara et al., 2024; Mennini et al., 2025; Wittenberg et al., 2020; Zissimopoulos et al., 2025).

As a neurodegenerative disorder (NDD) advances, prodromal clinical presentations may appear before the clinical cognitive disease manifests (Rossini et al., 2020; Almkvist & Winblad, 1999). For example, most adults who are diagnosed with isolated REM sleep behavior disorder over age 60 years have a prodromal form of Lewy body disease associated with a strong future risk of dementia with Lewy bodies or Parkinson disease (Alexandres et al., 2024; Cesari et al., 2022). Early detection of such often subtle prodromal physiological changes and clinical presentations using new technologies could result in earlier adoption of lifestyle changes and dementia interventions that could delay onset or slow progression of underlying evolving neurodegeneration (Reuben et al., 2024; Levendowski et al., 2024; Levendowski et al., 2025;

Meghdadi et al., 2024; Waninger et al., 2020).

Several studies have found that most prodromal stage NDD patients and community adults would prefer to know about their risk for future development of NDD in order to spur family discussions and plan for the future (Gossard et al., 2023; Levendowski et al., 2023; Levendowski et al., 2023). However, few studies have evaluated the impact of culture and nationality on NDD risk management preferences, despite reported age, gender and cultural differences in dementia stigmatization and care resources (Kim et al., 2023; Aranda et al., 2021). These observations point to demographic-based differences that should be considered when designing appropriately tailored NDD risk management initiatives (Giebel et al., 2025; Li & Li, 2025; Watson et al., 2021).

This study involved two surveys that explored preferences about receiving prognostic information about NDD risk across eight high income/resourced countries with different healthcare systems. The first survey targeted opinions about how having NDD risk might impact the participant's own life, and the second survey focused on how NDD risk of a parent might impact the participant.

Methods

Participants

Approximately, 100 participants (age range: 30 – ≥ 70 years old) were recruited via SurveyMonkey in February 2025 from 8 targeted countries [Australia (AU), Canada (CA), France (FR), Germany (DE), Italy (IT), Japan (JP), United Kingdom (UK), and United States (US)] with a self-reported minimum household income of approximately \$50,000 USD (to sample those who were at least middle-class). Participants from each country were recruited by age and household income to provide representative samples of middle-aged and older adults across relatively equivalent socioeconomic backgrounds.

Measures

Participants were asked to complete two assessments via SurveyMonkey. The first assessment, the "About Me" survey, combined 13-statements with 5-point Likert scale responses to assess how NDD risk might hypothetically impact one's own life. The second assessment, "About My Parent" survey, modified each of the 13 statements in the "About Me" survey, to explore opinions about gaining NDD risk knowledge about the participants' parent(s) and accordingly, the perceived impact of such knowledge on the participant. The About Me survey required individuals to be at least 50 years of age, and the About My Parent survey required participants to be between 30 and 59 years. No requirements were placed to sex-balance responses by country. Prior to uploading into SurveyMonkey, the two surveys were professionally translated into potential participant's native languages. Countries for which

the translated survey was validated in their native language are listed in Table 2.

Study Procedures

The About Me and About My Parent surveys were completed approximately one-week apart with no requirement for the surveys to be completed by the same people. Survey responses were obtained from a diverse, voluntary, online population of anonymous volunteers using SurveyMonkey’s Targeted Audience collector program. SurveyMonkey panellists take online surveys for a variety of incentives, including gifts to charity, credits that can be redeemed for gift cards, or a chance to win a sweepstakes prize, and must meet minimum quality and activity criteria. Given the responses were acquired across multiple countries with no personal identifiers, this study was determined to be Institutional Review Board exempt.

Statistical Procedures

Responses were tallied as positive (somewhat or strongly agree), negative (somewhat or strongly disagree), or neutral. Age, sex, and country were analyzed with logistic regression for both positive and negative responses to identify pair-wise comparisons, further analyzed using Chi-squared tests. Response results were then grouped into five topical categories: the future, family and friends, managing NDD risk, and physician interaction.

Results

Sample Description

Table 1 presents the sex and age distributions by country for the two surveys with the minimum household income denomination in local currencies and U.S dollar equivalents. A total of 802 (n = 100 -101 per country) participants completed the “About Me Survey”, and a total of 803 (n = 100 – 100 per country) participants completed the “About My Parent” survey. For both surveys, the majority of participants were men (total: 53% - 54%); however, gender distribution varied by country. For example, in the US, more women (63%) than men (37%) completed the “About Me” survey. In contrast, in Japan, more men (77%) than women (23%) completed the “About Me” survey. For the “About My Parent” survey, more women (62%) than men (38%) completed the survey in UK; however, a higher number of men (62%) compared to women (38%) completed the survey in Japan.

Across the countries, a larger proportion (53%) of older adults (≥60 years of age) completed the “About Me” survey; whereas a larger proportion (63%) of adults in middle to late midlife (≥40 years of age) completed the “About My Parent” survey. There was a greater cross-country difference in age for the “About Me” survey (p<0.005) compared to “About My Parent” (p<0.025). As noted in Table 1, the mean age of the respondents did vary based on the country of origin and the particular survey.

Table 1: Distributions of participants by country, sex, and age for the two surveys.

Country	Survey: “About Me”					Survey: “About My Parent”					House-hold income >	
	n	% Women	Age, %			n	% Women	Age			Local Currency	U.S. Dollar Equivalent
			50- 59	60-69	>70			30- 39	40-49	50-59		
Australia	100	54	43	26	31	100	50	38	40	22	\$60,000	\$45,750
Canada	100	46	49	42	9	100	46	48	32	20	\$80,000	\$58,960
France	100	43	63	26	11	101	41	36	36	29	€45,000	\$49,000
Germany	100	43	63	28	9	100	37	42	27	31	€39,000	\$42,425
Italy	101	40	57	33	10	100	48	32	48	20	€44,000	\$47,850
Japan	101	23	61	33	6	100	38	22	28	50	¥8,000,000	\$53,300
UK	100	55	61	20	19	101	62	47	35	18	£35,000	\$47,800
USA	100	63	33	33	34	101	51	33	28	39	\$50,000	\$50,000
Total	802	46	46	33	20	803	47	37	34	29		

Summary of Findings

Table 2 presents the statements used in the two surveys which are organized into five topical categories with multiple logistic regression results based on the combination of strongly or somewhat agree (“positive”) responses for age (A), sex (S), and country (C). The proportion of positive responses associated with the logistic regression results for the two surveys are additionally presented.

Q	Survey Statements	About Me		About My Parent	
Finding Out					
1	It is important for me to know if I (my parent(s)) have a risk of developing a neurodegenerative condition in the future, even if nothing can be currently done to prevent or cure those diseases.	A<0.001	50-59: 79% 60-69: 73% >70: 64%	C<0.005	AU-92% CA-85% DE-74% FR-86% IT- 86% JP-64% UK-83% US-78%
2	I would prefer not to know about my risk for developing a neurodegenerative condition.	A<0.025	50-59: 28% 60-69: 22% >70: 19%	n/a	-----
3	I would pay for a diagnostic procedure to determine my parent’s increased risk of a neurodegenerative condition if it was not provided by their healthcare.	n/a	-----	C<0.005	AU-78% CA-78% DE-55% FR-72% IT-77% JP-60% UK-70% US-60%
The Future					
4	My priorities and the way I plan on living my life would change if I learned that I was at increased risk for a neurodegenerative condition.	A<0.005	50-59: 81% 60-69: 75% >70: 68%	C<0.005	AU-77% CA-80% DE-75% FR-80% IT-79% JP-57% UK-77% US-66%
	My priorities would change if I learned that my parent(s) was at increased risk for a neurodegenerative condition.				
5	I believe that knowing about my (parent’s) risk for developing a neurodegenerative condition will help me plan for the (their) future.	A<0.025	50-59: 83% 60-69: 78% >70: 74%	C<0.025	AU-91% CA-84% DE-76% FR-87% IT-80% JP-70% UK-80% US-84%
6	I would change my future plans for health resources and support if I learned I was at risk for a neurodegenerative condition.	A<0.05	50-59: 79% 60-69: 75% >70: 70%	S<0.01	AU-91% CA-85% DE-82% FR-88%
	C<0.05			IT-90% JP-67% UK-90% US-83%	
7	If I (my parent) was found to be at risk for a neurodegenerative condition, I would feel anxious about not knowing when the (their) memory problems might begin.	ns	50-59: 74% 60-69: 79% >70: 73%	C<0.025	AU-78% CA-75% DE-76% FR-78% IT- 80% JP-60% UK-74% US-68%

8	I would feel more pessimistic about my (parent's) future after learning I (they) might be at increased risk for a neurodegenerative condition.	A<0.025	50-59: 64% 60-69: 57% >70: 54%	ns	AU-67% CA-61% DE-62% FR-74% IT-79% JP-49% UK-64% US-57%
9	I believe that knowing about my parent's risk for developing a neurodegenerative condition will influence how I plan for my future.	n/a	-----	C<0.025	AU-89% CA-81% DE-72% FR-84% IT-86% JP-64% UK-79% US-80%
Family and Friends					
10	I would worry that my family would be anxious knowing I could develop a neurodegenerative condition.	A<0.025	50-59: 70% 60-69: 70% >70: 57%	C<0.05	AU-81% CA-70% DE-63% FR-72% IT-78% JP-62% UK-68% US-67%
	My parent(s) would worry that our family would be anxious knowing they were at risk of developing a neurodegenerative condition.				
11	It would be important for my (parent's) family/friends to know if I (my parent(s)) was at risk for a neurodegenerative condition in the future.	ns	50-59: 72% 60-69: 68% >70: 64%	C<0.001	AU-79% CA-82% FR-80% DE-66% IT-70% JP-56% UK-67% US-64%
Managing NDD Risk					
12	If I (my parent(s)) was found to be at risk for a neurodegenerative condition, I would want to learn more about medications and adaptive therapies that could delay onset.	ns	50-59: 88% 60-69: 85% >70: 88%	S<0.001 C<0.05	AU-91% CA-78% DE-78% FR-87% IT-88% JP-60% UK-88% US-81%
13	I have a good understanding of what lifestyle patterns might help (my parents) delay the start of a neurodegenerative condition.	A<0.001 *A<0.025	50-59: 49% 60-69: 39% >70: 30%	ns	AU-55% CA-72% DE-49% FR-62% IT-64% JP-42% UK-56% US-55%
Physician Interaction					
14	I would want my (parent's) physician to ask my (parent about their) "preference for knowing" before sharing my (their) potential risk for a neurodegenerative condition.	A<0.025	50-59: 78% 60-69: 76% >70: 66%	C<0.005	AU-85% CA-78% DE-71% FR-86% IT-81% JP-67% UK-74% US-73%

15	I would lose trust in my (parent's) physician if they knew but did not discuss my (parent's) increased risk of a neurodegenerative condition.	ns	50-59: 75% 60-69: 79% >70: 78%	S<0.001 C<0.025	AU-82% CA-76% DE-73% FR-68% IT-82% JP-45% UK-75% US-72%
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Table 2: Statements used for the “About Me” and “About My Parent” surveys followed by the corresponding significant logistic regression findings and distributions of those who responded with strongly or somewhat agreed. Abbreviations: A=age (differences between 50–59 vs. >70-age groups, *A = age differences between the 50-59 vs. 60-69 age groups), S=sex and C=country. ns=not significant, and n/a=not asked, with. AU=Australia, CA=Canada, DE=Germany, FR=France, IT=Italy, JP=Japan, UK=United Kingdom, US=United States.

Participants’ NDD risk impacting their life

Significant age differences were observed across the five topical categories for the “About Me” Survey. Specifically, for the **Finding Out** category, the proportion of 50–59-year-olds who strongly or somewhat agreed “*It would be important to know if I have a risk of developing an NDD*” (Q1) was significantly greater than the 70-or-more year-old group ($p<0.0005$). The 50–59-year-olds also “*preferred not to know if they were at risk of developing an NDD*” (Q2) versus the 70-years-and-older group ($p<0.05$).

For **The Future** category, significant differences were found across the different age ranges on how the knowledge of NDD risk would affect their view of the future. The 50–59-year-old cohort strongly/somewhat agreed that “*knowing NDD risk would change their priorities and how they planned on living their life*” (Q4, $p<0.005$), “*particularly in planning for the future*” (Q5, $p<0.025$) compared to the 70 years and older group. A higher proportion of the youngest group would “*change their future plans for health resources and support*” (Q6) based on NDD risk compared to the oldest cohort ($p<0.05$). Despite more positive responses to those questions concerning NDD risk knowledge preference, the youngest cohort more frequently endorsed that they would “*feel more pessimistic about their future based on NDD risk*” (Q8) compared to the oldest group ($p<0.05$).

For the **Family and Friends** category, youngest age group expressed “*greater worry in sharing their NDD risk information with friends and family*” (Q10) compared to the oldest group ($p<0.01$).

For the **Managing NDD Risk** category, having a comfortable “*understanding of lifestyle behaviors associated with NDD risk reduction*” appeared to decrease with age (Q13) ($p<0.0001$). Conversely, the youngest group strongly/somewhat disagreed with this statement compared to 35% for the 60-69 years-old ($p<0.01$) and 39% for the 70-plus years-old ($p<0.005$).

Lastly, for the Physician Interaction category, the 50–59-year-olds more frequently agreed that “*they would want their physician to ask about their preference for knowing about a potential NDD*

risk” (Q14) compared to the 70-plus year-old group ($p<0.01$). No significant sex and country differences were observed across the categories for the “About Me” Survey.

Parents’ NDD risk impacting Participants’ Life

In the questions related to Finding Out, participants from Japan had the fewest positive responses (i.e., strongly or somewhat agree) to the statement “*It is important for me to know if my parent has a risk for developing a NDD condition*” (Q1) relative to all countries except Germany. Fewer positive responses were reported from Germany compared to participants in Australia and France (all $p<0.05$). Japan, Germany, and the US participants responded that they would be *less willing to pay for an NDD diagnostic procedure not provided by healthcare for their parent*” (Q3) compared to those in Australia, Canada, France, and Italy ($p<0.05$).

For questions related to **The Future** for their parent or themselves, fewer Japanese participants felt “*his/her priorities would change if their parent was at an increased NDD risk*” (Q4) compared to all of the other represented countries except the US ($p<0.025$), while US had fewer affirmative responses compared to France ($p<0.05$). Japan had fewer positive responses to the statement “*knowing about my parents’ NDD risk will help me plan for their future*” (Q5) compared to Australia, Canada, France, and the US ($p<0.05$), while German participants had fewer positive responses relative to Australia and France ($p<0.05$).

Positive responses to “*helping their parent plan with their health resource and support needs*” (Q6) were fewer in Japan compared to Australia, Canada, France, Germany, Italy, UK, and the US (all $p<0.025$). Respondents from Japan and US appeared to be less “*anxious in knowing when their parents cognitive problems might begin*” (Q7) compared to the other countries($p<0.05$).

Finally, when considering “*if a parents’ NDD risk would impact the participant’s future*” (Q9), respondents in Japan had fewer positive responses compared to Australia, Canada, France, Italy, UK, and the US ($p<0.025$), while German participants had fewer positive responses relative to Australia, France, and Italy ($p<0.05$).

For Family and Friends, the proportion of positive responses to “a parent with NDD risk worrying about the family being anxious” (Q10) were fewer in Germany, Japan, and the US relative to Australia ($p<0.05$), while Italian parents would be expected to worry more than those in Japan and Germany ($p<0.05$). The importance for “notifying friends and family of a parent’s NDD condition” (Q11) was greater in Australia, Canada, and France compared to Germany, Japan, and the US ($p<0.05$), while Canada’s positive responses were greater than in the UK ($p<0.025$).

As to Managing NDD Risk all countries had greater positive responses to “learning more about medications and adaptive therapies to delay NDD onset” (Q12) compared to Japan (all $p<0.01$).

Finally, when considering Physician Interaction, the proportion of participants who “wanted a physician to ask a parent about their preference for knowing about a potential NDD risk” (Q14) was greater in Australia relative to Japan and Germany ($p<0.05$), positive responses were greater in France relative to Germany and the US ($p<0.05$), and Italy was greater than Japan ($p<0.05$). Those who would “lose trust in the parent’s physician if they knew but did not discuss the parents increased NDD risk” (Q15) were proportionally less in Japan relative to the other seven countries (all $p<0.001$), while positive responses were less in Australia and Italy compared to France ($p<0.05$).

Differences between men and women were observed when considering the impact of a parent with NDD Risk. Women were more likely to express willingness to help their parent(s) with their future plans for health resources (Q6) (88% vs. 82%, $p<0.025$), a consistent pattern across all countries. Women agreed to the statement “I would want to learn more about medications and adaptive therapies that could delay my parent’s NDD onset” (Q12) more strongly than men (88% vs. 76%, $p<0.0001$), with agreements greater in Germany (89% vs. 71%, $p<0.05$) and in the UK (95% vs. 76%, $p<0.01$). Finally, more women reported they would lose trust in their parent’s physician if they knew but did not discuss their parent’s NDD condition (Q15) compared to men (78% vs. 66%, $p<0.0001$), with women agreeing to this statement in greater numbers in Japan (63% vs. 34%) and in the UK (84% vs. 61%) (both $p<0.01$).

Discussion

Interest in NDD Risk Assessment

This study evaluated perspectives and preferences about the future risk of developing a NDD, evaluating the effect of age, gender and geography. The surveys targeted age groups when cognitive decline is likely to begin to emerge, and from those likely to become caregivers to their parents, while evaluating between-

country differences, limited to those of similar socioeconomic conditions. These data provide evidence that suggests interest in pursuing an NDD risk assessment is age dependent and skewed toward older, middle-aged (ages 50-59) as compared to old-aged participants (70-years or older) across various income-resourced countries. Preferences for knowing about NDD risk may change across age groups as awareness grows about currently available and future disease-modifying interventions for NDD (Rose et al., 2004).

Interestingly, respondents’ preferences for wanting to know if a parent had increased NDD risk did not vary across countries as might be anticipated, given expectation for caregiving resources implicit in different healthcare systems. For example, the indirect costs contributed by the caregiver as a proportion of total dementia costs in France and Italy were substantially differ (i.e., 54% and 80% respectively), yet in our study participant interest in knowing their parent’s NDD risk in these two countries were similar (Jönsson, 2022). Conversely, the expected caregiver’s contributions in the UK and Germany were similar, yet in our study participant interest in assessing a parent’s NDD risk was 9% greater in the UK (Jönsson, 2022).

Our study confirmed that a clear majority of participants (64-72%) expressed preference for learning about their own NDD risk and an even higher proportion (81%) wanted to know if their parent was at increased risk of an NDD condition. This finding has clear implications for shared decision making in clinical practice settings and suggests that health care providers should ask their patients as well as their families about their individual values and preferences for receiving NDD risk counselling in clinically appropriate settings (Schaeffer et al., 2024; Stefani et al., 2023).

A participant’s apparent willingness to pay out-of-pocket (OOP) for a parent’s NDD risk assessment, interestingly, also did not seem to relate to the proportion of healthcare expenditures each participant would expect to pay in their country. The expected OOP payments as a proportion of total healthcare expenditures were similar in Canada, Germany, Japan, and the US (i.e., 12-14%), yet participant willingness to pay for a parent’s NDD risk assessment ranged from 57–80% (Baird 2016). In Australia and Italy, greater willingness to pay for a parent’s NDD assessment was consistent with greater expected OOP payments (18-19%), however, in France the willingness to pay was near the top of all countries surveyed while expected OOP payments was the lowest (8%) (Baird 2016).

Education and Communication

In the absence of a cure or an NDD treatment that is globally accessible, risk reduction aiming to slow progression remains the most feasible and proactive way to combat dementia (e.g., diet,

exercise, cognitive training and rehearsal, managing general and cardiovascular health, etc.). Our study highlighted across-country differences in awareness of disease mitigation interventions that may have important public health implications for future societal initiatives to improve community awareness of these low-cost yet potentially high-impact strategies. At least 40% of those in all countries except Canada were relatively unaware of lifestyle patterns that could help delay the start of a NDD condition. When available, the typical age for dementia screening and education target those 70-years and older. However, in this demographic group, only 30% were aware of lifestyle patterns that could delay the start of an NDD condition.

Physicians are expected to play a key role in helping to manage NDD risk. The degree to which primary care can serve as an effective channel for dementia education and screening is debatable. Survey results found 82% of primary care physicians believed they were gatekeepers for dementia care and over 50% fielded questions about dementia every few days (Sideman et al., 2023). A conflicting report suggests dementia screening is rarely performed at the primary care level and only half do a full workup even when there is a clear cognitive concern (Perales-Puchalt et al., 2023). Interestingly, 49% of those 50-59 years-of-age, were aware of lifestyle interventions that could delay dementia onset. We found younger adults placed a greater premium on transparency of physician communication regarding NDD risk, and there were important cultural differences impacting physician interaction expectations. It is possible that the relatively low rate of agreement and greater neutral responses in Japan concerning physician interaction resulted from greater institutional trust. Conversely, it's been suggested that Asian healthcare providers do not proactively involve caregivers in the medical and longer-term decision-making process, despite the preferences of the patient and caregiver (Ng & Indran, 2021).

The influence of age on positive responses to having “awareness of lifestyle patterns that delay the start of an NDD condition” was consistent across the two surveys. We found the average positive response ranged from 59% for those 30 to 50 years, 50% for those 50 to 60 years, and 36% for those 60 years and older. Given that we did not detect interactions between age and country with the logistic regression analysis, age-related differences in NDD awareness as it relates to communication strategies should be investigated further.

Our findings are consistent with other studies that found that women were more likely than men to serve as caregivers for a person with dementia (Martínez-Santos et al., 2021). Interestingly, we confirmed previously reported gender disparities related to caregiver burden and well-being were consistent across countries (de Graaff et al., 2025; Bjørge et al., 2024). This study suggests

resources for dementia education and care planning can be tailored towards women caregivers' interests/needs, given women more than men would seek information to help delay the onset or mitigate a NDD. Of interest would also be the effect that knowledge of a parent's NDD risk severity or changing severity has on the caregiver's burden and/or mental health, given both contribute to increased parental mortality risk (Jiang et al., 2024; Lwi et al., 2017).

Who to communicate with and how best to communicate results from an NDD risk assessment revealed additional themes with group-differences across both surveys. Participants perceived that sharing personal or parental NDD status with family members may cause anxiety due to uncertainty around disease onset or progression. These findings suggest routine follow-up testing would be helpful in reducing stress and anxiety and improve patient and family member engagement by monitoring critical changes in NDD risk trajectory (Park et al., 2018).

Study limitations

This study included a multi-national and multicultural sample population that may not be generalizable to middle- and lower-income economies. Future studies should include respondents from countries across all income levels is of particular importance since the presence, severity, and rate of progress for dementia appears to be higher in those with fewer years of education or from low/middle income countries (Hale et al., 2020; Gnanamanickam et al., 2018).

Another limitation of this study was the use of a new survey instrument that was administered but not validated across multiple languages. Additionally, the results were based on small samples for each country, an important limitation. While the 70 years of age and older group responded less positively than the 50-59 years-old cohort in the About Me survey it's possible that increased sampling from the US (26%), Australia (24%), and the UK (15%) in this older cohort contributed to group differences. We did not, however, detect interactions between age and country with the logistic regression analysis. It would be of great interest to see if the non-significant findings are consistent with a larger population sample representing a broader diversity of worldwide countries and a larger sample size.

Use of the SurveyMonkey platform to anonymously access privacy-protected survey responses without use of a consent form is another clear limitation, since only limited demographic, socioeconomic, and current health information concerning respondents could be ascertained, despite the platform being used for previous human subject studies (Carvalho et al., 2025; Ali et al., 2025; Hall et al., 2025). It's unclear if a greater tendency for neutral responses to some questions from Japan might be attributed to a

cultural tendency to provide more cautious or modest responses, or for perceived dementia stigma (Noguchi et al., 2025; Culpepper & Ballenger, 2022). It may also be more common in some Asian cultures for caregivers to perceive “losing face” and experience greater isolation and loneliness than in other cultures (Lwi et al., 2022). Future studies involving a larger and broader set of Asian countries should be performed, including further questions probing possible explanatory factors for different cross-cultural responses.

Conclusions and Implications

Our findings have implications for clinical settings for health care providers as well as future public health informational and screening initiatives concerning NDD. Providers and public health communication strategies will need to consider and incorporate different degrees of emphasis for older adults, and in countries with lower awareness rates of lifestyle and activity choices and habits that might mitigate NDD disease risk. We also found that compared to men, more woman was motivated to seek information to help delay NDD onset. It’s possible that targeting parental dementia prevention education toward adults in midlife will have the greatest long-term impact on reducing NDD risk, but only after younger generations reach an older age. Further investigations aimed at tailoring health education awareness and lifestyle changes favoring NDD risk prevention can facilitate optimized approaches toward meeting the needs of patients, their families, and the broader community.

Declaration of Conflict of Interest

Mr. Levendowski and Ms. Berka are employed by a company with technologies that can assess neurodegenerative disorder risk. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. Dr. Boeve receives honoraria for SAB activities for the Tau Consortium; research support from Alector, Biogen, Transposon and GE Healthcare. Dr. Lewis is a consultant for Pharmaxis Ltd.

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Ethics Approval and Informed Consent Statement

Survey responses were obtained anonymously with no identifiers other than gender, 10-year age bracket and country, and as such this study was determined to be Institutional Review Board exempt.

Data Availability Statement

Survey responses by age and country will be made available upon request.

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