


# Perceptions of community members in Australia about the risk factors, symptoms and impacts of dementia: A cross-sectional questionnaire study

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## Abstract

**Objectives:** Ensuring that the Australian public has an accurate understanding of the characteristics of dementia may assist in improving timely detection of dementia. This cross-sectional questionnaire study aimed to examine community members' perceptions of the risk factors, symptoms and impacts of dementia.

**Methods:** Participants were recruited from outpatient units at a major regional hospital and were aged at least 18 years, a patient or an accompanying support person, did not have a dementia diagnosis, had sufficient English knowledge and were well enough to complete a survey. Participants completed a web-based survey on a touchscreen computer including items exploring knowledge of dementia risk factors, symptoms and perceived impacts if they or a loved one had dementia. Counts and proportions were calculated and perceived impacts of dementia were compared for self versus loved one using a  $\chi^2$  test.

**Results:** Of 353 eligible individuals approached, 208 consented and were included in the study. Between 30% and 61% ( $n = 62$ – $127$ ) of participants believed modifiable factors such as high alcohol consumption and high blood pressure were associated with increased risk of dementia. While a majority of participants (87–96%;  $n = 164$ – $181$ ) identified memory-related symptoms, less than one-third recognised behavioural symptoms. Participants were more likely to identify emotional and practical impacts compared to physical or social impacts as most difficult if they or a loved one had dementia.

**Conclusions:** There remains a need for increased community education to address knowledge gaps regarding modifiable risk factors, behavioural symptoms and potential impacts of dementia on the individual diagnosed and their carers.

## KEYWORDS

cross-sectional study, dementia, impacts, knowledge, risk factors, symptoms

## 1 | INTRODUCTION

### 1.1 | Importance of improving public awareness regarding dementia

The World Health Organization (WHO) global action plan on the public health response to dementia (2017–2025)<sup>1</sup> highlighted improving community dementia awareness as a key area for improving outcomes for people with dementia. For example, a lack of understanding and awareness of dementia symptoms among community members may result in delays in dementia diagnosis.<sup>2,3</sup> Low levels of awareness of how dementia impacts the lives of those living with the condition may contribute to stigma and a lack of understanding of how best to support people with dementia in the community. Accordingly, national action plans across Europe, the Americas and the Asia-Pacific region emphasise the value of general public education to reduce stigma and promote the earlier detection of signs and symptoms of dementia,<sup>4–6</sup> suggesting strategies such as public awareness campaigns, a national helpline and population surveys to monitor public knowledge regarding dementia. Exploring current perceptions of dementia among community members will assist in shaping community education campaigns to promote awareness and understanding of the condition.

### 1.2 | Dementia risk factors

A recent review found that a number of modifiable risk factors including reduced physical activity, smoking, obesity, depression, diabetes, social isolation, hearing loss, alcohol consumption, head injury and air pollution are associated with an increased likelihood of developing dementia.<sup>7</sup> However a review of international studies examining awareness of dementia prevention among the general public found that a median of 48% of respondents across 26 included studies believed that dementia was not preventable.<sup>8</sup> Few Australian studies have explored community members' perceptions of dementia risk factors. In one study of 2000 community-dwelling adults that examined perceptions of factors contributing to the development of dementia, over 80% identified genetic factors and older age, while only 34.4–75.3% identified potentially modifiable factors such as heart disease, stress and social isolation or loneliness as contributing factors.<sup>9</sup> In another Australian study of community-dwelling adults,<sup>10</sup> 3–57% of participants identified lifestyle factors such as non-smoking, physical and mental activity as being potentially protective. Given advancements in scientific knowledge and Australian public awareness campaigns focusing on dementia risk reduction, it is timely to

#### Policy Impact

This study revealed misconceptions among community members regarding dementia risk factors, symptoms and impacts. Improving community awareness of dementia may improve timely detection of dementia, while also assisting communities to understand the experience of dementia. The findings may guide the development of education programs to raise awareness across these areas.

explore current perceptions regarding dementia risk factors among Australian community members.

### 1.3 | Symptoms of dementia

Low awareness of dementia symptoms has been identified as a persistent barrier to individuals and their families seeking assessment for possible dementia diagnosis.<sup>11</sup> A timely diagnosis may enable individuals and their families to plan for the future and access information and support to manage the condition.<sup>12</sup> Only one Australian study has explored community understanding of dementia symptoms, finding that 81.5% of participants were able to recognise dementia using a vignette.<sup>9</sup> However, this method is suboptimal for assessing awareness of symptoms, as results are limited to the specific set of symptoms included in the scenario. Further, this approach does not allow for assessment of variability in awareness across different types of symptoms.

### 1.4 | Impacts of dementia

A diagnosis of dementia can significantly impact psychological well-being and quality of life for the person diagnosed, with feelings of disengagement, loss of identity, loneliness and low self-esteem often reported.<sup>13–16</sup> The impact of dementia on informal caregivers' psychological, physical, social and financial well-being is also significant.<sup>17–20</sup> Dementia caregivers report high levels of physical strain, emotional stress and financial hardship,<sup>18,21,22</sup> with up to 32% experiencing depression.<sup>23</sup> Improving community awareness of the range of impacts of dementia may promote greater preparedness for future dementia diagnosis, while also assisting communities to understand the experience of dementia and better support those living with a diagnosis in their community. To our knowledge, no other Australian studies have explored

community members' perceptions of the impacts of dementia.

## 1.5 | Aim

This study aimed to examine, among people attending a hospital outpatient clinic, perceptions of:

1. Possible risk factors for dementia.
2. Symptoms of dementia.
3. The perceived impacts of having dementia on the individual and their support person/s.

## 2 | METHODS

### 2.1 | Design and setting

A cross-sectional self-administered web-based survey was conducted in a range of outpatient clinics of one major tertiary hospital in regional New South Wales (NSW), Australia. Of the patients presenting to this hospital in 2020–2021, there was an approximately even distribution of males and females, the highest presentation rate was for people aged older than 85 years, and 63% lived in major cities. Clinics included general surgery, orthopaedics, rehabilitation, cardiology, respiratory and gastroenterology. Data were collected from December 2017 to March 2018.

### 2.2 | Participants

Individuals attending outpatient clinics were eligible to participate if they were: aged at least 18 years; a patient or a support person accompanying a patient to an appointment; did not have a dementia diagnosis; had sufficient English knowledge to complete a survey and were judged to be well enough to complete a survey.

### 2.3 | Recruitment and data collection

A trained research assistant approached potentially eligible patients and support persons in the outpatient waiting room prior to their appointment. The research assistant provided verbal and written information about the study, confirmed eligibility and invited eligible individuals to participate. Consenting participants completed a web-based survey on a touchscreen computer while they waited for their appointment. Completion of the survey was taken as implied consent. Data were automatically uploaded to a secure online server. The age and gender

of non-consenting individuals was collected to assess consent bias.

### 2.4 | Measures

A study-specific measure was developed and included in a larger survey about dementia (other items reported elsewhere). The survey items are provided in Appendix S1. The survey items were developed based on comprehensive reviews of the literature (see details for each survey component below) and further refined with input from the study team. The survey was pilot tested with 20 participants to ensure adequate comprehension and acceptability of items. Items were preceded by the following introductory text: 'Dementia (sometimes called Alzheimer's disease) is a brain condition which affects people's thinking, memory and behaviour. These symptoms get worse over time and there is currently no cure.'

### 2.5 | Risk factors for dementia

Participants were presented with 15 possible risk factors for dementia and asked to rate how strongly they agreed that each played a role in whether a person gets dementia on a 5-point Likert scale (*strongly agree* to *strongly disagree*, including an *unsure* option). The items included a range of possible genetic, lifestyle, psychosocial and environmental factors, including items drawn from a 2017 review published in *The Lancet*.<sup>24</sup>

### 2.6 | Symptoms of dementia

Participants were presented with 15 symptoms of dementia and asked to indicate on a 5-point scale how strongly they agreed that each was a symptom of dementia (*strongly agree* to *strongly disagree*, including an *unsure* option). Items were based on a thorough review of the literature<sup>25,26</sup> and existing measures of dementia symptoms (e.g. Revised Memory and Behaviour Problems Checklist).<sup>27</sup> The items were selected to represent a range of early-, middle- and late-stage symptoms of dementia.

### 2.7 | Perceived impacts of dementia

#### 2.7.1 | Impacts for self

Participants were asked 'Besides memory problems, which of the following would you find most difficult if you had dementia?' Participants could select up to three responses

from the following list: emotional impact (e.g. stress), social impact (e.g. loss of friends or hobbies), practical issues (e.g. needing assistance with daily tasks), financial strain (e.g. difficulty paying for medical expenses), physical health (e.g. problems with toileting), legal issues (e.g. appointing someone to make decisions on my behalf), dealing with the health system (e.g. getting what I need from health providers) or other (please specify).

### 2.7.2 | Impacts for loved one

Participants were also asked 'Besides memory problems, which of the following would you find most difficult if a loved one had dementia?' Participants could select up to three responses from the following list: emotional impact (e.g. stress), social impact (e.g. loss of your friends or hobbies), practical issues (e.g. providing assistance with daily tasks), financial strain (e.g. difficulty paying for medical expenses), physical health (e.g. feeling tired), legal issues (e.g. appointing someone to make decisions on their behalf), dealing with the health system (e.g. getting what they need from health providers), other (please specify).

## 2.8 | Demographic characteristics

Participants self-reported their gender and age (by typing their age in years) in the survey.

## 2.9 | Statistical analysis

Participants were retained in the analysis if they had complete data (i.e. no missing data) for at least one aim of the study. For each aim, participants with any missing data were excluded from the analysis for that aim.

### 2.9.1 | Risk factors and symptoms of dementia

'Strongly agree' and 'agree' responses were collapsed, and 'strongly disagree' and 'disagree' responses were collapsed to form three categories: 'agree', 'disagree' and 'unsure'. Counts and proportions of participants selecting each response option for each item were calculated.

### 2.9.2 | Perceived impacts of dementia

Counts and proportions of participants selecting each impact of dementia were calculated for self and a loved

one. Proportions selecting each type of impact were compared for self versus loved one using McNemar's test to account for participants' completion of two related measures. This test was not performed on 'other' responses due to low cell counts. Data were extracted from the online server as a .csv file and analysed using R version 9.4.<sup>28</sup>

## 2.10 | Ethics approval

Ethics approval was provided by the Hunter New England Health Research Ethics Committee (HREC/17/HNE/76).

# 3 | RESULTS

## 3.1 | Sample

Of 353 eligible patients or support persons who were approached, 255 consented to participate (consent rate 72%). There was no difference in age ( $p = 0.08$ ) between consenting and non-consenting individuals, however females were significantly more likely to consent than males ( $p = 0.01$ ). Forty-seven participants were removed from the dataset as they did not have complete data for at least one of the aims, leaving 208 participants available for analysis. Participants' mean age was 54.6 years ( $SD = 17.4$ ) and 44% ( $n = 91$ ) were male.

## 3.2 | Beliefs about the risk factors for dementia

There was a high degree of variability in beliefs about dementia risk factors (see Table 1). Family history or genes was the most commonly perceived risk factor, identified by 74% ( $n = 153$ ) of respondents. Fewer participants ( $n = 62$ – $127$ , 30–61%) identified potentially modifiable risk factors as being associated with increased risk of dementia. For example, 61% ( $n = 127$ ) of participants identified high alcohol consumption, while only 30–34% ( $n = 62$ – $71$ ) identified overweight, smoking and high blood pressure as risk factors.

## 3.3 | Recognition of dementia symptoms

Table 2 shows the proportion of participants who were aware of each dementia symptom. A large proportion of participants were aware of memory-related symptoms of dementia. Between 87% and 96% ( $n = 164$ – $18$ ) identified trouble remembering recent events, trouble recognising family members and forgetting what day it is as symptoms.



**TABLE 1** Proportion of participants categorised as 'agree', 'disagree' and 'unsure' for each possible risk factor for dementia, rank ordered by proportion categorised as 'agree' ( $n = 208$ )

	Agree <i>n</i> (%)	Disagree <i>n</i> (%)	Unsure <i>n</i> (%)
Family history or genes	153 (74)	22 (11)	33 (16)
Brain injury (e.g. from a car accident)	128 (62)	28 (14)	52 (25)
Drinking too much alcohol	127 (61)	43 (21)	38 (18)
Lack of exercise	112 (54)	49 (24)	47 (23)
Stress or worry	93 (45)	63 (30)	52 (25)
Poor diet	92 (44)	57 (27)	59 (28)
Pesticides	90 (43)	44 (21)	74 (36)
Food additives/preservatives	81 (39)	49 (24)	78 (38)
Medications	79 (38)	54 (26)	75 (36)
High blood pressure	71 (34)	57 (27)	80 (39)
Smoking	71 (34)	71 (34)	66 (32)
Being overweight	62 (30)	83 (40)	63 (30)
Air pollution	58 (28)	70 (34)	80 (39)
Chemicals in the home (e.g. cleaning products)	55 (26)	62 (30)	91 (44)
Working hours (e.g. long hours, shift work)	48 (23)	81 (39)	79 (38)

In relation to physical symptoms, a majority ( $n = 161$ , 85%) understood that dementia caused difficulties carrying out daily tasks, however, fewer participants ( $n = 127$ , 67%) were aware that dementia could cause incontinence. There was a high degree of variability in awareness of behavioural and psychological symptoms of dementia. While almost all participants ( $n = 176$ , 93%) recognised wandering away from the home as a symptom, fewer were aware that people with dementia could be aggressive ( $n = 122$ , 65%) or exhibit clingy behaviour ( $n = 109$ , 58%). Only 37% ( $n = 69$ ) knew that sexually inappropriate behaviour was a symptom.

### 3.4 | Perceptions of impact of dementia

Table 3 shows participants' perceptions of the most significant impacts of dementia if they had a diagnosis or if a loved one had a diagnosis of dementia. In both cases, the emotional impact was most commonly selected, followed by the practical impact. Fewer participants selected physical difficulties, financial strain and legal issues as significant impacts of dementia ( $n = 33$ –76, 17–40% for

self;  $n = 31$ –63, 17–34% for loved one). Significantly more participants perceived practical issues ( $n = 119$ , 63% vs.  $n = 99$ , 53%,  $p = 0.018$ ) and social impacts ( $n = 91$ , 48% vs.  $n = 48$ , 26%,  $p < 0.001$ ) as significant impacts if they had dementia as opposed to a loved one. In contrast, significantly more participants identified the emotional impact ( $n = 146$ , 78% vs.  $n = 124$ , 66%,  $p = 0.007$ ), dealing with the health system ( $n = 82$ , 44% vs.  $n = 60$ , 32%,  $p = 0.005$ ) and financial strain ( $n = 63$ , 34% vs.  $n = 40$ , 21%,  $p = 0.001$ ) if a loved one had dementia as opposed to themselves.

## 4 | DISCUSSION

This study provides updated data on Australian community members' perceptions regarding the symptoms, risk factors and potential impacts of dementia. Gaps in awareness were observed for modifiable risk factors and behavioural symptoms of dementia, as well as the potential impact of caring for a person with dementia.

### 4.1 | Beliefs about risk factors for dementia

In line with previous Australian studies,<sup>9,10</sup> our study showed greater awareness of non-modifiable factors associated with dementia, such as genetic factors and brain injury, compared to the potentially modifiable risk factors presented in the survey. There was also a high degree of variability in beliefs about the modifiable factors thought to be associated with dementia. For example, there was low awareness of a range of factors shown to increase the risk of developing dementia, including smoking, overweight and high blood pressure. This is consistent with a recent systematic review and meta-analysis that showed low awareness of the relationship between cardiovascular risk factors and dementia.<sup>29</sup> Our findings highlight the need for increased efforts in Australia to promote awareness of actions that can be taken to reduce one's own risk of dementia. The need for further investment in public health strategies to assist people to adopt healthy lifestyles is also warranted, especially given that these modifiable risk factors are linked to other high-burden conditions such as heart disease and cancer.<sup>30</sup>

### 4.2 | Variable awareness of dementia symptoms

There was a high degree of variability in knowledge of the various types of symptoms. Our findings are in line with

**TABLE 2** Proportion of participants categorised as 'agree', 'disagree' and 'unsure' for each possible dementia symptom, rank ordered by proportion categorised as 'agree' ( $n = 189$ )

	Agree <i>n</i> (%)	Disagree <i>n</i> (%)	Unsure <i>n</i> (%)
<b>Memory-related symptoms</b>			
Trouble recognising family members	181 (96)	4 (2)	4 (2)
Trouble remembering recent events	172 (91)	11 (6)	6 (3)
Forgetting what day it is	164 (87)	15 (8)	10 (5)
Losing or misplacing things	162 (86)	19 (10)	8 (4)
Trouble finding the right word or misnaming things	158 (84)	16 (9)	15 (8)
<b>Physical symptoms</b>			
Needing assistance with everyday tasks (e.g. dressing)	161 (85)	19 (10)	9 (5)
Problems getting to the toilet on time	127 (67)	38 (20)	24 (13)
<b>Behavioural and psychological symptoms</b>			
Wandering away from home	176 (93)	9 (5)	4 (2)
Lacking interest in personal hygiene or grooming	145 (77)	17 (9)	27 (14)
Feeling paranoid or suspicious	128 (68)	21 (11)	40 (21)
Being aggressive towards others	122 (65)	34 (18)	33 (18)
Clingy behaviour (e.g. following spouse around)	109 (58)	24 (13)	56 (30)
Destroying property	78 (41)	53 (28)	58 (31)
Showing inappropriate sexual behaviours	69 (37)	43 (23)	77 (41)
Talking loudly and rapidly	62 (33)	64 (34)	63 (33)

**TABLE 3** Perceptions of most significant impacts of having a diagnosis of dementia or having a loved one with a diagnosis of dementia ( $n = 188$ )

Type of impact	For self <i>n</i> (%)	For loved one <i>n</i> (%)	<i>p</i>
Emotional impact	124 (66)	146 (78)	0.007
Practical issues	119 (63)	99 (53)	0.018
Physical health	76 (40)	62 (33)	0.080
Dealing with the health system	60 (32)	82 (44)	0.005
Financial strain	40 (21)	63 (34)	0.001
Social impact	91 (48)	48 (26)	<0.001
Legal issues	33 (17)	31 (17)	0.746
Other	1 (0.5)	1 (0.5)	–

Note: Proportions may not add up to 100 due to rounding.

international studies that have found low awareness of dementia symptoms. For example, in one population-based study of 1217 people in Ireland, only 39% were confident they could distinguish between symptoms of dementia and normal ageing,<sup>31</sup> while in a Brazilian study 22% of 500 respondents believed that dementia symptoms were a part of normal ageing.<sup>32</sup>

In our study, a large majority of participants identified the memory-related symptoms of dementia, and

over two-thirds knew that dementia caused difficulties performing daily tasks. However, few participants knew about some of the more severe behavioural symptoms of dementia, such as aggression or sexually inappropriate behaviours. This may be because memory symptoms are well-known as a hallmark of dementia and must be present for an individual to receive a dementia diagnosis.<sup>33</sup> In contrast, behavioural symptoms are not a core feature required for diagnosis and may or may not be

present, depending on the stage and type of dementia. Nevertheless, up to 80% of people with dementia will experience behavioural symptoms throughout the course of the condition.<sup>34</sup>

Behavioural symptoms result in high levels of distress and burden among carers of people with dementia.<sup>35–37</sup> The presence of a greater number and frequency of behavioural symptoms has been associated with earlier placement in institutional care.<sup>38</sup> Therefore, it is important that there is awareness among community members that these symptoms may emerge for some people with dementia, so that if a loved one shows these symptoms, they can prepare and seek support in advance for how to deal with these issues. Making the community aware of some of the common behavioural symptoms and the reasons why these occur may also assist in reducing the stigma associated with the condition.

#### 4.3 | Perceptions regarding the impacts of dementia

The practical and emotional impacts of dementia were most commonly perceived by participants as having the greatest impact if they or a loved one had dementia. This finding emphasises the need for a supported diagnosis of dementia, which includes referral to and information about appropriate practical and emotional support.<sup>39</sup> While almost half of the participants perceived that the social impact would be one of the greatest difficulties if they had dementia, only just over one quarter perceived this as one of their greatest difficulties if they were supporting a loved one with dementia. As a result of their caring responsibilities, carers of people with dementia may lose contact with friends or family. The resulting social isolation can lead to increased carer burden.<sup>40</sup> The current COVID-19 pandemic is likely to have intensified the isolation and associated burdens felt by carers. It is important that communities are educated about the importance of maintaining social support for carers, so that they are better able to provide such support to carers in their community and recognise the need to maintain social contact if they become a carer themselves.

In both scenarios, physical impacts were identified as a difficulty by fewer participants. Individuals caring for a person with dementia are more likely to experience physical burdens (e.g. lacking energy, experiencing sleep disturbance) compared to carers of people with other conditions.<sup>22</sup> These factors may lead to carer burnout and earlier placement of the person with dementia in a residential facility. Communities should be aware of the importance of providing practical and social support to carers of people with dementia.

#### 4.4 | Limitations and future directions

This study used a measure that was author developed and was not validated. There is a need to develop robust measures of awareness of dementia risk factors, symptoms and impacts.<sup>41</sup> While risk factor items presented here were backed by varying levels of evidence, with some not yet identified as established risk factors (e.g. pesticides, working hours), it is acknowledged that this is a continually and rapidly evolving area of research. For example, while a 2017 review identified reduced physical activity, smoking, high blood pressure and obesity as risk factors for dementia,<sup>24</sup> an update of this review only 3 years later found that new evidence supported the addition of alcohol consumption, head injury and air pollution as risk factors.<sup>7</sup> Therefore, awareness of dementia risk factors should be re-assessed in future as scientific knowledge in this area increases.

The study was conducted using a convenience sample from one regional hospital where there was an under-representation of younger adults and people from major cities, which limits the representativeness of the sample. While we achieved a high consent rate, males were less likely to consent, further limiting generalisability. Collecting additional socio-demographic data such as highest level of education and socioeconomic status may have allowed for a greater ability to assess sample representativeness.

Future studies may additionally collect qualitative data to further explore misconceptions about risk factors, symptoms and impacts of dementia, so that the source of these misconceptions can be more effectively addressed in future education strategies. In addition, to assess the impact of public awareness campaigns and other education initiatives, there may be value in conducting regular community-based surveys exploring these topics. This would allow for tracking of knowledge gaps which could then be used to shape future education initiatives.

#### 5 | CONCLUSIONS

This study identified that there may be a need for increased education of community members in Australia regarding cardiovascular risk factors for dementia as well as behavioural symptoms of dementia. Results require replication in a more representative sample of community members. Improving community awareness of some of the impacts of dementia on the lives of both people with dementia and their carers may promote greater community understanding and support for these individuals.

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## CONFLICTS OF INTEREST

No conflicts of interest declared.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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