Gerontology & Geriatric Medicine
Volume 4: 1–8

DOI: 10.1177/2333721418793442
journals.sagepub.com/home/ggm
SAGE

What Does the Australian General Public Know About Treatments for Dementia? A Population Survey

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Abstract

Objective: To identify the Australian general population's awareness regarding the presence and effectiveness of treatments for dementia. **Method:** An online survey administered through a consumer panel provider (PureProfile). Included were people aged 18 years or above living in Australia. The survey asked participants about their knowledge of treatments for dementia and attitudes toward the effectiveness of evidence-based treatments. **Results:** Of the 1,001 participants, more than half (63.5%) could not spontaneously name any treatments that improved outcomes for people with dementia. When asked about the efficacy of specific treatments, "brain training" was considered to be "very likely" to be effective by approximately half (49.4%) of the participants followed by "education for caregivers" (46.2%) and "healthy diet" (43.4%). **Discussion:** Knowledge of treatments for dementia among the Australian public is poor. There is a need to better educate the public about treatments that have demonstrated effectiveness to improve their uptake and use.

Keywords

dementia, population survey, health promotion, attitude to health

Manuscript received: May 13, 2018; **final revision received:** June 24, 2018; **accepted:** July 17, 2018.

Introduction

Dementia is a significant public health challenge and highly prevalent condition in Australia (World Health Organization, 2012). Almost one in 10 people above the age of 65 years and three in 10 people above 85 years have dementia in Australia (Brown, Hansnata, & La, 2017). People with dementia have impaired cognition, personality, memory, perception and language skills, and increasing difficulty participating in day-to-day activities (World Health Organization, 2012). As dementia progresses, a person becomes increasingly dependent on others to assist with care and many people require care in a residential aged care facility in their later years (Australian Institute of Health and Welfare, 2012).

The Australian Government has recognized that people with dementia, their families, and caregivers need to be better supported and there is a need to act to reduce the economic and societal impact of the condition (Brown et al., 2017). One of the biggest challenges in dementia care is timely and accurate diagnosis (World Health Organization, 2012). Many people with dementia never receive a diagnosis or delay seeking help (Phillips, Pond, & Goode, 2011). Estimates suggest that above 50% of dementia cases go undiagnosed (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Valcour, Masaki, Curb, & Blanchette, 2000). Potential barriers to receiving an early or timely diagnosis of dementia have been identified on consumer, primary care provider, health system, and service context level (Bradford et al., 2009). Examples of these barriers are financial and time constraints, attitudes, communication difficulties, and limited knowledge among health care providers, people with dementia, and their caregivers (Bradford et al., 2009). Yet, there are interventions that can delay cognitive and/or functional decline, or assist with management of symptoms (Brasure, Desai, Davila, & et al, 2018; Guideline Adaptation Committee, 2016; Livingston et al., 2017).

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Knowledge about an illness is associated with illness-related behavior (Hochbaum, 1958). In other words, how one manages one's health condition is determined by a person's awareness and attitude about the condition and the strategies available to decrease its impact (Hochbaum, 1958). This would suggest that people with symptoms of dementia and their carers who are more knowledgeable about dementia are more likely to seek information about diagnosis and health care services. Poor knowledge about dementia (and related treatment) is associated with people with symptoms of dementia and their carers to not pursue additional information as they do not believe there are effective treatments (Bradford et al., 2009). The Global Action plan on Dementia (World Health Organization, 2017) encourages countries to implement campaigns to raise awareness about dementia, including the development of "evidence-based, user friendly information and training tools concerning dementia and available services to allow timely diagnosis and enhance the continued provision of long-term care" (World Health Organization, 2017, p. 25). Campaigns in Australia aimed at improving knowledge about dementia already exist. These include the following: Your Brain Matters (see https://yourbrainmatters.org.au/), Dementia Awareness Month, Dementia Stigma Reduction (DESeRvE) Program by Dr. Sarang Kim (see http://science.anu.edu.au/news-events/news/award-anu-dementia-researcher), and the Community Radio Dementia Awareness Project that has developed audio messages about dementia for remote and/or Indigenous communities (see https://www.cbaa.org.au/about-community-education-programs-new/community-radio-dementia-awareness-project). However, these campaigns focus on prevention or stigma, rather than treatments.

The Australian Government has also committed more than $200 million (AUD) to dementia research (Commonwealth of Australia, 2014) and is currently undertaking reform of dementia services such as redesigning of dementia consumer supports (Commonwealth of Australia, 2016). To enhance accessibility and uptake of programs and services, it is vital to understand the public's current level of awareness and attitudes toward dementia. Such understanding means that initiatives can be promoted and provided in a way that is compatible. The public should be made aware of how they can access these programs, how the programs can help them reach their care needs or goals, the estimated costs involved, and the effects of accessing such programs. Thus, there is a need to understand what the public knows about dementia, including signs and symptoms, risk reduction, and treatment.

A systematic review that included 36 international studies (Cahill, Pierce, Werner, Darley, & Bobersky, 2015) found that the majority of the population has only fair to moderate knowledge and understanding about dementia. For example, a study conducted in South Korea found that half of the participants (n = 2,189) had an incorrect understanding regarding the curability of some types of dementia and about 20% did not know that drug treatment can be useful for dementia symptom management (Seo, Lee, & Sung, 2015). A more recent systematic review (Cations, Radisic, Crotty, & Laver, 2018) explored the public's understanding about prevention and treatment for dementia. The review (Cations et al., 2018) found that while the belief that there are effective treatments for dementia has increased over time, overall there is still poor knowledge about the potential for treatments. Furthermore, the review by Cations et al. (2018) included two Australian studies, but neither reported knowledge about treatments available. Only a few studies in Australia have explored people's knowledge and understanding about dementia (Garvey et al., 2011; Low & Anstey, 2009; B. J. Smith, Ali, & Quach, 2014). These studies have focused on exploring the participants' understanding about cause, signs, and symptoms and risk reduction, and indicate that there is a limited understanding in the Australian public for the potential to reduce risk of dementia (Garvey et al., 2011; Low & Anstey, 2009; B. J. Smith et al., 2014). To our knowledge, there are no Australian studies that have examined the current level of knowledge about treatments available for dementia. Such information could assist in forming recommendations for action about how to promote evidence-based services to reduce the societal impact of the condition in view of current beliefs and perceptions.

The purpose of this survey was to identify what the Australian general public knows about treatments for dementia.

Method

This survey was approved by the Flinders University Social and Behavioural Research Ethics Committee (Project No: 7626).

Participant Recruitment

A cross-sectional online survey was administered through a consumer panel provider PureProfile (see https://www.pureprofile.com/au/). PureProfile specializes in online survey programming and has an existing database of more than 33,000 active engaged members of the public (participants) who have volunteered to complete surveys for a small remuneration. PureProfile distributed the questions during their weekly survey period. The inclusion criteria were as follows: living in Australia and aged 18 years or above.

Data Collection

A pilot survey was distributed on May 19, 2017, formally launched on May 23, 2017, and data collection was completed on May 26, 2017. Data were collected from the first 1,000 participants who responded to the questions. Data collected included the following: gender, age group, place of residence (including post code), family

connections to dementia, knowledge of any treatments for dementia (free text space), and awareness of the benefits of existing treatments for people with dementia living at home (5-point Likert-type scale; Likert, 1932). The scores for the Likert-type scale ranged from 1 = *very likely*, 2= *somewhat likely*, 3 = *a little likely*, 4 = *not at all likely*, and 5 = *I don't know*. The questions posed in the survey were chosen based on recommendations for treatment and care for people with dementia as outlined by the Clinical Practice Guidelines in Australia (Guideline Adaptation Committee, 2016). For the purpose of the survey, some of the terms were simplified to cater for lower health literacy levels. The survey questions are attached as a supplementary file.

Socioeconomic status. The Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD; Australian Bureau of Statistics, 2013) was used to measure socioeconomic status based on the area of residence of the participants. The IRSAD is part of the Socioeconomic Indexes for Areas (SEIFA; Australian Bureau of Statistics, 2011) classification and includes measure of income, employment, education, and living circumstances (Australian Bureau of Statistics, 2013). The participants were allocated to one of five SEIFA categories from the lowest quintile (areas having the most disadvantage) to highest quintile (areas having the most advantage). The lowest quintile (Quintile 1) comprises 20% of areas ranked by socioeconomic status as the most disadvantaged; the highest quintile (Quintile 5) comprises 20% of areas ranked by socioeconomic status as the most advantaged. The IRSAD has been identified as an appropriate index for use in analysis when comparing the entire range of socioeconomic areas rather than focusing on disadvantaged areas only (Australian Bureau of Statistics, 2013).

Data Analysis

Statistical Package for the Social Sciences (SPSS) Version 22 (IBM Corporation, 2013) was used for quantitative data analysis. Descriptive statistics were used to summarize sociodemographic data and participants' understanding of treatments that have been reported beneficial for people with dementia who still live in their own homes. Logistic regression was used to ascertain the effects of age, gender, socioeconomic status (SEIFA IRSAD score in quintiles), and having a relative with dementia on the likelihood that participants had better knowledge about available treatments for dementia. Odds ratios, confidence intervals, significance, and Wald chi-square are reported. The scores for the Likert-type scale were reverse coded for ease of interpretation and "I don't know" responses were treated as missing data. QSR NVivo software version 10 (QSR International Pty Ltd., 2012) was used to aid data analysis from free text responses and to create an audit trail. This included memo writing to record ideas and justify codes used during data analysis.

Results

The number of responses received was 1,001. Table 1 summarizes the demographic characteristics of the participants. The table also presents the distribution of gender ratios and age groups in the Australian population for point of comparison. Data for this were derived from the Australian Bureau of Statistics estimates of resident populations as at June 2016 (Australian Bureau of Statistics, 2017). About half were female and the age groups represented were approximately even. All Australian states and territories were represented. Less than a third of participants identified that they had a family member who has or has had dementia.

Knowledge About Treatments for Dementia

When asked, "Please type in any treatments you are aware of that improve quality of life for people with dementia," more than half (n = 636, 63.5%) of the participants initially responded that they did not know of any treatments that improved outcomes. Of treatments that were recorded in this question "brain training" and "keeping the mind busy" were most commonly considered to improve outcomes (n = 166, 17%) and many considered games effective. Some participants (n = 74, 7%) reported that exercise and being fit improved outcomes for people living with dementia. Other responses for this question included music therapy (n = 51, 5%), pharmacological therapies (n = 45, 4%), and social support and participation (n = 45, 4%).

Table 2 depicts participant attitudes toward treatments that are frequently evaluated in research trials for people with dementia. Brain training was considered to be "very likely" to be beneficial by approximately half of the participants, followed by education and training for family members and caregivers and healthy diet. Many considered these interventions to be "somewhat likely" to be beneficial.

Ordinal logistic regression analyses found that out of the independent factors (age, gender, socioeconomic status, and having a relative with dementia), age and gender had a statistically significant effect on the prediction if a treatment was considered to be effective for people with dementia. The results from the logistic regression is presented in Table 3. Males were significantly less likely to agree that the treatments were likely to be beneficial apart from medication (p = .052). Older people were more likely to agree that most of the treatments were likely to be beneficial. Again, there was no statistically significant effect of age on the odds of considering medication to be an effective treatment (p = .885).

Discussion

The findings of this survey have provided valuable insight into the Australian general public's knowledge regarding treatments available for people living with dementia.

Table 1. Participant Characteristics.

	Study (*n* = 1,001) *n* (% of *n*)	Australia (*N* = 24,210,809)[a] *N* (% of *N*)
Gender		
Female	511 (51.0%)	12,198,963 (50.4%)
Age		
18-24 years	131 (13.1%)	2,305,576 (9.5%)
25-34 years	186 (18.6%)	3,614,747 (14.9%)
35-44 years	184 (18.4%)	3,236,348 (13.4%)
45-54 years	175 (17.5%)	3,157,138 (13.0%)
55-64 years	150 (15.0%)	2,783,662 (11.5%)
65+ years	175 (17.5%)	3,673,511 (15.2%)
State/territory[b]		
NSW	316 (31.6%)	7,739,274 (32.0%)
VIC	253 (25.3%)	6,179,249 (25.6%)
QLD	203 (20.3%)	4,848,877 (20.0%)
SA	74 (7.4%)	1,713,054 (7.1%)
WA	105 (10.5%)	2,558,951 (10.6%)
ACT	17 (1.7%)	403,468 (1.7%)
TAS	23 (2.3%)	517,588 (2.1%)
NT	10 (1.0%)	245,740 (1.0%)
SEIFA quintile[b]		
Quintile 1	137 (13.7%)	
Quintile 2	156 (15.6%)	
Quintile 3	237 (23.7%)	
Quintile 4	211 (21.1%)	
Quintile 5	257 (25.7%)	
A family member who has had dementia?		
Yes	294 (29.4%)	
Who is the closest relative to you who has dementia?		
Parent	104 (35.4%)	
Grandparent	142 (48.3%)	
Cousin	6 (2.0%)	
Aunt/uncle	32 (10.9%)	
Sibling	10 (3.4%)	

Note. SEIFA = socioeconomic indexes for areas.
[a]A total population of 24,210,809 includes also other Territories comprising Jervis Bay Territory, Christmas Island, the Cocos (Keeling) Islands, and Norfolk Island (Australian Bureau of Statistics, 2017).
[b]Based on SEIFA index of Socioeconomic Advantage and Disadvantage 2011. Three participants came from areas that have low populations or high levels of nonresponse in census and thus received no SEIFA score.

Table 2. Perceptions About Evidence-Based Treatment Effectiveness.

	Very likely	Somewhat likely	A little likely	Not at all likely
	n (% of *n*)	*n* (% of *n*)	*n* (% of *n*)	*n* (% of *n*)
Brain training (e g computer program, crosswords, card games)	468 (49.4%)	330 (34.8%)	126 (13.3%)	23 (2.4%)
Education and training for family and friends in caregiving	439 (46.2%)	359 (37.7%)	129 (13.6%)	24 (2.5%)
Healthy diet	434 (43.4%)	336 (35.5%)	144 (15.2%)	32 (3.4%)
Regular exercise	372 (40.4%)	347 (37.7%)	167 (18.1%)	35 (3.8%)
Heart health (e.g., managing blood pressure, cholesterol and blood sugar levels)	321 (34.7%)	361 (39.1%)	195 (21.1%)	47 (5.1%)
Medications	295 (31.6%)	405 (43.4%)	190 (20.3%)	44 (4.7%)

Note. "I don't know" responses were treated as missing data, hence numbers (*n*) do not total to 1,001.

Overall, there is limited awareness of treatments that can improve outcomes for this population group. Of the treatments that are frequently evaluated in research trials, less than half of the participants considered these very likely to be effective, for example, exercise was initially only nominated by 7% of respondents as an effective method

Table 3. Logistic Regression Predicting Likelihood of Agreeing That Treatments Are Beneficial for People With Dementia.

							95% CI for odds ratio	
	B	*SE*	Wald	*df*	*p*	Odds ratio	Lower	Upper
Regular exercise								
Male	−0.39	0.12	9.91	1	**.002***	**0.68**	0.53	0.86
Yes—Family member with dementia	−0.02	0.13	0.03	1	.865	0.98	0.75	1.27
Age	0.17	0.04	21.06	1	**.000***	**1.19**	1.10	1.28
SEIFA quintile	0.08	0.05	2.85	1	.091	1.08	0.99	1.18
Brain training								
Male	−0.41	0.13	10.75	1	**.001***	**0.66**	0.52	0.85
Yes—Family member with dementia	−0.25	0.14	3.37	1	.066	0.78	0.60	1.02
Age	0.13	0.04	11.23	1	**.001***	**1.14**	1.05	1.22
SEIFA quintile	0.01	0.05	0.02	1	.886	1.01	0.92	1.10
Healthy diet								
Male	−0.52	0.12	17.33	1	**.000***	**0.60**	0.47	0.76
Yes—Family member with dementia	−0.11	0.13	0.71	1	.401	0.89	0.69	1.16
Age	0.14	0.04	13.44	1	**.000***	**1.15**	1.07	1.23
SEIFA quintile	0.04	0.05	0.76	1	.383	1.04	0.95	1.14
Education								
Male	−0.79	0.13	39.23	1	**.000***	**0.45**	0.36	0.58
Yes—Family member with dementia	0.16	0.14	1.30	1	.254	1.17	0.89	1.52
Age	0.08	0.04	4.23	1	**.040***	**1.08**	1.00	1.16
SEIFA quintile	−0.02	0.05	0.28	1	.600	0.98	0.89	1.07
Medication								
Male	−0.24	0.12	3.79	1	.052	0.79	0.62	1.00
Yes—Family member with dementia	−0.08	0.13	0.36	1	.551	0.92	0.71	1.20
Age	0.01	0.04	0.02	1	.885	1.01	0.94	1.08
SEIFA quintile	0.04	0.04	0.66	1	.416	1.04	0.95	1.13
Heart health								
Male	−0.51	0.12	16.89	1	**.000***	**0.60**	0.47	0.77
Yes—Family member with dementia	0.04	0.13	0.08	1	.783	1.04	0.80	1.35
Age	0.11	0.04	8.68	1	**.003***	**1.12**	1.04	1.20
SEIFA quintile	−0.02	0.04	0.15	1	.702	0.98	0.90	1.07

Note. CI = confidence interval; SEIFA = socioeconomic indexes for areas; Bold faced values in column "odds ratio" are ones that are significant as indicated by the p-value in column *p*.
*$p < 0.05$.

to improve outcomes for people with dementia. There is scope to educate the Australian public about the treatments available and their effectiveness to improve the trajectory of people living with dementia.

This survey builds on earlier studies conducted in Australia about dementia related topics (Garvey et al., 2011; Low & Anstey, 2009; B. J. Smith et al., 2014). Although the earlier studies examined the knowledge about cause, signs and symptoms, and risk reduction of dementia, our focus was on attitudes about treatments for dementia. Our findings are consistent with findings from other Australian studies that report gender (being female; Low & Anstey, 2009; B. J. Smith et al., 2014) and older age (Garvey et al., 2011) are associated with better awareness about dementia and related topics. Dementia is still not recognized as a health priority by many young Australians (B. J. Smith et al., 2014). We also found that younger people were less likely to identify treatments as effective compared with older Australians, suggesting that they may have a limited understanding of the implications of a diagnosis.

Attitude is measured using direct or indirect methods (McLeod, 2009). A direct measure involves participants rating an issue or topic on a standard set (such as Likert-type scale) allowing for quantification and a more objective measure of an attitude than an indirect method (that provides more qualitative information about how a person interprets information given to them) (McLeod, 2009). Although these sets have been designed to present a valid measure of a particular attitude, their results can be biased due to participants adjusting their replies to be more socially desirable (McLeod, 2009). Culture, demographic variables, perceived stigma, exposure to media or advertising, individual differences, and personal experiences have been reported as causes for attitudes and respective behavior (Fishbein & Yzer, 2003). For example, the relationship between attitude and behavior has been studied by many (Glasman & Albarracín, 2006). It

appears that attitudes can predict behavior, such as seeking diagnosis or treatment if a person has direct experience with dementia. This association between an attitude and behavior is also considered stronger if formed on the basis of behavior-relevant information, such as knowledge about treatments (Glasman & Albarracín, 2006).

Contrary to surveys conducted in other countries that have reported general public's knowledge about the benefits of treatments for dementia (Roberts, McLaughlin, & Connell, 2014; Wortmann, Andrieu, Mackell, & Knox, 2010), we did not find a significant association between socioeconomic status or having a relative with dementia and knowledge about effective treatments for dementia. This is unexpected as socioeconomic status has been reported to be associated with better knowledge about cause, signs and symptoms, risk reduction, and treatment of dementia in other countries (Cahill et al., 2015). The lower socioeconomic status may refer to people living in poverty, which may not be represented in this sample.

Information regarding the public's awareness may assist in developing research and health education interventions; raising the public's awareness regarding effective treatments available is crucial for improving the quality of care for people with dementia (Rimmer, Wojciechowska, Stave, Sganga, & O'Connell, 2005). Improved knowledge about treatments available for dementia can lead to increased ability to seek the right kind of support (Low & Anstey, 2009). It can also reduce stigma (Mukadam & Livingston, 2012), caregiver burden (Jorm, 2012), and societal impact of dementia (World Health Organization, 2012). However, similarly to other surveys (R. W. Jones, Mackell, Berthet, & Knox, 2010), we found that members of the general public may not know or believe that there are effective treatments for dementia. Such lack of awareness and attitude needs to be considered when developing research and health education programs. Although it may be unclear what the enablers and barriers to improving dementia awareness are, the public needs to be made aware of the benefits (and possible barriers) of available treatments (Hochbaum, Rosenstock, & Kegels, 1952). This includes educating the public about positive effects treatments can have on a person's daily functioning, mobility, and independence (Hochbaum et al., 1952). There may also be beliefs about effective treatments being costly, time consuming, and inconvenient. Any misconceptions should be addressed through health education and research as there are a number of interventions that are cost effective and can improve outcomes for people with dementia (C. Jones, Edwards, & Hounsome, 2012; Knapp, Iemmi, & Romeo, 2013; Rahja, Comans, Clemson, Crotty, & Laver, 2018).

Strengths and Limitations

This is the first survey to report on the Australian general public's awareness and attitudes about treatments available for people with dementia. The survey used a nationally representative sample and all states and territories from within Australia were represented. Our findings suggest that there is a need to improve the awareness about available treatments for people living with dementia. A limitation of this survey is that it may underrepresent people from the lowest socioeconomic areas. It may also be that people participating in online surveys are likely to be higher users of technology and therefore they would be more exposed to information about dementia and treatments. The survey also does not evaluate different cultural groups and it is unclear to what extent Indigenous Australians were represented in the sample. This is particularly important as the prevalence of dementia in Indigenous populations in Australia is up to 5 times the rate of the general population (K. Smith et al., 2008). In addition, beliefs about dementia in the Indigenous people can be different to people from non-indigenous background. The term dementia is not used in some cultures and the concept of well-being is embedded in a diversity of beliefs, traditions, law, language, and the land (K. Smith et al., 2007).

Conclusion

An understanding of the general public's knowledge regarding treatments for dementia is important; such knowledge can help reduce the societal impact of the condition and guide future health education and service development campaigns. This survey found that many Australians are still unfamiliar with treatments available for people with dementia and still have a limited understanding of the benefits of treatments that have been proven effective in clinical trials. We have discussed factors that may contribute to this lack of knowledge and made recommendations for the need to better educate the public about effective treatments available.

Impact Statement

Dementia specific treatments that have been proven effective in randomized trials may not be recognized as effective by the general population in Australia. Health education and research programs need to focus on educating Australians about the effectiveness of these treatments to reduce the societal impact of the condition.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Health and Medical Research Council (NHMRC) Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (Grant no. GNT9100000). Dr. Laver is supported by a NHMRC-ARC Dementia Research Development

Fellowship. Assistant Professor Comans is supported by a NHMRC Boosting Dementia Research Leadership Fellowship.

Supplemental Material

Supplemental material for this article is available online.

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