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Running Head: Knowledge and misconceptions about AD

Knowledge of Alzheimer's disease amongst patients, carers, and non-carer adults:
Misconceptions, knowledge gaps, and correct beliefs.

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Abstract

Background: There is limited previous research that has examined level of Alzheimer's Disease (AD) knowledge and misconceptions using a structured questionnaire across a range of samples. To address this gap the current study investigated knowledge, knowledge gaps and misconceptions about AD in a sample of non-carers, caregivers, and individual's with Alzheimer's Disease. **Method:** A modified version of the Alzheimer's Disease Knowledge (ADK) test was administered to 13 carers, 20 non-carer older adults, and 10 people with AD. Two sets of analyses were undertaken, first to identify group differences in the amount of knowledge reported by each group and second, to determine the nature of peoples' understanding of AD. **Results:** Overall level of knowledge in the three groups was quite poor. Whilst carers had significantly greater AD knowledge than non-carers or patients, carers correctly answered approximately 50% of items only. Relative to non-carers and AD patients, carers demonstrated a higher number of commonly held correct beliefs than participants in the other two groups, who held relatively few correct beliefs. All three groups had some misconceptions about AD. **Conclusions:** These findings suggest that education programs targeting the elderly community in general and AD patients specifically may be needed, but also that carer knowledge of AD could be further improved. Future educational interventions could be tailored to address the knowledge needs of each of the groups identified in this study. In particular, the need to address misconceptions and knowledge gaps shared by more than one group should be a priority.

Keywords: Alzheimer's disease, Alzheimer's disease knowledge test, misconceptions

Knowledge of Alzheimer's disease amongst patients, carers, and non-carer adults:

Misconceptions, knowledge gaps, and correct beliefs.

In 2002, dementia and AD were the ninth leading cause of death in males over 65, and the third leading cause for females in Australia [1]. As such, AD represents one of the most challenging and significant health conditions affecting the elderly. One of the challenges with AD is providing education to those who experience it, their caregivers and relatives, and the wider community. This is important because patients and carers may be better able to cope with illness and enact relevant treatment plans when they have a sound knowledge of the causes and complications associated with Alzheimer's disease. Despite the apparent importance of illness-related knowledge on health outcomes [2], a structured approach to assessing AD knowledge in people with AD, their carers, and the general community of older adults who may become future patients or carers, has not been widely undertaken.

Of those studies that have used a structured approach to investigate AD knowledge, general findings indicate relatively poor levels of knowledge in the general community [3-6]. These studies have in common the use of a structured questionnaire or test of AD knowledge. For example, Price et al. developed a 20 item questionnaire assessing AD knowledge and found that only eight out of 20 items were answered correctly by more than 50% of elderly respondents (i.e., non-carers, non AD relatives). Laforce and McLean (2005) used a 40-item questionnaire assessing knowledge and fears of developing AD and demonstrated that whilst younger participants were more knowledgeable about AD than older participants, younger participants scored, on average, only 65% of items correct. Other studies have used the Alzheimer's Disease Knowledge Test (ADK; originally developed by Dieckmann et al., 1988) or variants thereof (e.g., [7]) and found similar results. For example, using undergraduate student samples, Dieckmann et al. found that, on average, only four out of the 20 ADK items were answered correctly by participants in their sample, Karlin and Dalley (1998) reported only

six out of 20 items answered correctly by more than 50% of their sample, and Sullivan and O'Connor reported that a mean correct response score of 5.76 items was obtained by participants in their sample.

In contrast to generally low levels of AD knowledge reported in community, higher levels of AD knowledge have been reported in some undergraduate student samples using the ADK. For example, advanced nursing and medical students correctly answered an average of 14 and 18 out of 20 ADK items respectively [8]. This difference in AD knowledge in community samples and some undergraduate student groups could reflect the higher level of education of the participants studied by Beall et al., but also the specialist nature of their education [5, 8, 9 but see also 10].

Undergraduate student knowledge of AD is important to the extent that undergraduate students may become AD carers or patients themselves in the future and such knowledge may inform advanced care planning [11]. In addition such studies show the potential of formal education to increase understanding of AD. However, it is also important to understand current caregiver knowledge of AD, as caregivers potentially spend the most time with patients, and can monitor and influence the day to day functioning of those with AD, including medication, nutrition, and general well-being. Although there have been no published studies of caregivers' knowledge of AD, an approximation of this may be gained from investigations of first-degree relative's knowledge of AD, since carers are often family members. In one such study, Roberts and Connell (2000) found that mean level of knowledge in first-degree relatives of those with AD was quite high, with an average of 83% of the questions about AD answered correctly, although the nature and extent of caregiving roles held by those relatives was not specified. Additionally, the 14-item true / false questionnaire they used to assess AD knowledge has not been extensively used in previous research thereby limiting statements of the approximate relative knowledge of relatives and other samples, such as undergraduate students.

The use of true / false format knowledge questionnaires such as that used by Roberts and Connell (2000) and others (see [9]), is problematic as it does not fully permit exploration of misconceptions people may have about AD. For example, if an individual incorrectly responds “false” to an item, it may indicate that they are misinformed about a particular fact. However, we cannot determine the *nature* of their misconception from this response. It may also be that they are not sure of the answer, and instead of being provided with an “I don’t know” option from which they can convey their knowledge gap, they are forced to guess. Whilst the misconceptions approach to the study of disease knowledge has less frequently been undertaken (for an exception see [9]), misconceptions can be potentially harmful if they negatively impact on health behaviour. In a study conducted by Wellwood, Dennis, and Warlow (1994) examining misconceptions about stroke, it was found that a small proportion of the sample reported that exercise should be avoided, rather than undertaken to reduce the risk of stroke [12]. Thus, the identification of misconceptions about disease knowledge may be more fully explored through the use of multiple-choice tests that allow information to be collected about the specific nature of misconceptions people hold, and an “I don’t know” option to discover the nature of self-identified knowledge “gaps”.

Notwithstanding discussions regarding appropriate test formats for studying disease misconceptions, there have been two previous studies of misconceptions in AD [9, 10]. These studies have identified a number of misconceptions held by community dwelling elderly adults [9] and first degree relatives of those with AD [10]. The study conducted by Roberts and Connell found that the role of heredity, mortality rate, and availability of drugs were items that were commonly answered incorrectly (41%, 35% and 19% respectively). Only a small proportion of the elderly sample in Edwards et al. study reported misconceptions about preventing AD through proper living habits (3%), believing there was a cure (5%) and pollution / toxic chemical causing AD (3%), on the basis of true or false answers to a three item test.

Given that relatively few studies have examined misconceptions about AD, the aim of this study was to further explore AD misconceptions using a well established multiple choice format measure of AD knowledge; a modified version of the ADK. Additionally, since neither of the previous studies of AD misconceptions included multiple sample types, the aim of this study was to conduct a preliminary investigation of the nature and extent of AD misconceptions in a sample of non- AD carers, AD carers, and people with AD, enabling comparisons across groups. This study also investigated self-identified knowledge gaps about AD and knowledge of AD in these three groups to determine the information the information needs of these groups.

Method

Participants

Twenty elderly participants were recruited from Senior Citizens' clubs in metropolitan Brisbane. This group consisted mainly of females ($n = 16$) with an average age of 77.5 years ($SD = 6.37$, age range 60 to 88). Participants in this group were non-carers, defined as persons without the primary responsibility for caring for someone with AD. Most of elderly participants reported an education level of primary to junior level high school. These participants had not been diagnosed with dementia, were free from depression, and were generally healthy.

Most of the thirteen caregivers were recruited from the Alzheimer's Association of Queensland (AAQ) metropolitan Brisbane region (>85% of this sample) with a minority of caregivers recruited from Senior Citizen clubs. Of the total 13 caregivers, 12 were female. The mean age for the total group was 66.53 years ($SD = 9.84$, range 51 to 79). Caregivers in this study were defined as such if they reported having a significant primary role in caring for someone with AD, and were mostly related by marriage to the person for whom they cared. Carers in this study were unpaid providers of non-institutional care.

Ten participants who had been diagnosed with Dementia of the Alzheimer's type (nine males, M age = 70.60 years, SD = 10.33, age range 53 to 85) were recruited from the AAQ (metropolitan Brisbane region). AD patients and carers recruited from the AAQ had all recently undergone a six-week education program called "Living with Memory Loss". AD patients were included in this study because relatively few investigations of AD knowledge have examined the understanding of those affected by it.

Group comparisons

Statistical comparisons of demographic characteristics across groups were undertaken to determine group similarity on key variables (e.g., age, education, gender). Whilst some group differences might be expected a priori, for example over-representation of women in elderly samples given the longer life expectancy of women generally [13], such information may influence the interpretation of group differences.

To be eligible for inclusion in this study, all of the non-caregiver elderly and caregivers were required to score 24 or above on the Mini-Mental State Examination (MMSE) [14]. This restriction was used to provide a further check that this group did not include people with dementia, since scores less than 24 may suggest the presence of this condition (see [15]). The AD group were required to have a MMSE score of 19 or above. The lowered MMSE cut off for the AD group was used to minimise issues with the provision of informed consent by focussing on people with early stage dementia only. There were significant group differences on the MMSE between AD patients, carers and non-carer adults, $F(2, 40) = 53.22, p = .000$. Post hoc comparisons using a Bonferonni adjustment and alpha set at 0.016 showed that the non-carer adults ($M = 27.15, SD = 1.98$) scored significantly higher than the AD group ($M = 20.30, SD = 1.15$). The caregivers also scored significantly higher ($M = 27.53, SD = 2.14$) than the AD group.

There was a significant difference between the three groups in terms of age, $F(2, 40) = 6.89, p = .003$. Bonferonni post hoc comparisons showed that the non-caregiver were significantly older than the caregiver group. There were no other significant age differences.

Significant differences in the gender distributions of these three groups were also noted, $F(2, 40) = 17.594, p = .000$. Specifically, Bonferonni post hoc comparisons showed that: a) males were significantly over-represented in the AD patient group (90% males), compared to caregiver (8% males) and non-carer (20% males) groups, which did not differ significantly from each other. No significant education group differences were identified, $F(2, 40) = 2.593, p = .087$. The overall level of education of participants in this group was at least equivalent to a nine years of formal schooling, and education to this level is not unusual among older adults (approximately 50% of Australians aged 65 and over left school before the age of 15; [16]).

Materials

Alzheimer's Disease Knowledge Test (ADK). The ADK was first published in 1988 by Dieckmann Dieckmann, Zarit, Zarit, and Gatz as a measure of AD knowledge. The version of the test used in this study was based on the original ADK, but modified for use in Australia [7]. Sullivan and O'Connor (2001) and Sullivan and Muscat [17] report on an 18 item version of the test that excluded items considered inappropriate in an Australian context. In this study, we incorporated data from two additional items that were added to extend the ADKⁱⁱⁱ. In addition, item one was changed to assess knowledge of the percentage of people over 65 years of age with *Alzheimer's disease* rather than "severe dementia" (cf [3]). The two new items included on the ADK assessed knowledge of personality changes associated with AD (rather than

ⁱⁱⁱ Item 2 of the original ADK was modified to assess knowledge of the prevalence of AD in Australia instead of United States of America (USA), and item 20 was modified to assess knowledge of Australian AD associations rather than those in the USA.

specific health system details that were assessed by item 19 of the original version), plus an item assessing knowledge of the percentage of people with AD who reside in their own homes or those of their carers (instead of item 11 of the original ADK that asked about the effectiveness of lecithin in treating AD). Thus, the version of the ADK used in this study included 20 items, each with five response categories including an “I don’t know” option. Responses to items were scored correct (one point) or incorrect (0 points), such that higher scores reflect greater knowledge of AD and the maximum score possible was 20. Items on this test assessed respondent’s knowledge of the prevalence and diagnosis of AD, its causes and symptoms, and the role of support organizations and the management of the disease. Preliminary data on the reliability and validity of the original [6] and a modified version of this test [7] suggest it has good psychometric properties.

Procedure

There were minor variations in the data collection methods for participants recruited from AAQ and Senior Citizens clubs related to the recruitment strategy used at each site. Specifically, those participants recruited from Senior Citizen’s Clubs were interviewed after normal club activities on site. AAQ participants were interviewed in their homes. Despite these differences, other aspects of study procedures were the same. Specifically, all participants were asked to complete several pen and paper questionnaires, including the ADK (the focus of this study) and the Reasons for wanting to know test (the focus of a related publication arising from this project; [17]) among others. The three groups were administered a semi-structured interview to assist test completion. The order of administration of questionnaires was counterbalanced across the test battery to minimise fatigue and order effects.

Data analysis. A total ADK score comparison was undertaken to determine group differences in overall level of Alzheimer’s knowledge. A series of analyses was then undertaken to examine response patterns to *individual* ADK items. These analyses included: a)

^{vi} Now known as Alzheimer’s Australia

an item-by-item comparison of group differences using chi-square tests, and; b) several descriptive comparisons to identify response trends. The first of these descriptive comparisons was performed by examining items on which a 50% or more endorsement of the correct response option was recorded. The knowledge assessed by relevant items was classified as a “commonly held correct belief”. Although somewhat arbitrary, this level of endorsement has been used previously and provides an indication of those items on which at least half of the sample answered correctly (e.g., 18,19]).

The second of these descriptive analyses was limited to items that were, on the whole, answered incorrectly or attracted “I don’t know” responses respectively. This focus was used to identify specific areas of AD knowledge that may be considered relatively poorly understood. Items attracting a relatively high rate of “I don’t know” responses or incorrect answers were identified and these were classified as “knowledge gaps” or “misconceptions” respectively. Specifically, if 25% or more of the sample endorsed an incorrect (but not “I don’t know”) response we defined this as a commonly held misconception. The cut-off for identifying misconceptions was based on that used in previous studies (e.g., [18]). Items on which 50% or more of the sample selected “I don’t know” were classified as self-identified knowledge gaps.

Results

Total ADK score

The three groups showed mean differences in the level of AD knowledge. Caregiver’s showed the highest mean level of knowledge about AD, correctly answering approximately 50% of questions. Specifically, on average, caregiver’s correctly answered 11 out 20 questions ($SD = 4.16$). The AD patients and non-carers both correctly answered about 25% of the questions on average. That is, the AD patient’s correctly answered a mean of six questions

correctly ($SD = 2.94$), while non-carers scored five out of 20 questions correctly on average ($SD = 2.59$).

To test if differences in mean level of knowledge were significant between the three groups, an ANOVA was conducted with group membership as the independent variable and mean level of AD knowledge as the dependent variable. Results showed a significant difference in ADK knowledge between the three groups, $F(2, 40) = 14.78, p = .000$. Post hoc comparisons revealed that the caregiver group had a significantly higher mean than non-carers and the AD group. There was no significant difference between the non-carer and AD groups.

To determine which ADK items were answered differently by patients, carers, and non-carers, a series of item by item analyses using chi-squared statistic were performed. Item-by-item analysis revealed significant group differences on nine items. This pattern of results is shown in Table 1.

Insert Table 1 here

Commonly held correct beliefs

Consistent with caregiver's having the highest level of AD knowledge overall, this group demonstrated the highest number of commonly held correct beliefs. That is, over 50% of the sample correctly answered 13 out 20 items. Items answered correctly related to the role of support services, the likely cause of personality change in AD, the likely impact of orienting information or note provision on AD patients, the typical response of AD patients to their illness, the most likely rate of progression of symptoms, common differential diagnoses, the role of aluminium in causing AD, the prevalence and cause of AD, and the role of memory loss in AD.

Both AD and non-carer participants showed poor levels of common knowledge about AD. In the AD group, there was only five out of 20 items that more than 50% of the sample correctly answered. These items related to the prevalence of AD, the role of memory loss,

depression in AD, the effectiveness of note provision, and the role of caregivers. For the non-carer group, there was only one question for which over half the sample knew the correct response. This item was assessed the primary role of caregiver's in assisting AD patients.

To examine general response trends not focused on group differences, the commonly held beliefs endorsed by more than one group were examined. There were four items for which over 50% of respondents in both the caregiver and AD gave correct answers (items two, nine, 17, and 18). These items assessed the changes in the prevalence of AD in the future, the primary symptoms of AD, the effectiveness of notes as reminders, and the role of mental health professionals, respectively. Additionally, there was one item (item 18) where all three groups showed over 50% endorsement of the correct answer (people with AD should be encouraged to remain as independent as possible with activities of daily living, even when abilities begin to fail). Commonly held correct beliefs endorsed by two or more groups are shown in Table 2.

Inset table 2 here

Misconceptions

Data from the three groups was then inspected to identify the nature and extent of misconceptions about AD held by these groups. Commonly held misconceptions were defined when 25% or more of either sample endorsed an incorrect response. All groups showed a moderate level of misconception about AD, with nine items for the non-carers, five items for the carers, and three items for the patients. In the AD group, these items concerned the role of heredity in AD, why early evaluation of AD is important, and the role of nutrition in AD. The topics about which caregivers held misconceptions were the prevalence of AD in those over 65 years, why prompt evaluation of AD is important, the diagnostic process, and how caregivers can manage patients' wandering. The topics about which non-carers held misconceptions for were the percentage of those over 65 years that have AD, the role of heredity, why prompt evaluation is important, diagnostic process, patients' reaction to their illness, how caregiver's

can manage patients' wandering, the role of nutrition, personality changes, and the primary function of Alzheimer's Australia.

To further explore the general response trends, common misconceptions held by more than one group were explored. There were seven misconceptions common across the groups. These were items that assessed the role of heredity in AD (non-carers and AD patients), the diagnosis of AD (caregivers and non-carers), the percentage of elderly people who have AD (caregivers and non-carers), the controllability of personality changes (non-carers and caregivers), the role of nutrition in AD (non-carers and patients) and how caregivers cope with AD patients wandering (non-carers and caregivers). One item was identified as a misconception in all three groups: believing that early treatment of AD can prevent the worsening of symptoms. These findings are shown in Table 2.

Self-identified knowledge gaps

Responses from caregiver's, non-carers, and person's with AD were inspected to identify items on which a high rate of "I don't know's" were recorded. Items were defined as such if 50% or more of the sample endorsed the "I don't know" option. All three groups showed a low incidence of self-identified knowledge gaps. There were no items for which over 50% of the caregiver group selected the "I don't know" option. There was four items for which a large proportion of the non-carers identified knowledge gaps and five such items found among patients (see Table 2). There was two items on which more than one group selected a high proportion of "I don't know's" (see Tables 2 & 3).

Discussion

The aim of this study was to compare the level and nature of AD knowledge in people with Alzheimer's disease, carers of people with AD, and non-carers. Specifically, using a standardised, well established test of AD knowledge (ADK), we sought to identify knowledge

gaps, misconceptions and commonly held correct beliefs about Alzheimer's disease in these three groups.

The results of this study showed that the level of AD knowledge among these groups was significantly different, and that caregivers knew more about AD than people with AD or non-carers. In addition, the overall level of knowledge of carer and non-carer participants was similar to that reported previously among non-carers (i.e., approximately 50% of items correct; [5]), but less than that found among relatives of people with AD [10]. Specifically, in this study, caregivers correctly answered about twice as many items as non-carers and AD participants; however, although caregivers were, on average, more knowledgeable about AD than the other groups tested, the absolute level of knowledge in this group was still relatively poor (only 50% of items answered correctly) suggesting the need for additional education for caregivers.

The higher level of AD knowledge among carers compared to non-carer participants may be attributable to the fact that carers in this study had all undergone some education about AD (the AAQ "Living with memory loss" program) or differences in the educational backgrounds of these groups (i.e., carers were more educated than non-carer participants). Disentangling these effects requires further study. Given that AD participants also experienced this program and had similar educational backgrounds as carers these results suggest that carers retained more information about AD from this program than their AD counterparts who presumably had similar potential to score as well as carers on the ADK, except for the presence of disease. Thus, although it seems reasonable to conclude that carers and non-carers would benefit from further AD education, since the general level of understanding of non-carers was poor and similar to that of AD patients, there may be a need to explore ways of improving the salience of AD information for AD patients, or exploring ways of optimising information provision (perhaps to very early stage disease) if the value of such endeavours is to be maximised.

The pattern of results identified using total ADK scores was consistent with that revealed by the item-by-item analysis. Such analyses showed that compared to patients and non-carers, a higher proportion of carers answered the ADK items correctly. The specific items on which statistically significant group differences were found may provide clues as to where patient and non-carer education programs in particular, need to be strengthened.

Whilst information about group differences on the ADK or individual items is important, it does not provide an indication of the actual level of performance on individual items (e.g., what percentage of the group answered each item correctly or incorrectly), and it does not enable exploration of patterns of incorrect responses. This additional information is important as it may further inform decisions regarding resource expenditure for future AD education programs. To provide this additional detail, a series of analyses was undertaken to determine commonly held correct beliefs, misconceptions, and gaps in knowledge of which people are aware. Although there was wide variability in responses, we attempted to categorise information this way to convey the nature of people's responses to the ADK.

The results of these analyses showed that people generally understand that the prevalence of AD is increasing, the primary symptoms of AD is memory loss, and that health professions typically recommend caregivers support and assist afflicted individuals to remain as independent as possible when abilities to manage activities of daily living begin to fail. That is, either two or three of the groups tested showed high endorsement rates of the correct response option for these issues. Thus broad scale public AD education programs may safely assume that this information is generally well understood, thereby allowing resources to be directed to correcting misconceptions or filling knowledge gaps.

In terms of misconceptions identified in two or more groups, seven such issues were identified. Issues about which misunderstanding was apparent concerned the role of heredity in AD, the belief that early treatment could prevent the worsening of symptoms, diagnostic procedures required to confirm AD, how caregivers cope with AD patients' wandering, the

percentage of elderly people who have AD, how controllable personality changes are by those with AD, and a belief that nutrition plays no role in AD. Specifically, more than 25% of people in two of the three groups tested reported that AD is *never* inherited. Interestingly, misunderstandings about the role of heredity and AD have also been reported by others [10], and whilst this is the subject of on-going research it is somewhat surprising that participants did not reject this extreme response option.

Similarly more than 25% of people in all three groups tested failed to indicate that prompt evaluation of AD is important because it may help identify reversible causes of dementia, instead reporting that prompt evaluation could prevent worsening of symptoms. Whilst the difference in these response options may be regarded as subtle, future education aimed at promoting greater awareness that there are a range of reversible causes of dementia-like symptoms could facilitate early evaluation.

The percentage of elderly people who have AD was overestimated by both the non-carer and carer groups. While the actual prevalence is thought to be about 10% of those over 65 years, over 25% of participant's in these two groups thought the prevalence was 20-25%. This suggests that individuals may overestimate the prevalence of dementia.

A misattribution about the nature of personality changes in AD was also identified by non-carers and carers. Both of these groups thought that damage to the brain (correct response) in addition to deliberate behaviours by the patient were responsible for observed personality changes. This response suggests that educational strategies designed to extend carers' understanding of the role of organic structures in moderating personality and behaviour may be need developed or enhanced to improve understanding of this particular issue.

A misconceptions about the need for autopsy as the only way that diagnosis of AD can be confirmed was also apparent, with 25% of people in two out of three groups reporting that they thought mental status testing could perform this function. Based on these results there would appear to be room for improving understanding of the specific role of AD diagnostic

tests, and this may influence autopsy consent rates since these have been noted to be decreasing in some countries despite the importance of such procedures in relation to AD diagnosis [20].

Responses to the item on wandering suggested that caregivers in particular (61% of this group) as well as 40% of non-carers believe that sharing feelings with the patient, plus making use of practical solutions such as locks was a preferable response to making use of practical solutions only. Whilst there may be debate about what is, in fact, the best strategy for managing such behaviour (physical restraint alone or in combination with reasoned explanation) as this may depend on factors such as stage of illness and environmental factors, there may be a need to provide education about the relative merits and appropriateness of such strategies.

The final issue about which misconceptions were identified related to the role of nutrition and AD. Twenty-five percent or more of participants in the non-carers and patient group reported that nutrition plays no role in AD, failing to recognise that poor nutrition can exacerbate AD symptoms. This result suggests that further education about this issue is warranted as ensuring dietary needs are met may be an important means of optimising functioning.

The third method of categorising the nature of AD knowledge involved the identification of knowledge gaps (items on which 50% or more of the sample endorsed the “I don’t know” option). Interestingly, carers did not endorse the “I don’t know” option for any of the 20 ADK items at this level, suggesting they were reasonably confident of answers they provided. Two items were endorsed at this level by the other two groups. AD patients and non-carers admitted they did not know (and did not want to make at guess at) the percentage of people with moderate to severe AD who are cared for in their own homes (or the homes of carers), and the life expectancy of a person after AD diagnosis. If an understanding of AD life expectancy is important for advanced care planning as has been argued previously, this may be an important area of patient education that needs further examination, such as a review of the type of information that is being provided and how it is being disseminated. In addition, a lack

of knowledge about numbers of people with AD who are cared for at home may suggest that AD participants and non-carers have an unrealistic view of the likely care arrangements for people diagnosed with AD.

It should be noted that on the basis of a recent meta-analysis the provision of short general AD education programs alone was described as an “unsuccessful” caregiver intervention, beyond the enhancement of knowledge [21]. However, the effects of tailored information provision on caregiver well-being have yet to be fully investigated. The results of this study may be useful for such an investigation and could be used to design population specific AD education programs that address the knowledge gaps and misconceptions held by specific groups, particularly since we have demonstrated these differ.

In addition, knowledge of AD has been shown to be a significant predictor of advanced care planning decisions [11]. Therefore, maximising such knowledge may be important for patients, if not care-givers, and for the general elderly community who may experience this illness in future. Price et al. (1986) found that only five percent of their sample of 148 elderly persons reported obtaining relevant information from their doctor. Therefore, whilst recognising there are a range of ways that information can be disseminated, improving the dissemination of information by doctors may be important, particularly if tailored information packages are to be provided to caregivers, patients, and the aged community in general and that this is to be done in a way that may be useful for advanced care planning.

The results of this study must be interpreted cautiously bearing in mind some important caveats. First, the cut-offs used to define categories of AD knowledge, such as misconceptions and so on, whilst based on those used in previously published studies were somewhat arbitrary. Future studies are needed to validate these categories against outcome measures. Second, it is difficult to determine the extent to which these results generalise to AD patients and carers who have not had formal AD education, such as that provided by the AAQ, or are not connected with such organizations. Thus, it is possible that these results may overestimate the extent of

knowledge in these groups although similar knowledge levels have been reported previously by others as noted above. Nevertheless, if we accept the absolute level of these results, they highlight the need for further AD education programs given that approximately 50% of items were not answered correctly by the most “knowledgeable” group of participants in this study. Third, sample size limitations may limit the generalizability of these results, particularly in relation to the AD patient group, and our results may only be applicable to mildly impaired AD patients, given the MMSE cut-off we imposed to minimise complications with informed consent procedures. In addition, our groups differed in terms age and gender and this may further impact on the generalizability of these results both across groups and to other samples. Further investigations are needed to determine the extent to which these results apply to other samples of people with AD in particular, and until such investigations are conducted these results should be regarded as preliminary.

Notwithstanding these limitations, this study is significant in that it is the first published report utilising a standardised test of AD knowledge in three key groups including patients, carers and the general older adult community (non-carers). Despite the small sample size, the results of this study serve to highlight issues about which people from these groups hold misconceptions about AD or admit to a lack of knowledge, and this is important as these issues can be made the focus of future of AD education programs. Such programs may be broad scale and targeted towards particular groups (e.g., carers, patients or the non-carer community) since we have shown the information needs of these groups differ.

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Table 1

Statistically significant group differences in the correct response endorsement rate on eight ADK items (item numbers shown in brackets).

Correct response	Proportion of correct items	Chi-square results
Alzheimer's Association of Australia ^{vi} provides family support and education (20)	Carers > non-carers = patients	$\chi^2 (2, N = 42) = 12.54, p = .002$
Caregiver should help patients remain as independent as possible (18)	Carers > non-carers - patients	$\chi^2 (2, N = 42) = 6.96, p = .031$
Notes may provide useful reminders in mild AD (17)	Carers > non-carers = patients	$\chi^2 (2, N = 42) = 6.75, p = .034$
Patients may be unaware of and deny their symptoms, and be depressed (12)	Non-carers > carers = patients	$\chi^2 (2, N = 43) = 7.66, p = .022$
Early evaluation is important to rule out reversible disorders (6)	Carers > non-carers = patients	$\chi^2 (2, N = 43) = 9.77, p = .008$
Persons with a close relative with AD have an increased risk of AD (4)	Carers > non-carers = patients	$\chi^2 (2, N = 43) = 15.39, p = .000$
The cause of AD is unknown (3)	Carers > non-carers = patients	$\chi^2 (2, N = 43) = 8.73, p = .013$

Table 2.

Misconceptions, commonly held correct beliefs, and self-identified knowledge gaps identified by two or more groups in relation to Alzheimer's disease.

Belief type	Belief	Held by
Misconception	Percentage of people over 65 with AD is 20-25	Carers, non-carers
	Alzheimer's disease is never inherited	Non carers, patients
	Early evaluation of symptoms may prevent worsening of symptoms	Non-carers, carers, patients
	AD diagnosis can be confirmed by mental status testing	Carers, non-carers
	Wandering can be managed by sharing feelings and locking doors	Carers, non-carers
	Personality changes are beyond the control of patients and are deliberate	Non-carers, carers
	Nutrition plays no role in AD	Non-carers, patients
Correct beliefs	Loss of memory is always present in AD	Carers, patients
	Assisting with activities to preserve independence is recommended when ADLS become difficult	Non-carers, carers, patients
	The prevalence of AD will increase proportionate to the number of people over 65 years.	Carers, patients
Knowledge gaps	Percentage of community dwelling persons with moderate to severe AD	Non-carers, patients
	Life expectancy after diagnosis is 6-12 years	Non-carers, patients

Table 3.

Knowledge gaps identified by 50% or more of individuals in non-carer (n =20) or patient groups (n = 10).

Type of information	Identified as unknown by
Percentage over 65 with AD	Non-carers
Role of heredity in AD	Non-carers
The role of aluminium in causing AD	Patients
Differential diagnoses	Patients
Life expectancy after diagnosis	Patients and non-carers
Percentage of community dwelling dementia patients	Non-carers and patients
Managing wandering	Patients

