

## Distinguishing between Knowledge Gaps and Misconceptions of Alzheimer's disease among caregivers in the UK

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### Abstract:

A popular scale for assessing knowledge about Alzheimer's disease is the Alzheimer's Disease Knowledge Scale (ADKS). The aim of the study was to investigate the effect of adding 'don't know' to the original 'true' or 'false' response option. It was assumed that this modification would provide insight into the reasons underlying incorrect responses and could distinguish between misconceptions and knowledge gaps. To investigate this, carers (care home carers and informal carers) and members of the general population were recruited. The results showed that percentage correct responses was lower than previously reported, suggesting potential inflation of knowledge by guesses without the 'don't know' option. Moreover, care-home workers were more likely to select the incorrect response than 'don't know' compared to informal carers for several items related to the earlier stages of AD, suggesting a higher level of misconceptions around this topic and highlighting potential training needs for care home carers.

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**Running title:** Misconceptions about AD among caregivers

## Introduction

With a growing global population, prevalence of dementia is increasing world-wide. It is estimated that approximately fifty percent of all residents in long-term care settings have dementia [1, 2] and the resulting heterogeneity in behaviours of residents can challenge the demands on knowledge and skills of carers in residential care homes [3, 4, 5]. Knowledge of dementia and Alzheimer's disease (AD) has been shown to vary among caregivers in residential settings and among informal carers [6, 7]. Poor understanding of the impact of dementia on patient behaviour can result in suboptimal care-choices and can increase agitation or anxiety unnecessarily [8, 9, 10]. Reliable assessment of knowledge among carers is therefore paramount for patient well-being and for guiding decisions about training strategies by residential care homes or for development of training programs for informal carers [8, 11].

A popular scale for assessing knowledge and misconceptions of Alzheimer's disease is the Alzheimer's Disease Knowledge Scale (ADKS [11]). The ADKS consists of 30 'true/false' statements related to seven 'knowledge domains': risk factors, symptoms, assessment and diagnosis, course of the disease, treatment and management, caregiving and life impact. So far, the questionnaire has been used to assess knowledge in the general population or among students (UK [12]; Norway [13]; USA [14, 15, 16]; South Korea [17] among health professionals and care staff [18], among psychologists [19] and it has been used as an outcome measure for validation of an online training program for care-workers [20].

One potential limitation of the ADKS is that 'true/false' responses in knowledge questionnaires provide only limited information about the reasons why an incorrect response is given [21, 22, 23, 24]. As suggested by Courtenay and Weidemann [21], true-false statements fail to distinguish between true

misconceptions (incorrect responses) and lack of knowledge ('don't know') about a given topic. The aim of the present study is to investigate whether addition of a 'don't know' option would allow a more reliable separation between misconceptions and self-reported knowledge gaps in a sample of the general population and carers of people with dementia (care home carers of elderly residents and informal home carers). This separation is particularly relevant for responses of carers as different answers could be associated with different care choices. For instance, selection of the incorrect answer when 'don't know' is available suggests that the answer is given with confidence and could result in suboptimal caregiving responses, whereas selection of 'don't know' suggests admission of a knowledge gap and is more likely associated with information seeking. In addition, inclusion of the 'don't know' response could provide an index of genuine knowledge that is not inflated by guesses when only 'true' and 'false' are the available response options.

## Method

### Participants

A total of 228 participants took part in the study, of which 51 were men and 173 were women (4 participants did not disclose their sex). One hundred and eighteen participants were recruited from care homes, 20 participants cared for people with Alzheimer's disease at home, and an opportunity sample of 80 people were recruited from the general population and university staff and students. Care home workers were recruited from residential care homes for the elderly via a local care trust responsible for 15 care homes in Lincolnshire. Job roles of care home workers were as follows: Caregiving (63.6%), kitchen staff (16.1%) housekeeping (15.3%) and other (5.1%). Informal caregivers were recruited via meetings organized by the Alzheimer's disease society for patients with Alzheimer's disease living at home.

## Materials

The ADKS (Carpenter et al, 2009) assesses knowledge about seven knowledge domains: risk factors (e.g., 'Genes can only partially account for the development of AD'), symptoms (e.g., 'Most people with AD remember recent events better than things that happened in the past'), assessment and diagnosis (e.g., 'AD is one type of dementia'), caregiving (e.g., 'People with AD do best with simple instructions, given one step at a time'), treatment and management (e.g., 'AD cannot be cured'), life impact (e.g., 'It is safe for people with AD to drive, as long as they have a companion in the car at all times') and course of the disease (e.g., 'In rare cases, people have recovered from AD'). The original ADKS was modified for the purpose of this study by adding a third response option ('I don't know') to the two original response options ('True' or 'False') for each statement.

In addition to the ADKS statements, the questionnaire included questions about education and specific dementia training. Education was rated on a 6 point scale: 1='left school before 15', 2=GCSE, 3=A-level, 4=Diploma, 5=1<sup>st</sup> degree, 6=higher degree. Specific dementia training was categorized as follows: 'Tertiary training' (undergraduate or post-graduate course include specific AD course content); 'Dementia training' (dementia specific conferences, in-service dementia course or workshop); 'Other dementia learning' (self-directed learning (e.g. on-line); 'No training at all'. Three additional questions were asked about their level of experience with AD: Question 1 (E-Q1): 'Do you personally know anyone who has had Alzheimer's disease (or a related disorder)'; Question 2 (E-Q2): 'Are you currently, or have you previously been a caregiver to a family/friend with Alzheimer's disease (or a related disorder)'; Question 3 (E-Q3): 'Do you have any experience of working with people who have Alzheimer's disease (or a related disorder)'. These three questions required either a 'yes' or 'no' response.

Participants were also asked to rate their own knowledge of Alzheimer's disease on a 10-point Likert scale (where 1= I know nothing at all and 10= I am very knowledgeable).

## Results

### Group formation

For analysis of ADKS responses as a function of experience with AD, participants were organised into four groups: Group 1 consisted of people who work in care homes as caregivers (70 females, 1 male), group 2 were all caregivers recruited via the AD society who at the time of participation cared for a spouse with Alzheimer's disease at home (informal carers: 14 females, 6 males). Of the volunteers recruited via care homes, 63.6% were caregivers whereas the remaining participants were either involved in housekeeping or had other roles (e.g. hair-dressing). We categorized this latter group as participants who have contact with people with Alzheimer's disease at their workplace but who are not caregivers. These volunteers were combined with participants from the general population who also have contact with AD patients at work but who are not involved in direct care of people with AD on a daily basis (e.g. social workers, nurses, police officers). All participants in this combined group answered 'yes' to E-Q3 and 'no' to E-Q2 (in total 51 females, 11 males). The fourth group consisted of volunteers recruited from the general population who were not in the caregiving profession and who had no contact with people with AD at work or cared for people with AD at home (37 females, 33 males): All volunteers in this group answered 'no' to E-Q2 and E-Q3. Details about the four groups are presented in Table 1.

### Response profiles for each knowledge domain

Percentages correct, incorrect and 'don't know' responses were compared between the four groups, separately for each knowledge domain, using one-way ANOVA and post-hoc pair-wise comparisons with Bonferroni corrections (see Figure 1).

**Table 1:** Details of the four groups (see text for a description of the groups). Age in years (standard error), Education, level 1-7 (as described in the text), Self-rated knowledge (min-max = 0-10), Specialized training (ST), tertiary, dementia, other or no training: Values refer to percentage of group members who received the different types of specialized training.

	Group 1	Group 2	Group 3	Group 4
	Caregivers in care-homes	Informal carers	Contact with AD at work	No contact
	N=75	N=20	N=63	N=70
Age (in years)	41.2 (1.4)	55.5 (3.3)	45.2 (1.8)	29.9 (1.6)
Education (1-7, see text)	2.8 (0.1)	3.8(0.37)	3.2 (0.2)	4.1 (0.2)
Self-rated knowledge (1-10)	6.8 (0.16)	6.9 (0.3)	5.6 (0.3)	4.1 (0.2)
ST: tertiary	0.027	0	0.071	0.014
ST: dementia	0.916	0.25	0.517	0.029
ST: other	0.055	0.2	0.125	0.058
ST: none	0	0.55	0.285	0.899

*Correct responses:* Significant effects of Group were found for life impact [F(3,221)=7.5;  $p < 0.001$ ], assessment and diagnosis [F(3,223)=13.07;  $p < 0.001$ ], caregiving [F(3,223)=8.2;  $p < 0.001$ ] and symptoms [F(3,224)=3.34;  $p = 0.02$ ]. Both for life-impact and assessment/diagnosis, Groups 1, 2 and 3 achieved a higher percentage correct responses than group 4 ( $p \leq 0.03$ ), whereas differences between Groups 1, 2 and 3 were not significant. For caregiving, care-home carers achieved a significantly higher proportion correct responses than Groups 3 and 4 ( $p \leq 0.05$ ) whereas for symptoms, informal carers (Group 2) scored highest and significantly better than Group 4 ( $p = 0.02$ ).

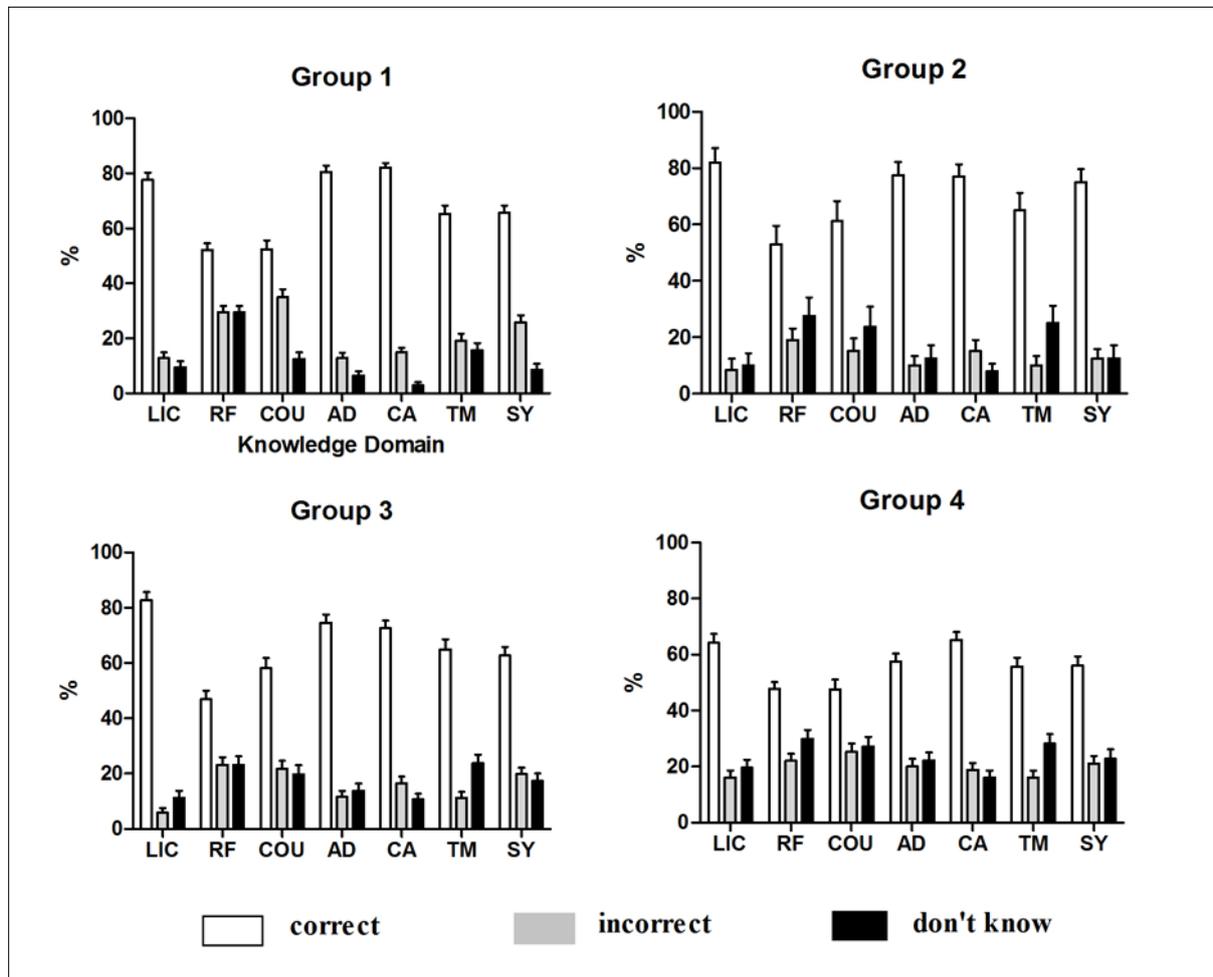
*Incorrect responses:* Significant differences were only found for life impact [F(3,218)=3.9;  $p = 0.009$ ] and course of the disease [F(3,220)=5.5;  $p = 0.001$ ]. Figure 1 shows that for course of the disease, care home carers gave significantly more incorrect responses compared to groups 2 and 3 ( $p \leq 0.06$ ). Similarly, for life impact, most incorrect responses were given by groups 1 and 4, resulting in a significant difference between groups 3 and 4 only ( $p = 0.007$ ).

*Don't know responses:* The effect of Group was not significant for the domain risk-factors, but significant group differences were found for all remaining

knowledge domains [F(3,223)  $\geq 3.1$ ;  $p \leq 0.027$ ]. Percentages don't know responses were significantly lower for care home carers compared to group 4 for life impact ( $p = 0.03$ ), course of disease ( $p = 0.005$ ) treatment and management ( $p = 0.02$ ) and symptoms ( $p = 0.002$ ). For the domain caregiving, a significant difference was only found between Groups 3 and 4 ( $p = 0.002$ ). Groups 1, 2 and 3 did not differ significantly in their percentages of don't know responses.

#### Items with low accuracy

Percentage correct responses on individual questions varied between 90.4% correct (Q5: *People with Alzheimer's disease do best with simple, instructions given one step at a time*) to 18.4% (Q18: *Having high cholesterol may increase a person's risk of developing Alzheimer's disease*). To analyse potential group differences in response profiles for items with low accuracy, frequency distributions for correct, incorrect and don't know responses were extracted for questions with percentage correct responses lower than 55% (Q3, 7, 9, 12, 14, 18, 20, 22, 26). Associations between these frequency distributions and the variable Group were analysed using chi-square tests of associations. Fisher's exact test was used when any expected cell value was lower than 5. These analyses showed significant



**Figure 1:** Mean percentage correct responses (white bars), incorrect responses (grey bars) and 'don't know' responses (black bars) for each knowledge domain (LIC = Life impact, RF = Risk Factors, COU = Course of the disease, AD = Assessment and Diagnosis, CA = Care, TM = Treatment and Management, SY = Symptoms), separately for the four groups (see text for an explanation of the four groups).

associations for questions 7 (*"If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day"*), 14 (*"A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse"*), 17 (*"Eventually a person with Alzheimer's disease will need 24 hour supervision"*) and 22 (*"Trouble handling money or paying bills is a common early symptom of Alzheimer's disease"*) [ $\chi^2 \geq 12.4$ ;  $p \leq 0.04$ ]. For all four questions, care home carers selected the incorrect response significantly more often than the 'don't know' option (*all*  $p \leq 0.05$ ), whereas this trend was either absent or reversed (although not significantly) in the remaining three groups (see Table 2). Interestingly, informal carers selected the correct response significantly more often than care-home carers for questions 7, 17, 22 ( $p \leq 0.02$ ) and marginally for Q14 ( $p = 0.058$ ). Informal carers were also more likely to select the correct response compared to group 4 for Q7 ( $p = 0.023$ ), and compared to groups 3 and 4 for questions 17 and 22 ( $p \leq 0.002$ ).

**Effect of the 'don't know' option on percentage correct and incorrect responses:** Percentages correct and incorrect responses of Groups 3 and 4 were directly compared with responses collected previously from a sample from the general population using the ADKS version with only 'true' and 'false' response options [12]. Independent t-tests showed that both correct and incorrect responses reduced significantly for all knowledge domains [ $t(548) \geq 2.3$ ;  $p \leq 0.015$ ], except correct responses for the knowledge domain life impact. When Bonferroni correction was applied, the difference became non-significant for percentage correct responses to items related to course of disease, and for incorrect responses to items related to symptoms. All remaining differences remained significant [ $t(548) \geq 3.02$ ;  $p \leq 0.003$ ].

**Discussion**

The present study used a modified version of the ADKS to assess knowledge about AD among carers and in a sample of the general population. Inclusion of the 'don't know' option (selected ~23% of the time)

**Table 2:** Percentages correct (C), incorrect (IC) and don't know (DK) responses for each group (G1-G4) for Questions (Q) 7, 14, 17 and 22.

	Q7			Q14			Q17			Q22		
	C	IC	DK	C	IC	DK	C	IC	DK	C	IC	DK
G1	39	52	9	48	42	9	51	44	4	39	51	10
G2	60	15	25	60	15	25	70	15	15	75	15	10
G3	51	23	25	58	23	19	52	34	14	43	33	24
G4	46	28	28	49	27	24	51	29	20	46	28	28

**Additional analyses**

**Correlations:** Table 3 shows that ADKS scores correlated significantly with age and self-reported knowledge but not with education. A few correlations may be specific to the sample used in the present study: Age of the participant correlated positively with ADKS score, negatively with education and positively with self-reported knowledge (see Discussion).

reduced both correct responses (-10%) and incorrect responses (-11%) in the sample from the general population compared to percentages reported in our previous study [12] suggesting that percentage correct responses may be a better index of true knowledge about AD when the 'don't know' option is included. Furthermore, consistent with findings of previous studies using true/false/don't statements to investigate knowledge about effects of ageing on memory [21, 22]

**Table 3:** Correlations: \*\*\*= $p < 0.001$ , \*\*= $p < 0.1$ , \*= $p < 0.05$

	Age	Education	SK	Total ADKS
Age		-0.24***	0.23***	0.23**
Education			-0.14*	-0.02
SK				0.42***
Total ADKS				

the 'don't know' option distinguished between real knowledge, misconceptions and self-reported knowledge gaps. Care home carers, informal carers and other professionals with dementia-experience at work all obtained a higher percentage correct response compared to those who had no experience with dementia, whereas only care home carers selected the *incorrect* answer more often than the other two groups for the knowledge domain 'course of the disease'. Conversely, only care home carers selected 'don't know' significantly *less* often for this knowledge domain compared to group four. Combined, these results seem to suggest that the carers who work in care homes had a relatively high level of misconceptions about the course of Alzheimer's disease. One possible explanation that may require consideration for the interpretation of this result is that responses of carers may have been influenced by a systematic responses bias [25]. Specifically, care home carers may have felt that they should know the answers to all ADKS items given their profession and as a result may have avoided the 'don't know' option. Whilst not implausible, the anonymous completion and treatment of all questionnaires should have eliminated any potential external pressures that could have resulted in avoidance of don't know response. Moreover, if care home carers adopted this general strategy, then higher percentages of don't know responses for care home carers would be expected compared to all other groups, not just compared to group 4. Nevertheless, future studies will be required to address potential influences of response biases in care home carers, for example by allowing further elaboration

on individual answers in focus groups following completion of the ADKS.

The tendency of care home carers to select the wrong answer instead of don't know was particularly pronounced for four ADKS items associated with relatively low accuracy overall. Two of these items concerned statements about the course of the disease (Q17 "*Eventually a person with Alzheimer's disease will need 24 hour supervision*" and Q14: "*A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse*"), one question concerned knowledge of symptoms (Q22: "*Trouble handling money or paying bills is a common early symptom of Alzheimer's disease*) and one question was related to treatment and management (Q7: "*If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day*"). The fact that care home workers selected the incorrect response for these questions is surprising as they describe situations that carers could be assumed to be familiar with. Whilst these results indicate true misconceptions, a few alternative possible explanations should be considered. One such explanation is unintended incorrect interpretation of some of the items. For example, even when living under supervision in residential care 24 hours per day, patients with AD may not need 'eyes-on' supervision at all times of the day. Alternatively, responders may have relied too heavily on their observations at work for some of the items. For example, although statements 14, 17 and 22 may be familiar to those who have followed the progression of the disease closely (such as informal carers), care home carers are more likely to meet their residents when dementia has already progressed to later stages of the disease. Care home carers may therefore not necessarily have observed the gradual increase in falls or the first few times that residents experienced difficulties with handling money. Whilst speculative, this interpretation

seems to be supported by the high percentage of correct responses for these four questions by informal carers. It will require further research with a larger sample, particularly of informal carers, to investigate the potential influence of item interpretation and the type of experience professionals have with dementia on their ADKS answers.

Consistent with our previous findings [12], knowledge about risk factors related to life-style (hypertension, cholesterol) were only answered correctly by a very small percentage of participants (~20%) and were associated with a high percentage of incorrect responses (~38%). Frequency distributions were comparable for the four groups suggesting that misconceptions about this topic were similar for carers and non-carers alike. These findings seem to suggest that scientific advances on the relationship between cholesterol, hypertension and AD [26], including new insights into the potential positive effect of statins in treatment plans [27, 28] are not effectively communicated to informal carers, care home workers and the general population. Given that both our studies were conducted in the UK implies little awareness about these factors in the British population, despite ongoing national dementia awareness campaigns [29, 30].

A few results were consistent with previous findings [18, 9] (Smyth et al, 2013; Robinson et al, 2014). Specialist dementia training was associated with higher total percentages of correct ADKS responses, confirming existing evidence for the beneficial effects of specialist training on knowledge of dementia [31]. Higher ADKS responses were also associated with those who rated their own knowledge higher, replicating our previous findings and those obtained from Australian health professionals [12, 18]. Conversely, a few correlations may have been unique to the sample used in the current study and require further consideration. Table 3 shows that age of the participant correlated positively with ADKS score, negatively with education

and positively with self-reported knowledge. This pattern of correlations is likely due to differences between groups in terms of age (*reducing* from Group 1 to 4) and level of education (*increasing* from Group 1 to 4) (see Table 1), which could be explained by the relatively high proportion of university students in this group (N=26) compared Group 3 (N=6) and Groups 1 or 2 (none). Although multivariate regression analysis would have been informative for exploring the predictive value of group membership (Group 1-4), age, education and self-reported knowledge, multicollinearity can be problematic for interpretation of regression models [32]. Future studies investigating knowledge of AD in carers may consider matching the control group more carefully with the carers in terms of age and education.

## Conclusion

The present study demonstrates that inclusion of the 'don't know' option in the ADKS provides valuable insight into the reasons why respondents select incorrect responses (misconceptions versus knowledge gaps). The study revealed that care-home carers were more likely to select the incorrect response with confidence for several items, suggesting a higher level of misconceptions than for informal carers. Possible item-specific explanations were considered, highlighting training needs for improving knowledge of care home workers about the impact of AD on behaviour at earlier stages of the disease.

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