

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Knowledge and attitudes towards dementia in adolescent students

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DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

ABSTRACT

Background: Improving people's knowledge, perceptions and attitudes of dementia is important in the formation of dementia-friendly communities. However at present, there is very little evidence from adolescents, who are already the junior members of such communities and will be carers in their own rights in the future. Our aim was to evaluate adolescents' knowledge and attitudes of dementia.

Methods: Four-hundred and fifty adolescents, aged 15 to 18, from schools in Sussex (UK) were invited to complete a series of questions that assessed their dementia knowledge and attitudes.

Results: A total of 359 adolescent students completed the questionnaire. Out of 15 questions on dementia knowledge, participants were on average able to answer less than half correctly ($M=6.65$, $SD= 2.34$). Responses to the attitudes questionnaire showed that adolescent students had both positive and negative attitudes toward dementia.

Discussion: There is scope for adolescents attending school to improve their dementia knowledge and attitudes. More effort is needed to embed initial dementia understanding in the school curriculum which will improve awareness about dementia at an earlier age and will enhance dementia-friendly communities.

Declaration of interest: None

Key words: adolescents, teens, students, dementia, knowledge, attitudes

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

BACKGROUND

Currently there is an estimated 850,000 people with dementia in the UK, with numbers set to rise to over 2 million by 2051 (Prince et al., 2014a). Dementia has a profound effect on those with the disease, as well as on friends and family who often become carers. In addition to the burden to the individual, the total cost of dementia to society in the UK is £26.3 billion, with an average cost of £32,250 per person (Prince et al., 2014a). It is estimated that two thirds of all people with dementia are living in the community (Prince et al., 2014b).

As highlighted in NICE/SCIE guidelines (National Collaborating Centre for Mental Health (UK), 2007) and various high impact government documents (Department of Health, 2009, 2012; Department of Health & Prime Minister's Office, 2013) there is a need to improve attitudes, knowledge and skills of professionals caring for people with dementia, but also to increase broader public understanding of dementia and make communities more 'dementia-friendly'. The objective of a dementia-friendly community is to engage people with dementia and their carers so that their opinions are at the heart of any considerations or decisions made (Alzheimer's Society, 2013; Crampton et al., 2012), enabling them to have choice and control over their lives thus remaining independent for as long as possible (Prior, 2012).

Promoting knowledge and positive attitudes of dementia in young people is particularly important because of the ever increasing exposure to the disease.

Educating young people about some dementia aspects in schools may be a route to achieve this in a standardised fashion. The healthcare education literature can provide

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

us with an insight into the attitudes of young adults (Aged 18+). Internationally, nursing and medical students generally have positive attitudes of people with dementia (Scerri & Scerri, 2013; Tullo & Young, 2014), although there are concerns about the depth of knowledge these healthcare students have about the disease (e.g. Kwok et al., 2011; Scerri & Scerri, 2013). One study of first year medical students in the US found that only 2.5% were able to correctly answer at least 10 items (out of 12 items) on an Alzheimer's Disease knowledge scale (Nagle et al., 2013). However, the generalisability of these findings in UK adolescent students is limited because it is unclear when such attitudes and knowledge form, whether it is dictated by their common career goals, and to what extent culture influences these outcomes.

To our knowledge, little is known about adolescent students' attitudes and knowledge of dementia. In a single Taiwanese study, authors found that 93% of 10-15 year olds were aware of dementia, but were still likely to have misconceptions about the disease (e.g. it was contagious)(Fuh et al., 2005). Notably, this evidence is limited to both the culture and age of the sample. In the Dementia Awareness & Intergenerational Exchange in Schools Project, a dementia education programme for schools across England, there is evidence that secondary school children have some knowledge gaps about dementia (Atkinson & Bray, 2013). In the evaluation report, 82% of secondary school and college students correctly answered that dementia is not a normal part of ageing, whilst 77% of students believed that you could improve your life if you get dementia. Whilst both percentages are high, it is hoped that all adolescents should have this basic level of knowledge. To our knowledge, there is no peer-reviewed evidence about UK adolescent students' attitudes and knowledge towards dementia.

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Establishing positive attitudes and dementia knowledge in adolescents is important because of the ever growing exposure to the disease. In the future, many of these young people will become active members of dementia-friendly communities, or even carers themselves. Understanding whether adolescents have gaps in their knowledge and negative attitudes toward dementia could provide focus for future educational programmes within the UK. This study aims to present descriptive data on the knowledge and attitudes of adolescent students toward dementia.

METHODS

All participants were recruited from two schools (a private school and state school) in Sussex, UK. Schools were chosen to reflect both education sectors, but also due to ease of access. We approached the head teacher of each school and explained the project and obtained his/her agreement for distribution and collection of the questionnaires. The logistics of distributing the questionnaire was subsequently agreed with form tutors and teachers of the students. We then met with the students during form time, in the presence of a teacher, where the purpose of the study was explained and an information sheet was provided. All students were informed that participation in the research was voluntary, that the questionnaires were anonymous, and that they were able to miss questions if they do not feel comfortable answering them. Students were then invited to answer the questionnaire. A total of 450 participants, aged between 15 and 18 years old, were provided questionnaires to complete on their attitudes and knowledge about dementia. There were no other inclusion or exclusion criteria.

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

At the time of testing there was no validated questionnaire for this age group, so a questionnaire was designed by combining appropriate questions from the Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988), and the Northern Ireland Life and Times Survey (McParland et al., 2012), as well as deducing questions from the Alzheimer Society fact sheet. The questionnaire consisted of 15 multiple choice questions on dementia knowledge and 8 questions on attitudes toward dementia (Appendix 1). All questions were piloted on 10 students to ensure that there was no ambiguity in wording. The questionnaire was found to be user friendly with no problems experienced when completing it.

Descriptive data was reported on demographic information (e.g. gender, year of study), as well as knowledge and attitudes toward dementia questionnaires. For knowledge questions, responses were scored based on correct and incorrect answers, multiple or missing responses were scored as being incorrectly answered. Total dementia knowledge scores were compared between demographic outcomes using a Mann-Whitney U statistic.

RESULTS

Of the 450 questionnaires that were handed out, 359 were returned (79.7%). The typical participant was female, from a state school and in year 11 (aged 15-16). Less than a quarter of respondents (23.4%) reported knowing someone with dementia (See Table 1.)

(Table 1. here)

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Dementia knowledge

Of the 15 multiple choice questions, not a single participant answered all questions correctly, with the average participant scoring under half correct ($M=6.65$, $SD=2.34$).

The question that most participants answered unsuccessfully was the effect of delaying the onset of dementia on death rates, with only 36 (10%) answering correctly. Closely followed by question on the cost of dementia, with only 43 (12%) answering correctly. Participants were most successful in answering that dementia is a disease of the brain and that a person becoming confused doesn't mean that they have dementia, with 279 (77.7%) and 269 (74.9%) participants answering each question correctly, respectively.

Neither year of study, school, nor gender, affected scores on the dementia knowledge questionnaire ($p>0.05$). Adolescents that knew someone with dementia scored significantly higher on the knowledge questionnaire ($M = 7.15$, $SD = 2.23$) compared to those that did not know anyone with dementia ($M = 6.52$, $SD = 2.34$) ($U = 9718.00$; $p=0.03$).

Attitudes toward dementia

For several statements, responses reflected that adolescent students had positive attitudes toward dementia. For example, the statement "There is no point talking to someone with dementia as they won't be able to understand", there was a skew towards disagreement, with the majority of responses being disagree or strongly disagree ($Mdn = 4.0$, $IQR = 1.0$). Whilst most students agreed with the statement

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

“People with dementia should be involved in activities in the community” (Mdn = 2.0, IQR = 1.0). Conversely, some responses to items reflected more negative attitudes. For example, most students agreed with the statement “There comes a time when all you can for someone with dementia is to keep them clean health and safe” (Mdn = 2.0, IQR = 0.0). Notably, across all items, the mode (or median) response was never ‘Strongly agree’ or ‘Strongly disagree’, see Table 2 for full descriptive data.

(Table 2. here)

DISCUSSION

The aim of this survey was to determine the current knowledge and attitudes of dementia in adolescents in the UK. The present sample consisted of adolescents who attended two schools in Sussex in years 10-13 (Aged 15-18).

In the present study, the results show there is scope for adolescent students to improve their dementia knowledge, with adolescents accurately answering less than half of the questions correctly. Whilst it could clearly be argued that the need of knowing certain items (e.g. the cost of dementia care) is neither essential nor expected, it is of note that a number of participants were also unable to correctly answer some more basic questions, e.g. basic symptoms of the disease (44.3% incorrect), that there is no cure (42.9% incorrect) and the cause of the disease (81.9% incorrect).

Interestingly, less than a quarter of adolescents knew someone with dementia (23.4%). Those that did know someone with dementia had, on average, a greater dementia knowledge than those that did not ($p=0.03$). Previous studies in a wider

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

adult population have shown that increased contact with dementia resulted in better dementia knowledge (Dowds et al., 2012; McParland et al., 2012; Reid et al., 2015), though these findings are not always consistent (Lundquist & Ready, 2008). It is therefore possible that spending time with a person with dementia as part of an education programme maybe a simple yet effective way to improve knowledge in adolescents.

Adolescents' attitudes toward dementia were slightly more mixed. Participants generally responded positively to statements that reflect people with dementia as a person. For example, participants generally felt that individuals' life was still worth living and that you should talk to them. However, there were more negative responses towards the progression and care for people with dementia, with close to half of participants agreeing that the person will eventually disappear (55.2% of responses) and that they are better off in a residential home (47.1% of responses).

The South East of England has a higher than average prevalence of dementia in the UK (Knapp et al., 2007), and therefore schools selected would represent a sample who are/will have the greatest exposure to the disease. However, as the current results come from only two schools in Sussex (England), the findings may not be generalisable to other schools nationally or internationally. In particular, schools already implementing some dementia education programmes, or engaging in additional dementia teaching materials may yield different results. The Dementia Awareness & Intergenerational Exchange in Schools, one example of an education programme for school children, has been shown to be effective in increasing knowledge in adolescents (Atkinson & Bray, 2013). In fact, some children had the opportunity to meet someone with dementia as part of the programme, which was reported to have a positive impact on elements of knowledge and attitudes. This

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

further supports our findings, but also the supports the future use of contact between students and people with dementia as an educational tool. There are current efforts by Alzheimer's Society and Alzheimer's Research UK, to provide school children free learning resources about dementia, in the form of the 'Youth Engagement Project' (previously the 'Dementia4schools project'; Dementia Action Alliance, 2015) and 'Dementia Explained' respectively. However, this is not compulsory and therefore many school aged children may not receive any formal education about dementia.

A key limitation of this study is the use of a non-validated measure of dementia knowledge and attitudes. Whilst the majority of questions were derived from established questionnaires (Dieckmann et al., 1988; McParland et al., 2012), the fact that the measure was not specifically developed from the ground up for this sample could influence students' responses, either in wording used, or the questionnaire responses. For example, "I don't know" was not an option for all dementia knowledge questions and therefore they may have guessed the correct answer. As previously stated, the level of knowledge that adolescent students should know is questionable, and therefore achieving 100% on the dementia knowledge questionnaire may not be a necessity. Until a validated measure of dementia knowledge has been developed specifically for an adolescent sample, researchers should avoid summary statistics (i.e. total score) and instead focus on interrogating where the gaps in knowledge lie. It is however revealing that there are obvious gaps that may impact their role as members of a dementia-friendly community. The self-devised questionnaire will also prevent comparisons with other sample populations, however we have made the items available (see Appendix 1) so future studies are able to make comparisons if necessary on individual items.

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

This survey provides emerging evidence of dementia knowledge gaps and negative attitudes toward dementia in adolescents within the UK. Future studies need to explore whether this is unique to the schools identified in this study, and if not, what are the most effective ways to improve knowledge and attitudes toward dementia in adolescents in general. Increasing adolescents' exposure to dementia maybe one method of improving dementia knowledge and attitudes, though this needs to be evaluated further. Regardless of the format, ensuring that dementia education is part of the school curriculum, will help to increase awareness and knowledge of the disease, thus providing a generation of individuals that are positive members of dementia-friendly communities.

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Appendix 1

(Please tick one box)

Dementia is a disease of the brain

TRUE FALSE I don't know

Dementia is part of the normal process of ageing

TRUE FALSE I don't know

Dementia is another term for Alzheimer's Disease

TRUE FALSE I don't know

People who eat healthily and exercise are less likely to get Dementia

TRUE FALSE I don't know

Dementia can be cured

TRUE FALSE I don't know

How many people have Dementia in the UK?

300,000
800,000
1,100,000

Most of these people are over the age of

35
65
75

Delaying the start of Dementia by 5 years would reduce deaths

by 1,000 a year
by 15,000 a year
by 30,000 a year

The cost of looking after people with Dementia in the UK in 2012 is approximately

£23,000
£23 million
£23 billion

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

What percentage of people with Dementia receive a diagnosis?

- 15%
- 43%
- 66%
- 80%

How many carers for patients with Dementia are there in the UK?

- 330,000
- 630,000
- 830,000
- 1,030,000

If a person becomes confused it means that they have a Dementia.

- TRUE FALSE I don't know

The cause of Dementia is:

- Old age
- Hardening of the arteries
- Unknown
- I don't know

Which of the following sometimes resemble Dementia?

- Depression
- Confusion
- Stroke
- All of the above
- I don't know

People with Dementia have problems with:

- Thinking clearly
- Communicating
- Remembering things
- Day to day activities i.e. getting dressed
- All of the above

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

There comes a time when all you can do for someone with Dementia is to keep them clean, healthy and safe

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

Once they have Dementia the person you knew eventually disappears

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

As soon as someone is diagnosed with Dementia they are not treated like a thinking human being anymore

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

There is no point talking to someone with Dementia, as they won't be able to understand

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

It is better for people with Dementia and their families if they are cared for in a residential unit or a nursing home

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

People with Dementia should be involved in activities in the community

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

People with Dementia are like children and need to be cared for as you would for a child.

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

For people with really bad Dementia I don't think life is worth living

Strongly Agree [] Agree [] Neither [] Disagree [] Strongly Disagree []

THANK YOU FOR COMPLETING THIS
QUESTIONNAIRE

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

References

- Alzheimer's Society. (2013). *Guidance for communities registering for the recognition process for dementia-friendly communities*. London: Alzheimer's Society.
- Atkinson, T., & Bray, J. (2013). *Dementia Awareness & Intergenerational Exchange in Schools: A Pioneer Project supporting Dementia Friendly Communities*. University of Worcester. Retrieved from http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2306
- Crampton, J., Dean, J., & Eley, R. (2012). *Creating a dementia-friendly York*. York: Joseph Rowntree Foundation York.
- Dementia Action Alliance. (2015). Dementia 4 Schools Project. Retrieved November 3, 2015, from http://www.dementiaaction.org.uk/dementiafriendlyschools/dementia_4_schools_project
- Department of Health. (2009). *Living well with dementia: A National Dementia Strategy*. London: Department of Health.
- Department of Health. (2012). *The Prime Minister's 'Dementia Challenge': Delivering Major Improvements in Dementia Care and Research by 2015*. London: Department of Health.
- Department of Health, & Prime Minister's Office. (2013). *G8 dementia summit agreements*. Retrieved April 27, 2014, from <https://www.gov.uk/government/publications/g8-dementia-summit-agreements>
- Dieckmann, L., Zarit, S. H., Zarit, J. M., & Gatz, M. (1988). The Alzheimer's Disease Knowledge Test. *The Gerontologist*, 28(3), 402–408.

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

- Dowds, L., McParland, P., Devine, P., & Gray, A. M. (2012). *Attitudes to and knowledge of Dementia in Northern Ireland 2010*. Belfast: University of Ulster.
- Fuh, J.-L., Wang, S.-J., & Juang, K.-D. (2005). Understanding of senile dementia by children and adolescents: why grandma can't remember me? *Acta Neurologica Taiwanica*, 14(3), 138–142.
- Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J., Ferri, C., et al. (2007). Dementia UK. *London: Alzheimer's Society*, 7.
- Kwok, T., Lam, K.-C., Yip, A., & Ho, F. (2011). Knowledge of Dementia Among Undergraduates in the Health and Social Care Professions in Hong Kong. *Social Work in Mental Health*, 9(4), 287–301.
- Lundquist, T. S., & Ready, R. E. (2008). Young Adult Attitudes About Alzheimer's Disease. *American Journal of Alzheimer's Disease and Other Dementias*, 23(3), 267–273.
- McParland, P., Devine, P., Innes, A., & Gayle, V. (2012). Dementia knowledge and attitudes of the general public in Northern Ireland: an analysis of national survey data. *International Psychogeriatrics*, 24(10), 1600–1613.
- Nagle, B. J., Usita, P. M., & Edland, S. D. (2013). United States medical students' knowledge of Alzheimer disease. *Journal of Educational Evaluation for Health Professions*, 10. Retrieved July 24, 2014, from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3674970/>
- National Collaborating Centre for Mental Health (UK). (2007). *Dementia: A NICE-SCIE Guideline on Supporting People With Dementia and Their Carers in Health and Social Care*. National Institute for Health and Clinical Excellence:

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

- Guidance. Leicester (UK): British Psychological Society. Retrieved May 9, 2014, from <http://www.ncbi.nlm.nih.gov/books/NBK55459/>
- Prince, M., Albanese, E., Guerchet, M., & Prina, M. (2014b). *World Alzheimer Report 2014*. London: Alzheimer's Disease International (ADI).
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., et al. (2014a). *Dementia UK: Update* (Second.). London: Alzheimer's Society.
- Prior, P. (2012). *Knowing the foundations of dementia friendly communities for the North East*. North East Dementia Alliance. Retrieved February 11, 2015, from http://www.phine.org.uk/uploads/doc/vid_16756_Dementia_Friendly_Communities_Report_Final.pdf
- Reid, S., Waterton, J., & Wild, A. (2015). *Attitudes to dementia: Scottish Social Attitudes 2014*. Edinburgh: ScotCen.
- Scerri, A., & Scerri, C. (2013). Nursing students' knowledge and attitudes towards dementia — A questionnaire survey. *Nurse Education Today*, 33(9), 962–968.
- Tullo, E. S., & Young, T. J. (2014). Medical students' attitudes toward people with dementia: an international investigation. *International Psychogeriatrics*, 26(01), 165–171

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Table 1. Demographic information of participants

	N (%)	Missing Data, N (%)
Gender	Male: 127 (35.4)	1 (0.3)
	Female: 231 (64.3)	
Year of Study	Year 10 / Aged 14-15: 142 (39.6)	2 (0.6)
	Year 11 / Aged 15-16: 143 (39.8)	
	Year 12 / Aged 16-17: 43 (12.0)	
	Year 13 / Aged 17-18: 29 (8.1)	
School	State School: 224 (62.4)	25 (7.0)
	Independent: 110 (30.6)	
Do you know anyone with dementia?	Yes: 84 (23.4)	1 (0.3)
	No: 274 (76.3)	

DEMENTIA KNOWLEDGE AND ATTITUDES IN STUDENTS

Table 2. The number of responses (and valid percent) per item on attitudes toward dementia questions. Median and Interquartile Range is reported for each item.

	Strongly agree [1]	Agree [2]	Neither [3]	Disagree [4]	Strongly Disagree [5]	Median, IQR
1) There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe:	66 (19.9%)	197 (59.5%)	44 (13.3%)	20 (6.0%)	4 (1.2%)	Mdn = 2.0 IQR = 0.0
2) Once they have dementia the person you knew eventually disappears:	27 (8.2%)	154 (47.0%)	64 (19.5%)	64 (19.5%)	19 (5.8%)	Mdn = 2.0 IQR = 2.0
3) As soon as someone is diagnosed with dementia they are not treated like a thinking human being anymore:	16 (4.8%)	83 (25.2%)	73 (22.1%)	113 (34.2%)	45 (13.6%)	Mdn = 3.0 IQR = 2.0
4) There is no point talking to someone with dementia as they won't be able to understand	6 (1.8%)	24 (7.3%)	40 (12.2%)	142 (43.3%)	116 (35.4%)	Mdn = 4.0 IQR = 1.0
5) It is better for people with dementia and their families if they are cared for in a residential or nursing home:	23 (7.0%)	132 (40.1%)	108 (32.8%)	51 (15.5%)	15 (4.6%)	Mdn = 3.0 IQR = 1.0
6) People with dementia should be involved in activities in the community:	58 (17.8%)	178 (54.6%)	62 (19.0%)	24 (7.4%)	4 (1.2%)	Mdn = 2.0 IQR = 1.0
7) People with dementia are like children and need to be cared for as you would for a child:	18 (5.5%)	117 (35.8%)	112 (34.3%)	68 (20.8%)	12 (3.7%)	Mdn = 3.0 IQR = 1.0
8) For people with really bad dementia I don't think life is worth living:	8 (2.4%)	39 (11.9%)	79 (24.1%)	106 (32.3%)	96 (29.3%)	Mdn = 4.0, IQR = 2.0