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Adolescents' experiences and perceptions of dementia

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Abstract

Objectives: There is a lack of understanding about how adolescents perceive dementia, and what their dementia related experiences are. Without such information, it is hard to make a case for the need to raise awareness of dementia in adolescents, and the best strategies to achieve this.

Methods: In a cohort of 901 adolescents (aged 13-18) from the South East of England, we explored what the experiences and perceptions of dementia were using a series of questionnaires. Descriptive data of individual items were reported, comparing differences between genders.

Results: The adolescents within this study tended to have positive or neutral attitudes towards dementia, though there was evidence that a proportion of adolescents had misconceptions or held negative attitudes (e.g. 28.5% of adolescents disagreed with the statement “In general, I have positive attitudes about people with dementia”). We also identified that the adolescents had a range of experiences of dementia including providing some form of care for someone with dementia (23.2%), though most had indirect contact with dementia through TV and movies (77.3%), or adverts (80.2%). Females nearly always had better attitudes towards dementia and had significantly more contact with dementia.

Conclusions: Considering that adolescents are already forming negative attitudes and misconceptions of dementia, it is important that we raise awareness about dementia in this age group.

Key Words: gender, teenagers, attitudes, dementia, ageing, contact

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Conclusions: Considering that a proportion of the adolescents had negative attitudes and misconceptions of dementia, it is important that we raise awareness about dementia in this age group. It might be important to target the attitudes and knowledge of dementia in males.

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Introduction

National and international dementia strategies have called for increased awareness of dementia to help combat stigma related to the condition (Alzheimer's Disease International, 2018; World Health Organisation, 2017). Whilst there is an ever-expanding literature about attitudes and knowledge of dementia within select groups such as healthcare students and professionals (Larkin, 2017; Macdonald & Woods, 2005; Scerri & Scerri, 2013; Wang et al., 2018), there is far less literature within the general adult population. Similarly, there is very little evidence available about what adolescent perceptions of dementia are and how they form. Such information is important considering that stigma towards mental health develops at a young age (Corrigan et al., 2007) and is maintained across the lifespan.

We already have some insights into how adolescents perceive people with dementia, describing them as “weird” (Cowley, 2005), “crazy”, or “child-like” (Baker et al., 2018). However, much of this evidence is derived from a small, selective group of participants, thus limiting its generalisability. However, quantitative studies identified that adolescents (n=359) have gaps in dementia knowledge and some negative attitudes (Isaac, Isaac, Farina, & Tabet, 2017), though stigma is generally low towards people with Alzheimer's disease (Werner, Jabel, Reuveni, & Prilutzki, 2017).

It is also unclear what adolescents' experiences of dementia are. In Australia, 31.0% of adolescents had never seen (or only seen in passing) someone with dementia, whilst 23.6% said they had a friend or family member with dementia (Baker et al., 2017). Whilst in England, 23.4% of adolescents reported to know someone with dementia (Isaac et al., 2017).

Understanding adolescents' experiences of dementia is important so that we can ensure that these experiences are framed in a manner that is positive.

The aim of this paper is to describe the perceptions and experiences of dementia in an adolescent sample.

Methods

Participants were adolescents that attended four different schools across Sussex, England. Adolescents were required to be in school years 9 to 13 (typically aged 13-18 years). There was no other inclusion or exclusion criteria.

Procedure

In brief, following approval from individuals' schools, adolescents were provided a series of questionnaires about attitudes and experiences of dementia. All adolescents were provided an information sheet about the research and informed that participation was voluntary. Consent was obtained through virtue of completing the questionnaire. No personal identifiable information was collected.

The study was ethically approved by Brighton and Sussex Medical School Research Governance and Ethics Committee.

Measures

Adolescents' experiences of dementia (i.e. contact) were captured through a nine-item questionnaire. The questions included were in part adapted from a level of contact questionnaire for mental illness (Holmes, Corrigan, Williams, Canar, & Kubiak, 1999). Conceptually, the scale was designed to capture the frequency of direct or indirect contact with dementia. The questionnaire has a total of 11-items, with each item rated on a 5-point Likert scale ranging from "never" to "a great deal".

Adolescents' perceptions of dementia were captured through the Adolescent Attitudes towards Dementia Scale (A-ADS) (Griffiths, Parveen, Shafiq, & Oyebode, 2018). The A-ADS is a 23-item measure of dementia attitudes and knowledge of dementia in adolescents, capturing "perceptions of dementia", "empathy towards people with dementia", and "personal sacrifice". Each item is rated on a 5-point Likert scale, ranging from "strongly disagree" to "strongly agree".

The Allophilia scale (Kinney, Yamashita, & Brown, 2017; Pittinsky, Rosenthal, & Montoya, 2011) is a 17-item questionnaire of positive attitudes towards outgroups (i.e. dementia). It was

developed with the notion that people find it more comfortable reporting positive attitudes rather than negative ones. In accordance with the findings from Kinney and colleagues (Kinney et al., 2017), a single item was removed (“I would like to be more like people with dementia”) as conceptually people do not aspire to develop dementia. Each item is rated on a 6-point Likert scale ranging from “Strongly Disagree” to “Strongly Agree”.

A single item ‘*Would you like to learn more about dementia?*’ was also included to understand whether adolescents would be resistant to being taught about dementia in the future.

For the purpose of this paper individual item responses were reported.

Analysis

Descriptive data (Median and Interquartile Range, or frequency and percentage) for each item of the whole sample was reported.

For perceptions of dementia (A-ADS and Allophilia scale items), responses were treated as categorical data for gender comparison. Responses were dichotomised into two categories; 1) *agree*, and 2) *disagree*. In doing so, this allows for a clearer presentation of positive and negative attitudes towards individual items. As such, the midpoint response (“neither agree nor disagree”) for the A-ADS was not included in the between group analysis. The added benefit is that it removes potential bias introduced through having a mid-point, which has been identified to be primarily used by non-attitude participants or undecided participants (Baka, Figgou, & Triga, 2012; Nadler, Weston, & Voyles, 2015). A Pearson’s Chi-square was used to compare between gender groups for the A-ADS and Allophilia items.

For experiences of dementia, responses were treated as nominal data for gender comparison. A Kruskal-Wallis test was used to compare between genders.

For each set of comparisons, *P* values were adjusted for multiple tests according to Holm-Bonferroni (Holm, 1979) and only corrected *P* values less than 0.05 were considered significant.

Results

Nine hundred and forty-seven participants were included in study, however, we excluded 46 participants from the analysis because they reported to have not heard of dementia (n=41, 4.3%), or the item was missing (n=5, 0.5%). As a result, 901 participants remained were included in the analysis. Participants were an average of 14.9 years old (SD=1.4), of which 478 participants were female (53.3%). Six hundred and sixty-six participants reported as being White British (80.0%).

Perceptions of dementia

Across all items there was a tendency to have neutral or positive attitudes towards dementia, with the median either lying at the mid-point of the response, or towards a response indicating positive attitudes. Gender was associated with attitude responses across the majority of items, with females holding attitudes that are more positive compared to males. There were only eight items, all from the A-ADS, in which there were no significant difference (Holms-Bonferroni corrected $p>0.05$) between groups. See Table 1 and 2 for full results.

[Table 1 near here]

[Table 2 near here]

Experiences of dementia

Across all items there was a positive skew towards having little to no experience of dementia. Adolescents had the most contact with dementia through adverts (80.2%) and had least experience with “looking after” someone with dementia (23.2%). Females have significantly more contact with dementia across all items, except for learning about dementia in school, spending time with a family member with dementia and looking after someone with dementia. See Table 3 for full results.

[Table 3 near here]

Learning more about dementia

Two-hundred and eighty-seven adolescents responded 'yes' to wanting to learn more about dementia (32.0%), which is a similar number to those who responded 'no' (n=321, 35.7%) or 'maybe' (n=290, 32.3%). Gender was significantly associated with how the adolescents would respond to the question ($\chi^2 = 32.53$, $p < 0.0001$), with females being more open to learning more about dementia.

Discussion

Across all items, adolescents on average responded to questions that would indicate that they have either neutral or positive attitudes towards dementia. For example, the majority of adolescents agreed that they would help someone with dementia if they saw them struggling. However, it is still of notable that 11.2% were unable to agree with this statement. Further investigation of the results highlights that there is a proportion of adolescents that do hold misconceptions. Only 55.5% of adolescents were able to agree that people with dementia can be creative, and only 57.9% of adolescents agreed that people with dementia can tell when others are kind to them. Whilst there is no absolute target in which adolescents should achieve, this should be common knowledge. Similarly, there appears to be a proportion of adolescents that held less positive attitudes towards dementia, with 28.5% of adolescents disagreeing with the statement "I am interested in hearing about the experiences of people with dementia", and 20.7% disagreeing with the statement "I feel positively toward people with dementia".

The present study also found that being female was associated with better attitudes and knowledge of dementia across nearly every item. This is in line with the broader literature of aging and mental health (two areas that overlap with dementia), in which gender commonly differentiates between attitudes towards these groups. For example, male children are more likely to have negative attitudes of older adults (Flamion, Missotten, Marquet, & Adam, 2017; McGuinn & Mosher-Ashley, 2002), and are more likely to hold stigmatizing attitudes towards mental illness (Ng & Chan, 2000; Watson, Miller, & Lyons, 2005). Understanding that gender affects perceptions of dementia may have implications in future career choices and likelihood of taking on a caring role.

Raising awareness and contact with people affected by dementia is important to improve attitudes and reduce stigma towards dementia (Mukadam & Livingston, 2012). However, there is no absolute level of attitudes and knowledge needed, and the perceived needs are likely to vary between individuals and between stakeholders. For example, Australian adolescents (and children) felt that raising awareness that people with dementia are “still people” and that it’s not their fault was seen as being important (Baker et al., 2018), whilst adolescents within England wanted to learn more about the signs, symptoms and causes of dementia (Parveen, Farina, Shafiq, Hughes, & Griffiths, 2019). It is promising that there are between one and two thirds of adolescents wanting to learn more about dementia, though as this too has gender differences, it is likely that females would be more engaged with the topic.

Many adolescents reported to have had contact with dementia in the past, both directly and indirectly. Most frequently, adolescents’ experiences of dementia come through indirect contact via TV, movies, and adverts. In the current sample 77.3% had watched a movie or TV show with someone with dementia in it, this is much higher than an adolescent Australian sample, with only 36.9% of participants having seen “short news story, movie, documentary, read a book about a person with dementia” (Baker et al., 2017). Also, within the present sample a large proportion had direct contact with dementia, with nearly half (45.8%) spending time with someone with dementia in the past. Again, this figure would appear to be much higher than previous studies that have attempted to capture similar outcomes (Baker et al., 2017; Isaac et al., 2017). Almost a quarter of adolescents (23.2%) reported to have looked after someone with dementia in the past, which is important because being a carer for family members with dementia can have a profound negative impact on adolescents’ lives (National Children’s Bureau, 2016; Sikes & Hall, 2017, 2018). Despite having these experiences, it occurs within the context that adolescents are not having any formal education of dementia, 66.4% never had been taught about dementia in school. We are aware that many secondary schools (South East of England) do not teach about dementia (Farina, 2017).

Female adolescents reported to have significantly more contact with people with dementia. This was observed across nearly all items and could indicate that female adolescents are already more engaged with dementia as a topic. In support of this, there was no significant difference in three items (whether dementia was taught at school, spending time family members with dementia and

looking after someone with dementia) that represent experiences that adolescents, irrespective of gender, have little control over. It is also telling that searching for information about dementia online showed the greatest difference between groups ($Z = -5.03$, $p < 0.0001$). Across a range of ages and settings, being female is associated with seeking health-related information online (AlGhamdi & Moussa, 2012; Cotten & Gupta, 2004; Ek, 2015; Powell, Inglis, Ronnie, & Large, 2011). The explanations of the gender differences in contact with dementia, could also be partially attributed to male adolescents being less aware when they have contact with dementia, or that it is socially undesirable to admit that they have contact with dementia, suggesting that issues around stigma still exist.

Despite have a modest sample size, the study is limited by only representing a predominantly White British group of adolescents from a relatively affluent region in South East England, as such the findings from this study may not reflect those of a more culturally diverse sample from elsewhere in the UK, or internationally. It is important to recognise that ethnicity of Israeli adolescents has previously been shown to be associated with stigmatising beliefs towards Alzheimer's disease (Werner et al., 2017). Another limitation of this research is that the findings are derived from subjective reports of dementia attitudes, and therefore is susceptible to social desirability bias, in which participants may try to present a favourable image of themselves by falsifying their responses (van de Mortel, 2008). Future research should consider including a social desirability scale to identify whether social desirability bias exists on this topic and whether it needs to be adjusted for (Althubaiti, 2016; Fadnes, Taube, & Tylleskär, 2008). It is worth noting that future research, particularly those evaluating education programmes, should seek to use psychometrically valid measures to enable researchers to better compare attitudes between time-points and settings. Two such measures have recently been developed; the KIDS (Baker et al., 2017) and A-ADS (Griffiths et al., 2018).

This study highlights that whilst many adolescents do hold positive attitudes and have a good understanding of dementia, there is a significant proportion that do not. This is concerning because nearly half of adolescents had spent time with someone with dementia in the past and almost a quarter have looked after someone with dementia. Importantly, the majority of adolescents had not been taught about dementia in school, thus were reliant on gaining information about dementia from other sources such as the media and the internet. Females tend

to have more positive perceptions of dementia and more experience of dementia, making it difficult to interpret whether it is gender that results in improved attitudes, or whether it is due to their experiences. It is important to disentangle the relationship in the future. Future outputs from this study will report how domain and total scores from dementia attitudes scales are associated with level of contact.

Accepted Manuscript

References

- AlGhamdi, K. M., & Moussa, N. A. (2012). Internet use by the public to search for health-related information. *International Journal of Medical Informatics*, 81(6), 363–373.
<https://doi.org/10.1016/j.ijmedinf.2011.12.004>
- Althubaiti, A. (2016). Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, 9, 211–217.
<https://doi.org/10.2147/JMDH.S104807>
- Alzheimer's Disease International. (2018). *The state of the art of dementia research: New frontiers*. London, England: Alzheimer's Disease International.
- Baka, A., Figgou, L., & Triga, V. (2012). “Neither agree, nor disagree”: a critical analysis of the middle answer category in Voting Advice Applications. *International Journal of Electronic Governance*, 5(3–4), 244–263. <https://doi.org/10.1504/IJEG.2012.051306>
- Baker, J. R., Jeon, Y.-H., Goodenough, B., Low, L.-F., Bryden, C., Hutchinson, K., & Richards, L. (2018). What do children need to know about dementia? The perspectives of children and people with personal experience of dementia. *International Psychogeriatrics*, 30(5), 673–684. <https://doi.org/10.1017/S1041610217002022>
- Baker, J. R., Low, L.-F., Goodenough, B., Jeon, Y.-H., Tsang, R. S. M., Bryden, C., & Hutchinson, K. (2017). The Kids Insight into Dementia Survey (KIDS): development and preliminary psychometric properties. *Aging & Mental Health*, 0(0), 1–7.
<https://doi.org/10.1080/13607863.2017.1320703>
- Corrigan, P. W., Watson, A. C., Otey, E., Westbrook, A. L., Gardner, A. L., Lamb, T. A., & Fenton, W. S. (2007). How do children stigmatize people with mental illness? *Journal of Applied Social Psychology*, 37(7), 1405–1417.

- Cotten, S. R., & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science & Medicine*, 59(9), 1795–1806. <https://doi.org/10.1016/j.socscimed.2004.02.020>
- Cowley, K. (2005). Assessing children's views of dementia, 13, 36–37.
- Ek, S. (2015). Gender differences in health information behaviour: a Finnish population-based survey. *Health Promotion International*, 30(3), 736–745. <https://doi.org/10.1093/heapro/dat063>
- Fadnes, L. T., Taube, A., & Tylleskär, T. (2008). How to identify information bias due to self-reporting in epidemiological research. *The Internet Journal of Epidemiology*, 7(2). Retrieved from <http://ispub.com/IJE/7/2/9194>
- Farina, N. (2017). What is taught about dementia in secondary schools? A survey of schools in Sussex, England (Innovative Practice). *Dementia*, 1471301217720016. <https://doi.org/10.1177/1471301217720016>
- Flamion, A., Missotten, P., Marquet, M., & Adam, S. (2017). Impact of Contact With Grandparents on Children's and Adolescents' Views on the Elderly. *Child Development*, 0(0). <https://doi.org/10.1111/cdev.12992>
- Griffiths, A. W., Parveen, S., Shafiq, S., & Oyebode, J. R. (2018). Development of the Adolescent Attitudes towards Dementia Scale (A-ADS). *International Journal of Geriatric Psychiatry*, 33(8), 1139–1145. <https://doi.org/10.1002/gps.4907>
- Holm, S. (1979). A simple sequentially rejective multiple test procedure. *Scandinavian Journal of Statistics*, 65–70.
- Holmes, E. P., Corrigan, P. W., Williams, P., Canar, J., & Kubiak, M. A. (1999). Changing attitudes about schizophrenia. *Schizophrenia Bulletin*, 25(3), 447–456.

- Isaac, M. G., Isaac, M. M., Farina, N., & Tabet, N. (2017). Knowledge and attitudes towards dementia in adolescent students. *Journal of Mental Health*, 26(5), 419–425.
- Kinney, J. M., Yamashita, T., & Brown, J. S. (2017). Measuring positive attitudes toward persons with dementia: A validation of the Allophilia scale. *Dementia*, 16(8), 1045–1060. <https://doi.org/10.1177/1471301216633247>
- Larkin, A. (2017). The Knowledge of Attitudes of Nurses and Doctors caring for Dementia Patients in Hospital. *International Journal of Integrated Care*, 17(5). <https://doi.org/10.5334/ijic.3855>
- Macdonald, A. J. D., & Woods, R. T. (2005). Attitudes to dementia and dementia care held by nursing staff in U.K. “non-EMI” care homes: what difference do they make? *International Psychogeriatrics*, 17(3), 383–391. <https://doi.org/10.1017/S104161020500150X>
- McGuinn, K. K., & Mosher-Ashley, P. M. (2002). Children’s Fears About Personal Aging. *Educational Gerontology*, 28(7), 561–575. <https://doi.org/10.1080/03601270290099769>
- Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, 8(4), 377–386. <https://doi.org/10.2217/ahe.12.42>
- Nadler, J. T., Weston, R., & Voyles, E. C. (2015). Stuck in the Middle: The Use and Interpretation of Mid-Points in Items on Questionnaires. *The Journal of General Psychology*, 142(2), 71–89. <https://doi.org/10.1080/00221309.2014.994590>
- National Children’s Bureau. (2016). *Young people caring for adults with dementia in England*. London, England: National Children’s Bureau.

- Ng, P., & Chan, K. F. (2000). Sex differences in opinion towards mental illness of secondary school students in Hong Kong. *The International Journal of Social Psychiatry*, 46(2), 79–88. <https://doi.org/10.1177/002076400004600201>
- Parveen, S., Farina, N., Shafiq, S., Hughes, L. J., & Griffiths, A. W. (2019). What do adolescents perceive to be key features of an effective dementia education and awareness initiative? *Dementia: The International Journal of Social Research and Practice*.
- Pittinsky, T. L., Rosenthal, S. A., & Montoya, R. M. (2011). Measuring positive attitudes toward outgroups: Development and validation of the Allophilia Scale. In *Moving beyond prejudice reduction: Pathways to positive intergroup relations*. (pp. 41–60). Washington, DC, US: American Psychological Association. <https://doi.org/10.1037/12319-002>
- Powell, J., Inglis, N., Ronnie, J., & Large, S. (2011). The Characteristics and Motivations of Online Health Information Seekers: Cross-Sectional Survey and Qualitative Interview Study. *Journal of Medical Internet Research*, 13(1). <https://doi.org/10.2196/jmir.1600>
- Scerri, A., & Scerri, C. (2013). Nursing students' knowledge and attitudes towards dementia — A questionnaire survey. *Nurse Education Today*, 33(9), 962–968. <https://doi.org/10.1016/j.nedt.2012.11.001>
- Sikes, P., & Hall, M. (2017). 'Every time I see him he's the worst he's ever been and the best he'll ever be': grief and sadness in children and young people who have a parent with dementia. *Mortality*, 22(4), 324–338.
- Sikes, P., & Hall, M. (2018). The impact of parental young onset dementia on children and young people's educational careers. *British Educational Research Journal*.
- van de Mortel, T. F. (2008). Faking It: Social Desirability Response Bias in Self-report Research. *Australian Journal of Advanced Nursing, The*, 25(4), 40.

- Wang, Y., Xiao, L. D., Luo, Y., Xiao, S.-Y., Whitehead, C., & Davies, O. (2018). Community health professionals' dementia knowledge, attitudes and care approach: a cross-sectional survey in Changsha, China. *BMC Geriatrics*, 18(1), 122. <https://doi.org/10.1186/s12877-018-0821-4>
- Watson, A. C., Miller, F. E., & Lyons, J. S. (2005). Adolescent Attitudes Toward Serious Mental Illness. *The Journal of Nervous and Mental Disease*, 193(11), 769. <https://doi.org/10.1097/01.nmd.0000185885.04349.99>
- Werner, P., Jabel, H. A., Reuveni, Y., & Prilutzki, D. (2017). Stigmatic beliefs toward a person with Alzheimer's disease among high-school students: Does majority–minority status make a difference? *Educational Gerontology*, 43(12), 609–618. <https://doi.org/10.1080/03601277.2017.1376461>
- World Health Organisation. (2017). *Dementia: a public health priority*. Geneva, Switzerland: World Health Organization. Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/

Table 1. Descriptive statistics of the A-ADS. Median and Interquartile range are reported for the whole sample. For gender comparisons, responses were dichotomised into “disagree” and “agree”, removing neutral responses when available. Pearson’s Chi-square analysis and p-value are reported for between gender comparisons.

A-ADS	Whole sample [n (%)]							Sig. statistic between gender χ^2 (p-value)
	Mdn	IQR	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)	
I would volunteer to spend time with people with dementia	3.0	1	54 (6.0%)	98 (10.9%)	344 (38.4%)	311 (34.7%)	90 (10.0%)	95.82 (p<0.0001)
I would be annoyed if my parents asked me to spend time with a family friend who has dementia rather than see my friends	2.0	2	243 (27.0%)	309 (34.3%)	233 (26.1%)	78 (8.7%)	31 (3.4%)	30.16 (p<0.0001)
I would donate my time or money to help people with dementia	4.0	1	32 (3.6%)	67 (6.5%)	318 (35.5%)	392 (43.8%)	87 (9.7%)	71.23 (p<0.0001)
If I saw someone with dementia struggling to do something, I would help them	4.0	1	7 (0.8%)	10 (1.1%)	83 (9.3%)	427 (47.8%)	367 (41.1%)	2.97 (p=0.09)*
I do not think that people with dementia can make a positive contribution to society	2.0	2	315 (35.5%)	302 (34.0%)	219 (24.7%)	39 (4.4%)	13 (1.5%)	17.61 (p<0.0001)
People with dementia deserve my sympathy and support more than	3.0	1	81 (9.1%)	198 (22.3%)	446 (50.3%)	119 (13.4%)	43 (4.8%)	0.03 (p=0.86)*

people with other conditions

I feel bad for people with dementia because they may have trouble remembering happy events and memories from their life.	4.0	1	13 (1.5%)	18 (2.0%)	100 (11.2%)	460 (51.5%)	302 (33.8%)	9.93 (p=0.002)
It is rewarding to work with people who have dementia	3.0	1	19 (2.1%)	33 (3.7%)	471 (53.0%)	285 (32.1%)	80 (9.0%)	24.51 (p<0.0001)
People with dementia can be creative	4.0	1	12 (1.3%)	19 (2.1%)	357 (40.1%)	367 (41.2%)	135 (15.2%)	16.66 (p<0.0001)
I feel confident around people with dementia	3.0	1	28 (3.2%)	118 (13.3%)	499 (56.3%)	181 (20.4%)	61 (6.9%)	1.25 (p=0.26)*
I am comfortable holding hands with people with dementia	3.0	1	48 (5.4%)	72 (8.2%)	424 (48.0%)	252 (28.5%)	87 (9.9%)	32.98 (p<0.0001)
Every person with dementia has different needs	4.0	1	8 (0.9%)	11 (1.2%)	253 (28.6%)	434 (49.1%)	178 (20.1%)	18.43 (p<0.0001)
I would avoid a person with dementia who was all 'worked up'	3.0	1	128 (14.5%)	289 (32.7%)	360 (40.8%)	86 (9.7%)	20 (2.3%)	6.18 (p=0.01)*
It is important to know the past history of people with dementia	4.0	1	13 (1.5%)	42 (4.7%)	296 (33.4%)	421 (47.5%)	115 (13.0%)	5.53 (p=0.02)*
It is possible to enjoy spending time with people with dementia	4.0	1	15 (1.5%)	13 (1.9%)	135 (19.9%)	313 (46.1%)	203 (29.9%)	3.40 (p=0.07)*
I feel relaxed around people with dementia	3.0	1	30 (3.4%)	101 (11.5%)	516 (58.6%)	195 (22.1%)	39 (4.4%)	8.52 (p=0.004)
People with dementia can enjoy life	4.0	1	18 (2.0%)	31 (3.5%)	182 (20.6%)	463 (52.4%)	189 (21.4%)	9.56 (p=0.002)
People with dementia can tell when others are kind to them	4.0	1	8 (0.9%)	19 (2.2%)	324 (37.1%)	392 (44.9%)	130 (14.9%)	8.01 (p=0.005)
I feel annoyed because I do not know	3.0	1	45 (5.1%)	101 (11.5%)	402 (45.7%)	268 (30.5%)	64 (7.3%)	5.12 (p=0.02)*

how to help people with dementia

I cannot imagine looking after someone with dementia	3.0	1	86 (9.8%)	223 (25.4%)	407 (46.3%)	132 (15.0%)	31 (3.5%)	22.82 (p<0.0001)
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I admire how people with dementia deal with things	4.0	1	11 (1.3%)	23 (2.6%)	327 (37.2%)	378 (43.0%)	140 (15.9%)	17.47 (p<0.0001)
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We can do a lot now to improve the lives of people with dementia	4.0	1	13 (1.5%)	26 (3.0%)	270 (30.8%)	407 (46.4%)	161 (18.4%)	6.83 (p=0.01)*
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I would feel uncomfortable being around people with dementia	2.0	1	184 (20.9%)	309 (35.2%)	292 (33.2%)	75 (8.5%)	19 (2.2%)	17.50 (p<0.0001)
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* P values that were non-significant after Holm-Bonferroni Sequential Correction

Table 2. Descriptive statistics of the Alophillia Scale. Median and Interquartile range are reported for the whole sample. For gender comparisons, responses were dichotomised into “disagree” and “agree”. Pearson’s Chi-square analysis and p-value are reported for between gender comparisons.

Allophilia Scale	Whole Sample [n (%)]								Gender Comparison
	Mdn	IQR	Strongly Disagree (1)	Disagree (2)	Slightly Disagree (3)	Slightly Agree (4)	Agree (5)	Strongly Agree (6)	χ^2 (p-value)
In general, I have positive attitudes about people with dementia	5.0	1	10 (1.2%)	11 (1.3%)	114 (13.4%)	288 (33.8%)	279 (32.7%)	151 (17.7%)	11.59 (p=0.001)
I respect people with dementia	5.0	2	4 (0.5%)	8 (0.9%)	63 (7.4%)	194 (22.8%)	339 (39.8%)	243 (28.6%)	14.02 (p<0.0001)
I like people with dementia	4.0	1	5 (0.6%)	18 (2.2%)	161 (19.3%)	322 (38.6%)	212 (25.4%)	117 (14.0%)	35.03 (p<0.0001)
I feel positively toward people with dementia	4.0	1	8 (0.9%)	19 (2.2%)	149 (17.6%)	303 (35.8%)	236 (27.9%)	131 (15.5%)	12.68 (p<0.0001)
I am comfortable when I hang out with people with dementia	4.0	2	19 (2.2%)	47 (5.6%)	264 (31.2%)	276 (32.6%)	162 (19.1%)	78 (9.2%)	11.05 (p=0.001)
I am at ease around people with dementia	4.0	1	25 (3.0%)	53 (6.3%)	281 (33.3%)	285 (33.8%)	130 (15.4%)	69 (8.2%)	7.52 (p=0.01)
I feel like I can be myself around people with dementia	4.0	2	29 (3.5%)	70 (8.3%)	235 (28.0%)	252 (30.0%)	162 (19.3%)	91 (10.8%)	13.01 (p<0.0001)
I feel a sense of belonging	3.0	2	73 (8.7%)	141	311 (37.2%)	212	71 (3.5%)	29 (3.5%)	5.88 (p=0.02)

with people with dementia				(16.8%)		(25.3%)			
I feel a kinship with people with dementia	3.0	1	52 (6.3%)	114 (13.7%)	292 (35.1%)	251 (30.2%)	77 (9.3%)	46 (5.5%)	6.56 (p=0.01)
I am truly interested in understanding the points of view of people with dementia	4.0	2	35 (4.1%)	76 (9.0%)	168 (19.8%)	237 (28.0%)	207 (24.4%)	124 (14.6%)	46.92 (p<0.0001)
I am motivated to get to know people with dementia better	4.0	2	40 (4.8%)	102 (12.2%)	224 (26.7%)	244 (29.1%)	156 (18.6%)	73 (8.7%)	48.76 (p<0.0001)
To enrich my life, I would try and make more friends who are people with dementia	3.0	1	59 (7.1%)	143 (17.1%)	280 (33.5%)	230 (27.5%)	92 (11.0%)	31 (3.7%)	12.27 (p<0.0001)
I am interested in hearing about the experiences of people with dementia	4.0	2	31 (3.7%)	57 (6.8%)	151 (18.0%)	268 (31.9%)	204 (24.3%)	128 (15.3%)	69.34 (p<0.0001)
I am impressed by people with dementia	4.0	2	34 (4.1%)	53 (6.3%)	226 (27.1%)	262 (31.4%)	176 (21.1%)	84 (10.1%)	12.31 (p<0.0001)
I feel inspired by people with dementia	4.0	2	39 (4.7%)	63 (7.6%)	222 (26.7%)	250 (30.0%)	170 (20.4%)	89 (10.7%)	32.26 (p<0.0001)
I am enthusiastic about people with dementia	4.0	1	47 (5.7%)	93 (11.2%)	270 (32.5%)	271 (32.6%)	100 (12.0%)	50 (6.0%)	20.29 (p<0.0001)

Table 3. Descriptive statistics of adolescents' experiences of dementia. A Mann-Whitney U analysis was used to compare between gender groups, Z statistic and p-values are reported.

	Whole Sample					Gender Comparison (Male – Female)	
	Never	Rarely	Occasionally	Moderate	A great deal	Z	p
I have come across people living with dementia	235 (26.3%)	276 (30.8%)	194 (21.7%)	123 (13.7%)	67 (7.5%)	-4.88	<0.001
I have spent time with people living with dementia	486 (54.2%)	154 (17.2%)	99 (11.0%)	81 (9.0%)	77 (8.6%)	-3.19	0.001
I have spent time with a family friend who is living with dementia	613 (68.3%)	126 (14.0%)	72 (8.0%)	52 (5.8%)	35 (3.9%)	-2.64	0.008
I have spent time with a family member living with dementia	563 (62.5%)	93 (10.3%)	68 (7.6%)	80 (8.9%)	96 (10.7%)	-1.53	0.127*
I have looked after someone living with dementia	686 (76.8%)	92 (10.3%)	56 (6.3%)	28 (3.1%)	31 (3.5%)	-2.24	0.025*
I have watched TV shows or movies in which a character has dementia	203 (22.7%)	293 (32.8%)	259 (29.0%)	100 (11.2%)	39 (4.4%)	-3.45	0.001
I have come across adverts (e.g. billboards, leaflets) about dementia in my community	178 (19.8%)	316 (35.1%)	254 (28.2%)	108 (12.0%)	44 (4.9%)	-3.46	0.001
I have come across people living with dementia on social media (e.g. Twitter, Facebook)	449 (50.0%)	268 (29.8%)	118 (13.1%)	44 (4.9%)	19 (2.1%)	-3.80	<0.001
I have searched for information on dementia	604 (67.0%)	179 (19.9%)	83 (9.2%)	23 (2.6%)	12 (1.3%)	-5.03	<0.001

on the internet

I have learnt about dementia in school	596 (66.4%)	229 (25.5%)	51 (5.7%)	14 (1.6%)	8 (0.9%)	-0.24	.811*
I have spoken to family or friends about dementia	357 (39.6%)	231 (25.6%)	152 (16.9%)	103 (11.4%)	58 (6.4%)	-4.48	<0.001

* P values that were non-significant after Holm-Bonferroni Sequential Correction

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