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The Kids Insight into Dementia Survey (KIDS): development and preliminary psychometric properties

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The Kids Insight into Dementia Survey (KIDS): development and preliminary psychometric properties

Abstract

Objectives: Children may have a foundational role in efforts to raise community awareness about dementia. There is some qualitative work with children with a relative with dementia, but little work into the insights of children as general citizens without affected family. One issue is an absence of measurement tools; thus the study aimed to design and pilot a psychometrically sound self-report measure of dementia attitudes for children.

Method: Using a multi-staged scale development process, stakeholder and expert input informed a 52-item Kids Insight into Dementia Survey (KIDS). After a pretest of KIDS with 21 Australian schoolchildren aged 10-12 years, exploratory factor analysis and reliability and validity testing were run on a revised KIDS with data from 203 similar-aged schoolchildren.

Results: The KIDS was reduced from 52 to 14 items, and a three-factor solution identified: 'Personhood', 'Stigma', and 'Dementia Understanding'. A strong positive correlation with an adult measure of dementia attitudes ($r = .76$) and a moderate positive correlation with a child measure of attitudes towards older adults ($r = .47$) indicated good concurrent validity. Internal consistency of .83 indicated good reliability.

Conclusion: Results support the use of KIDS as a tool to measure children's insight into dementia, and to evaluate dementia education initiatives targeting the youth.

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

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Abstract

Objectives: In global movements to build dementia friendly societies, children are an overlooked citizen group. Yet children may have a foundational role in efforts to raise community awareness and address dementia-related stigma in the general public. While there is a small body of qualitative work on the child's experience of having a family member with dementia, there is a dearth of research into the insights of children as general citizens without affected family. Part of the problem is a lack of measurement tools. The study aimed to fill this gap with the design and pilot of a psychometrically sound self-report measure for children on attitudes towards dementia.

Method: A multi-staged scale development process was employed. Stakeholder and expert input informed a 52-item Kids Insight into Dementia Survey (KIDS). After a pre-test of KIDS with 21 schoolchildren aged 11-12 years old, exploratory factor analysis and reliability and validity testing was run on a revised KIDS with data from 203 Australian schoolchildren aged 10-12 years old.

Results: The KIDS was reduced from 52 to 14 items, and a three-factor solution identified: "Personhood", "Stigma"; and "Dementia Understanding". A strong positive correlation with an adult measure of dementia attitudes ($r=.76$) and a moderate positive correlation with a child measure of attitudes towards older adults ($r=.47$) indicated good concurrent validity. Internal consistency of .83 indicated good reliability.

Conclusion: Results support the use of KIDS as a tool to measure children's insight into dementia, and as an outcome evaluation tool for dementia education initiatives targeting youth.

Keywords: dementia; children; attitudes; measure development; exploratory factor analysis

In 2015, 46.8 million people worldwide were estimated to be living with dementia. By 2050, this number is forecast to triple to 131.5 million (Alzheimer's Disease International, 2015; Jackson, Cherry, Smitherman, & Hawley, 2008). In response to this global health issue, several countries have begun to implement a "dementia-friendly" movement, with a vision to "transform the whole community" to enable the ongoing participation and meaningful social interaction of people with dementia in everyday life (Alzheimer's Disease International, 2016). At the centre of this movement are initiatives to understand and improve public attitudes in order to reduce the stigma, discrimination, and social exclusion experienced by people with the condition (Alzheimer's Disease International, 2012).

The research on attitudes toward dementia has focused predominantly on adults. Yet children must be a part of this whole community transformation given the increasing probability that they will know or meet a person with dementia. For example, one third of 8-17 year olds in a British government poll indicated that they knew someone with dementia, and two-thirds reported that they would like to help people with dementia but that a lack of understanding holds them back (Alzheimer's Society, 2015). In our recent qualitative study with 9-12 year olds from the community, after being shown videos of people with dementia, the children reported negative affect, feeling confused, intentions to avoid or laugh at such persons, as well as misattributing the dementia-related behaviour to stupidity or hearing loss (Baker et al., in press). These types of responses illustrate the need for public dementia education programs which prioritise children, and corresponding measures of impact.

To-date however, there is no valid and reliable measure of children's attitudes towards people with dementia. Attitudes are typically conceptualised as having three core elements - cognition, affect and behaviour (Eagly, 1993). For example, an individual who believes that a person with dementia is dangerous (cognition), might fear (affect), and thus avoid (behaviour) people with the condition. There are several dementia knowledge tests or

“quizzes” for adults or for staff who care for people with dementia (Annear et al., 2015; Lintern, 2000; Norbergh, Helin, Dahl, Hellzén, & Asplund, 2006; Spector, Orrell, Schepers, & Shanahan, 2012; Williams, 2011). These tap a predominantly cognitive component likely too complex for children. There is one validated tripartite measure of attitudes towards people with dementia, designed for lay adults in the community (O'Connor & McFadden, 2010). To our knowledge there is no comparable measure for children.

The measurement gap becomes even more pertinent when we consider intergenerational research exploring the benefits for youths and older adults participating in a shared activity. Out of 27 articles identified in a recent scoping review of intergenerational programs for persons with dementia, eight investigated children's change in attitudes towards older adults; not one study assessed children's attitudes specifically towards people with dementia (Galbraith, Larkin, Moorhouse, & Oomen, 2015). This is an important distinction. Intergenerational dementia programs may offer unique improvements in children's attitudes towards people with the condition, separate to children's attitudes towards older adults more generally.

Our research addresses this absence of a child measure that is sensitive to dementia attitude changes. As part of larger program developing a dementia education product for schools (Baker et al., 2016), the study aimed to develop and validate a new self-report tool to measure children's tripartite attitudes towards people with dementia. Beyond the needs of our research program, we argue that such a tool would be useful in advancing research into how children think and feel about people with dementia. It would also improve the methodological strength of effectiveness evaluations of intergenerational and dementia education campaigns with youth. Our approach was based on a stepped strategy incorporating multiple sources of stakeholder and expert input, and best practice principles in psychometric assessment (Krause, 2002). Specifically, the paper describes three stages: (1)

item content development and design; (2) a small-scale pre-test of the measure; and (3) a larger scale pilot of the measure and companion exploratory factor analysis and construct validity and reliability testing.

Method

In line with the University Human Ethics Committee approval (HC14328), all child participants provided informed verbal assent and written parental consent.

Stage 1: Content Development and Design of the Kids Insight into Dementia Survey

Content Development and Validity

We examined information from two sources (a) a review of the dementia attitude/stigma literature and existing (adult) dementia knowledge and attitude scales (Annear et al., 2015; Lintern, 2000; Norbergh et al., 2006; O'Connor & McFadden, 2010; Spector et al., 2012; Williams, 2011); and (b) themes emerging from our qualitative study (full study detailed elsewhere (Baker et al., in press). The qualitative study used innovative focus groups with 22 Scouts in the community aged 9-12 years old, to explore what children might, know, feel and behave around people with dementia; whilst individuals with personal experience of dementia (five people with early-stage dementia, 12 adult primary carers; four non-primary carers; and six grandchildren of a person with dementia) were interviewed about what they felt was most important for children to understand or learn about dementia and what attitudes they might like educational efforts about dementia to confer. This qualitative data was transcribed and content analysed using NVivo10.

Based on these sources, author JB generated an item pool, incorporating a mix of cognitive, affective and behavioural intention items. These were reviewed and edited (for

content and child comprehension) in a workshop format by an advisory committee (n=6) comprising a primary school teacher, a person living with dementia, and academic experts in dementia and knowledge translation. All six committee members met unanimous consensus on the final master list of 52-items ~~was generated~~. Several items emphasised that individuals with dementia are “still people”. These reflected the dominant theme of the qualitative inquiry and also the recent call in a systematic review of dementia knowledge outcome measures, for a measure that incorporates personhood or person-centred care (Spector et al., 2012). Several items addressed stigma or negative beliefs about people with dementia. Items also touched on the importance of nursing homes, the impact on the family of a person with dementia, and the ways a person can reduce their risk of developing dementia. Other items identified that dementia is not solely about memory loss or old age but rather that the conduct of people with dementia can be diverse and unpredictable; that people can develop dementia in their thirties; that the condition is not contagious, is relatively common, and cannot be cured; and that Alzheimer’s disease is one type of dementia.

Measure Design

It was apparent from our qualitative work and advisory committee discussions, that the aim to create a measure that could assess dementia attitude change in children needed to accommodate children who may not have heard of, or did not know what the words “dementia” or “Alzheimer’s” meant. For this reason, items were prefaced by a short vignette about a 75 year old lady with dementia named “Mrs Jones” (see Appendix) (Low & Anstey, 2009).

The item format was a statement followed by a 5-point Likert scale of agreement: agree a lot (5) / agree a little (4) / don’t know/unsure (3) / disagree a little (2) / disagree a lot (1). We included a “don’t know/unsure” option at the midpoint, on the basis of evidence that

in instances of participants lacking the necessary information and/or experience with which to form an attitude on a topic, this strategy would reduce arbitrary guessing and result in a more sensitive assessment (Krosnick, 2010; O'Muircheartaigh, Krosnick, & Helic, 2001) - particularly for items assessing memory change due to pathological rather than 'normal' ageing .

Stage 2: Pre-test of the Kids Insight into Dementia Survey

Setting

A public primary school in Sydney, Australia.

Participants

The class teacher distributed an Information and Consent form to the students' parents, which parents signed and returned. A class of 21 schoolchildren (10 boys) aged 11-12 years old ($M = 11.43$; $SD = .051$) participated. The majority ($n=15$) were Australian-born.

Measures

52-item Kids Insight into Dementia Survey – KIDS (see above). Children read a vignette about a lady with dementia and rated how much they agreed with each of the 52-statements about people with dementia, ranging from “Agree a Lot” (5) to “Disagree a Lot” (1).

Modified Level of Contact Report (Corrigan et al., 2005). This scale assessed children's familiarity with individuals similar to the person in the vignette, or to people with dementia. The scale described eight situations in which intimacy of contact varied from the lowest – “I have never seen a person with dementia or someone similar to Mrs Jones”, to “I live with a

person with dementia or a condition similar to Mrs Jones”. The index of familiarity was the rank order score of the most intimate situation that the children checked. Children also indicated whether or not they had heard of the words “Alzheimer’s disease” or “Dementia”.

Procedure

Children completed the measure as a class, in the presence of author JB. Children were invited to raise their hand for any words or items that they did not understand, or that were unclear. Based on cognitive interviewing techniques (Campanelli, 1991), the children were asked what they thought each item was referring to, whether they felt pressured to respond to an item in a certain way, and whether the item made sense and was easy to use. Children were asked to comment on the survey as a whole, and their opinion of the rating scale, including the “don’t know/unsure” option. Item descriptives explored any ceiling or floor effects or limited variance range for each item. No analyses were run on the survey outcomes.

Results

No issues were raised regarding the vignette. Three survey items were reworded to aid comprehension. For instance, for the item “It can be very hard for the family of a person with dementia?” some children queried “hard in what way?” Thus, this item was changed to “It can be upsetting for the family of a person with dementia.” Thirteen items were removed for ambiguity or complexity. For example, for the items “people with dementia can be crazy” or that “people with dementia can be weird”, some children argued that people with dementia can sometimes act “crazy” or “weird”. The result was a 39-item survey (reduced from 52).

Children’s feedback instigated the addition of an extra situation to the “Level of Contact Report”; specifically, “I have seen short news stories about a person with dementia

or someone similar to Mrs. Jones”. One situation was expanded to include “I have watched a movie *or read a book about* a person with dementia or someone similar to Mrs Jones.”

Children were enthusiastic towards the inclusion of the ‘don’t know/unsure’ response option. Specifically, at the start of survey completion, some children protested that they could not complete the survey because they did not know anything about dementia. Author JB (and the written instructions) highlighted the “don’t know/unsure” option to the children, and reassured them that many children have not heard of dementia and that it was okay to tick this option.

Stage 3: Pilot Testing and Psychometric Evaluation of Kids Insight into Dementia Survey

Setting

Three independent Christian denomination schools in New South Wales, Australia.

Participants

Participants were students in classes that had been selected by the school to participate in a trial of a dementia education program. A total of 203 students (n=122; 60% female) aged 9-12 years old (mean=10.49; SD=0.62) participated in Time 1 data collection before the education program commenced, and upon which this report is based. The majority (n=193; 95.1%) were Australia-born. The sample size met recommended case criterion of at least 100 or 200 cases for factor analysis (Arrindell & Van Der Ende, 1985; Gorsuch, 2003; Hutcheson & Sofroniou, 1999; Kline, 1979; MacCallum, Widaman, Zhang, & Hong, 1999).

Measures

39-item Kids Insight into Dementia Survey - KIDS. A reduced and revised version of the KIDS as described in Stage 2. The mean item score was computed, with negatively-worded items reverse-scored. Higher scores indicate more favourable (i.e. positive) attitudes toward people with dementia.

Modified Level of Contact Report (Corrigan et al., 2005). As above but with nine situations in which intimacy of contact varies.

Children's Perceptions of Aging and Elderly - CPAE (Rich, Myrick, & Campbell, 1983). A 4-point Likert scale of 20 items that measures children's attitudes towards older persons. The measure has good test-retest reliability ($r=.73$) and high internal consistency ($\alpha=.86$). Higher summed scores (range 20-80) indicate more favourable attitudes toward older people. ~~A 20-item measure of children's attitudes towards older persons (e.g., 'I like visiting old people'), rated on a 4 point scale from 1 'Strongly disagree', to 4 'Strongly agree'. The measure reports good test-retest reliability (.73) and high internal consistency ($\alpha=.86$). Scores are summed to derive a total score ranging from 20 to 80. Higher scores indicate more favourable attitudes toward older persons.~~

Dementia attitudes Scale – DAS (O'Connor & McFadden, 2010). A 7-point Likert scale of 20 items that is designed to assess The DAS comprises 20 items on a 7-point Likert Scale (strongly disagree—strongly agree) that reflect the affective, behavioural and cognitive aspects of assesses adults' attitudes towards people with “Alzheimer's disease and related disorders”. The phrase was changed to “dementia” for the present study, and the scale changed to a 5-point Likert scale to keep consistent with the other study measures and minimise participant confusion. Some item wording was also adapted to be more “child-

friendly”. For example, the item “It is rewarding to work with people who have dementia” was changed to “It is rewarding to play with people who have dementia.” ~~Negatively worded items were reverse scored.~~ A higher score indicates a more positive attitude. The DAS has shown excellent internal consistency ($\alpha = 0.83$) and convergent validity ~~with scales about ageism and attitudes towards disabilities~~ (O'Connor & McFadden, 2010).

Children's Social Desirability (CSD) Scale (Baxter et al., 2004). Children answer 14 yes/no questions (e.g. “Do you always listen to your parents?”) ~~Responses that match the socially desirable choice receive one point. Scores are added to produce a total from 0-14 with~~ Higher scores reflecting a greater tendency toward socially desirable responding. The ~~14-item CSD~~ scale reports excellent internal consistency ($\alpha = .88$) and test-retest reliability ($r = .83$).

Procedure

Children completed the measurement suite as a whole class or year, in order of the social desirability scale first, followed by KIDS, the Level of Contact report, and lastly the DAS and CPAE. The measures took between 20-40 minutes to complete.

Analysis

For all scales missing $\leq 20\%$ of items, mean substitution was used to compute total scores. Scales with $> 20\%$ of missing items were excluded. KIDS items that showed $> 50\%$ of participants endorsing an extreme response (i.e., “agree a lot” or “disagree a lot”) were excluded for ceiling or floor effects. The remaining KIDS items were entered into an exploratory factor analysis (EFA) using R version 3.1.0 (Team, 2014). Polychoric correlations were computed, as factor analysis based on Pearson correlations can lead to substantial underestimation of the associations between ordinal variables and may produce

spurious factors based solely on item distribution similarity (Holgado-Tello, Chacón-Moscoso, Barbero-García, & Vila-Abad, 2009). Data was screened for extreme multicollinearity or singularity.

Sampling adequacy was assessed using the Kaiser-Meyer-Olkin (KMO) test, individual item measure of sampling adequacy (MSA) and Bartlett's test of Sphericity. EFA was then conducted using the weighted least squares (WLS) estimator, with Promax (i.e. oblique) rotation because of anticipated correlation between the factors. The lowest number of factors to be retained was guided by a combination of Cattell's scree test (Cattell, 1966), Horn's parallel analysis (PA) (Horn, 1965), and Velicer's minimum average partial (MAP) criterion (Velicer, 1976).

Items were eliminated sequentially for low communalities ($<.2$) (Child, 2006), low primary factor loadings ($<.32$), or multiple cross-loadings ($>.32$ on more than one factor) (Tabachnick & Fidell, 2001), with the EFA rerun each time an item was eliminated. Scale reliability change was also considered as each item was dropped.

Once the final KIDS items were identified, validity tests were conducted using IBM SPSS Statistics Version 22 (IBM Corporation, 2013). Two-tailed Pearson correlations between the final KIDS, DAS, CPAE, and CDS measures were conducted. It was reasoned that a positive correlation with an adult measure of attitudes towards dementia would indicate convergent validity; and that a positive correlation to a lesser extent with a children's measure of attitudes towards older adults would indicate divergent validity. The hypothesis that social desirability was no more problematic on the target measure than on the two other named scales was also tested.

Based on responses from the Level of Contact report, two groups of children were identified: those who had a relative or family friend with dementia, and those who had "never seen" or "only seen in passing" someone with dementia. KIDS scores were compared using

an independent-samples t-test. It was to be taken as an additional indicator of construct validity if the group with a relative or family friend with dementia had significantly higher scores on the attitude measure than the group with no personal experience of dementia (Jackson et al., 2008). Reliability analyses were conducted using R version 3.1.0 (Team, 2014). Cronbach's alpha can produce negatively biased estimates when computed from ordinal data or when the tau-equivalence assumption is violated (i.e. when all items measure a single latent trait or factor) (Tavakol & Dennick, 2011); thus McDonald's omega (ω_t) was computed for the KIDS and DAS (Dunn, Baguley, & Brunsden, 2014; McDonald, 1978; Revelle & Zinbarg, 2008), and ordinal alpha based on polychoric correlations (α) was computed for CPAE and CDS (Gadernann, Guhn, & Zumbo, 2012).

Results

Sample Descriptives. Over one-third of the children ($n=70$; 34.5%) had not heard of either "Dementia" or "Alzheimer's disease". A third of children had never seen, or only seen in passing, someone with dementia or someone similar to the person in the vignette ($n=63$; 31.0%); 36.9% ($n=75$) had seen a short news story, movie, documentary, or read a book about a person with dementia; 6.9% ($n=14$) had frequently seen a person with dementia; and 23.6% ($n=48$) said they had a family friend or family member with dementia or lived with a person with the condition.

Exploratory Factor Analysis and Construct Validity. There was $\leq 2.5\%$ missing data per item in the KIDS, specifically one item was missing data from five participants; five items were missing data from four participants; six items were missing data from three participants; nine items were missing two participants' data; five items were missing one participant's data; and

seven items had complete data. There was no evidence of extreme multicollinearity or singularity on the KIDS. Six items were dropped due to ceiling effects (see Table 1). There were no item floor effects. Following the iterative process of item reduction on the remaining 33 items (see Table 1), 14 items were retained. For the most part, communality or primary loading was so low that the item was dropped regardless of item reliability data. Sampling adequacy for the 14-item scale was adequate ($KMO = .80$, all individual item MSAs $> .5$ (Kaiser, 1970), Barlett's test of sphericity $p < .05$). Both the scree plot and PA suggested that three factors should be retained while Velicer's MAP suggested one factor. Analyses were conducted with one and three factor(s) extracted. The three-factor solution appeared most interpretable and accounted for 43.1% of the total variance of the polychoric correlations between items (see Table 2). On inspection of the item clusters by the advisory committee, Factor 1 was named 'Personhood', Factor 2 was named "Stigma", and Factor 3 was named "Dementia Understanding'. The 'Personhood factor was significantly correlated with both 'Stigma' and 'Dementia Understanding' factors ($\phi = .62$ and $.37$, respectively).

<Tables 1 and 2 around here>

The descriptives for the final 14-item KIDS (and the other study scales) are presented in Table 3. The CDS was positively skewed and corrected using a square root transformation. All other total scores were within the acceptable range of skewness and kurtosis.

<Table 3 around here>

Concurrent Validity. Inter-scale correlations are listed in Table 4. There was a significant strong positive correlation between the 14-item KIDS and the adult measure of dementia attitudes, the DAS. There was also a significant moderate positive correlation between KIDS

and children's attitudes to older adults on the CPAE. Children categorised as having high level of contact with people with dementia (i.e. a relative or family friend) scored significantly higher on the KIDS than those categorised as having low level of contact (i.e. had never seen or only seen in passing a person with dementia); mean difference = 7.48, $t(109) = -5.399$, $p < .001$). ~~*Socially Desirable Responding*~~. There was a significant weak positive correlation between the KIDS and socially desirable responding on the CDS. The DAS and CDE showed no correlation with socially desirable responding (see Table 4.)

<Table 4 around here>

Reliability. The McDonalds Omega indicated a good internal consistency of .83 for the KIDS (Barker, Pistrang, & Elliott, 2002).

Discussion

This paper describes the development and good psychometric properties of the KIDS. The scale was developed on current best evidence and stakeholder priorities in relation to what children know or might need to know about people with dementia. Psychometric analyses indicated that the final 14-item KIDS had good construct validity comprising three factors. The first factor clearly described the “personhood” of a person with dementia and the emphasis that individuals with dementia are “still people”. The second factor addressed the stigma or discrimination that people with personal experience of dementia can experience (Alzheimer's Disease International, 2012); for example, avoiding a person with dementia, perhaps because of a belief that the condition is contagious. The third factor was more diverse and aligned with factual concepts testifying to the pathology of dementia, the

importance of nursing homes and the diverse and often unpredictable conduct of people with dementia.

The final 14-item KIDS retained mix of cognitive, affective and behavioural intention items, supporting the construct validity of the tripartite framework of attitudes. It was noticeable that most items dropped were knowledge-based items (see Table 1). Our psychometric analyses (and additional investigations not reported) indicated that the dropped knowledge items simply did not correlate with one another. We speculate that asking children about a topic that they might know very little about may have provoked an unreliable degree of guessing for the markedly factual items (e.g. “Alzheimer’s Disease is one type of dementia” or “People with dementia cannot be cured”).

Evidence of initial convergent validity of the scale was seen in the strong positive correlation between KIDS and the Dementia Attitude Scale for adults. The positive, but weaker, correlation between KIDS and a children’s measure of attitudes towards older adults was taken as evidence of divergent validity. As a further indication of concurrent validity, and also the potential ability of KIDS to differentiate between groups, children with a friend or family member with dementia scored higher on the KIDS than children with little or no experience of people with the condition. This complements the literature showing that participants with higher levels of contact with people with dementia report more positive attitudes about the condition than participants with less contact (Jackson et al., 2008; O’Connor & McFadden, 2010). The KIDS also evidenced good internal consistency or reliability, indicating that all items measured the same underlying construct of dementia attitudes.

The KIDS showed a weak positive correlation with socially desirable responding, unlike the other two attitude measures which showed no significant relationship to this reporting bias. Social desirability bias is an important consideration in attitude research.

Whilst the correlation between the KIDS and social desirability responding was statistically significant, the magnitude of the correlation was small ($r=.2$). Moreover, at baseline, when we know that a third of the children reported never having heard of the word “dementia”, it seems reasonable to expect some degree of socially desirable responding, especially within a school context where civic standards are emphasised.

The modest portion of variance accounted for by the 14-item KIDS (43.1%), parallels the variance explained by other dementia attitude or knowledge measures. For example, the DAS (used in the present study) and Dementia Knowledge Assessment Scale reported 37% and 44.2% of variance explained, respectively (Annear et al., 2015; O'Connor & McFadden, 2010). ~~Useful follow-up investigations with a larger sample permitting confirmatory analysis, could examine goodness of fit and parameter estimates.~~ Indeed, further research on the psychometric properties of KIDS, with a broader age range and in other countries is recommended. Moreover, one of the primary translational uses of the KIDS is as an outcome evaluation measure for dementia education and intergenerational initiatives. **It could also be used to complement school assessments of an increased focus on educating students to become active and informed citizens.** Future research with KIDS as a pre and post measure would generate required knowledge regarding the KIDS ~~test-retest reliability~~ ~~and~~ sensitivity to change. As with all measures of attitude change, the KIDS is limited in that it does not assess real behaviour change. However, the scale does include behavioural intention items (e.g. “I would be happy to be friends with a person with dementia”, and “I wouldn’t know what to say or do if I met someone with dementia”), which have been shown to predict behaviour (Webb & Sheeran, 2006).

Dementia is a global issue. Standardised measures are important to enable accurate comparison across studies, across countries. To the best of the authors’ knowledge, the KIDS offers the first promising, psychometrically sound measure of children’s attitudes towards

dementia. It is hoped that the KIDS will provide a resource for expanding research into our presently limited understanding of children's insight into dementia, and offer a standardised validated evaluation tool for dementia education efforts with youth.

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Appendix

Dementia Vignette

Mrs. Jones is 75-years old. Her husband died last year. Mrs. Jones' family thinks that her memory is getting worse and worse. She tells the same stories over and over and frequently talks about her husband as if he were still alive. Somebody can say something to Mrs. Jones, but a few minutes later she has forgotten what they said. She finds it hard to keep a conversation going, and can get confused or angry at times. Her family has taken charge of her bank account because she was not paying her bills. They also have hired a cleaner because her home was getting very dirty. They worry that Mrs. Jones has not been showering regularly. Mrs. Jones stopped seeing her friends over the last 5 years and very rarely leaves her home now. She told her family that a strange man had broken into the house and is still living in the spare room, but nobody else could see the man or find anything wrong in the house.

Table 1. Item Reduction Process of the Kids Insight Into Dementia Survey

Item Dropped	Reason	No. factors by PA/ scree/Velicer's MAP	No. items remaining
It doesn't matter what you say to people with dementia because they forget it anyway.	Ceiling Effect	-	39
If I saw a person with dementia confused in the street, I would try to help them	Ceiling Effect	-	38
I might ignore someone with dementia	Ceiling Effect	-	37
People with dementia can still have fun	Ceiling Effect	-	36
When children go to visit a person in a nursing home, it can make that person really happy.	Ceiling Effect	-	35
Doing puzzles and keeping physically active is good for your brain.	Ceiling Effect	-	34
People with dementia cannot be cured	Low communality and primary loading	7/4/2	33
You can treat people with dementia like children	Low communality and primary loading	6/4/3	32
People with dementia all show the same behaviours	Low communality and primary loading	6/4/3	31
People in their 30s can have dementia	Low communality and primary loading	6/4/3	30
Wearing a helmet in sport can reduce your risk of getting dementia when you are older	Low communality and primary loading	7/4/3	29
Eating fish and less sweet treats are good ways to keep you brain healthy	Low communality and primary loading	5/5/3	28
It is best for the person with dementia not to talk to others about it	Low communality and primary loading	5/3/2	27
You need to be able to remember things to have a good time	Low communality and primary loading	6/3/3	26
Alzheimer's Disease is one type of dementia	Low communality and primary loading	6/3/3	25
People do not get better with dementia, it will just get worse.	Low communality and primary loading	4/3/3	24

It is a good thing to talk about dementia	Low communality and primary loading	4/3/3	23
Playing music and going through old photos are just two things you can do during a nursing home visit.	Low communality and primary loading	4/3/3	22
Saying the wrong thing or taking your clothes off in public could be the behaviour of someone with dementia.	Low communality and primary loading in wrong direction	4/3/3	21
I believe that people with dementia can't help or control some of the things that they do	Primary loading in wrong direction	4/3/3	20
It can be upsetting for the family of a person of dementia	Low communality	4/3/3	19
A person with dementia can be fine one day, but then have difficulty the next	Low communality	4/3/3	18
People with dementia can feel if they are being treated with respect or not.	Low communality	3/3/3	17
People with dementia are sometimes pretending or just making it up	Low primary loading	3/3/3	16
You can tell if someone has dementia just by looking at them	Significant cross-loadings	3/3/1	15
		3/3/1	14

Note: PA – Parallel Analysis; MAP – Minimum Average Partial.

Table 2. Factor structure of the final 14-item KIDS.

Item	Factor 1: Personhood (17.3%)	Factor 2: Stigma (16.1%)	Factor 3: Knowledge (9.7%)
(Variance Explained)			
Spending time with people with dementia can be fun.	.98		
I would be happy to be friends with a person with dementia.	.63		
People with dementia can feel when others show them love and understanding.	.56		
People with dementia have hobbies and interests.	.53		
Like most people, people with dementia like it when you smile at them.	.48		
I would feel a bit scared if I met someone with dementia in the street.*		.80	
People with dementia can be creepy.*		.77	
It would be annoying or frustrating to spend time with someone with dementia.*		.52	
You can “catch” dementia from other people.*		.47	
I wouldn’t really know what to say or do if I met someone with dementia.*		.46	
It is unlikely that I would meet someone with dementia.*		.43	
Dementia is when something has gone wrong in your brain.			.85
Nursing homes provide important care to people with dementia.			.45
Dementia is unpredictable; families of people with dementia need to expect the unexpected.			.42

* Reverse scored item.

Table 3. Study Measure Descriptives and Reliability.

Measure	<i>n</i>	<i>M</i> (<i>SD</i>)	Range	Reliability statistic
Final14-item KIDS	203	50.48 (7.51)	32 – 70	$\omega_t = .83$
DAS	201	70.21 (10.85)	44 – 99	$\omega_t = .89$
CPAE	199	60.18 (6.48)	42 – 76	$\alpha = .84$
CDS	203	4.77 (3.02)	0 – 13	$\alpha = .87$

Note: KIDS – Kids Insight into Dementia Survey; DAS – Dementia Attitudes Scale;
 CPAE – Children’s Perception of Ageing and Elderly; CDS – Children’s Social Desirability;
 ω_t – McDonald’s Omega; α – Ordinal alpha.

Table 4. Pearson correlations between the KIDS (14-item), DAS, CPAE and CDS.

Scale	KIDS	DAS	CPAE	CDS
KIDS (14-item)	-	.76**	.41**	.20*
DAS	-	-	.47**	.12
CPAE	-	-	-	.11

Note: KIDS – Kids Insight into Dementia Survey; DAS – Dementia Attitudes Scale;

CPAE – Children’s Perception of Ageing and Elderly; CDS – Children’s Social Desirability;

** $p < .01$, two-tailed; * $p < .05$, two-tailed.