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The development and validation of the adolescent level of contact with dementia scale

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Objectives: As the number of people living with dementia increases, reducing stigma has become a policy priority. One way of decreasing stigma is through contact with the stigmatised group. However, the impact of this is difficult to establish due to a lack of validated measures suitable for adolescents. The aim of this study was to develop and validate a level of contact questionnaire designed to assess adolescents' contact with people living with dementia.

Methods: Participants were recruited from five schools in two studies (N = 446 and N = 488) and completed the preliminary 11-item version of the adolescent level of contact of dementia (ALoCD).

Results: Study 1 explored the factor structure of the ALoCD, revealing two factors 'direct contact' and 'indirect contact'. Study 2 confirmed the structure of the ALoCD and tested for discriminant validity. These two studies resulted in a 9-item scale that showed adequate internal consistency (α = .89, α = .62) and discriminant validity between those who did and did not live with a person with dementia.

Conclusion: The development of this scale enables assessment of direct (eg, living with a person with dementia) and indirect (watching a TV show about dementia) contact with dementia, and the extent of this contact. This initial validation suggests a psychometrically sound scale but further research should be undertaken to fully explore the properties of the scale.

KEYWORDS
Alzheimer's disease, children, measurement, stigma, contact, scale

1 | BACKGROUND

Stigma towards dementia can come in many forms, from the use of negative and disempowering language[1] to the misconception that people with dementia cannot have a good quality of life.[2] Such stigma can lead to social isolation, reduced quality of life and loss of independence[3]; whilst also being a major barrier for seeking and accessing support, diagnosis, treatment and information.[4,5] It is therefore unsurprising that reducing the stigma towards people with dementia is a key policy priority at a national (UK) and global level (Batsch and Mittelman; Department of Health; Scottish Government[3,6-8]; particularly in light of the growing prevalence of dementia.[9]

Negative attitudes and stigma towards dementia appear to exist in adolescents,[10,11] which is in line with the broader literature that negative attitudes towards mental illness form early during childhood.[12,13] It has been proposed that reducing stigma towards mental illness can be achieved through increased contact with the stigmatised group, education[14,15] and protest. Within the mental health literature there has been considerable debate as to whether education is enough to reduce stigma or whether education needs to be paired with contact with the

discriminated group.[16] There have been a number of studies that have explored the impact of education and contact on mental health stigma amongst adolescents, but have produced contradictory results.[17,18]

Within the field of dementia, there has been an increasing interest in the 'Human Rights based approach'.[19] This approach has tended to make use of contact based interventions to reduce discrimination against people living with dementia and increase positive opportunities for them. The approach views the stigma associated with dementia as a civil rights issue and assumed contact with those living with dementia will dispel erroneous myths and reduce the associated stigma.

As such, researchers have attempted to capture the level of contact with people with mental illness, to increase understanding of its role in stigma towards mental illness.[20]

In adolescents and adults more generally, there is a dearth of knowledge about what level of contact people have with dementia (and mental health). In part, this is due to a lack of validated measures to capture this level of contact, with researchers opting to use dichotomised descriptive outcomes instead. For example, 'Have you ever met a person with dementia?'[21] and 'Have you ever heard of dementia?'[22] However, whilst this is useful information, such measures do not capture the full breadth or frequency and the quality of contact that individuals may have with people with dementia due to their overly simplistic nature. As such, researchers have attempted to capture the level of contact with people with mental illness, to increase understanding of its role in stigma towards mental illness.[20]

Understanding adolescents' level of contact with people with dementia will better enable us to understand how their experiences impact stigma towards dementia, and be more accurately able to identify whether we need to provide additional support to those that currently have contact with dementia. The aim of this study is therefore to develop and validate a novel level of contact questionnaire designed to assess adolescents' contact with those individual's living with dementia.

2 | METHOD

Ethical approvals were obtained through the Brighton and Sussex Medical School Research and Governance Ethics Committee.

2.1 | Participants

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

2.2 | Scale development and testing

Adolescent level of contact of dementia (ALoCD) questionnaire was, in part, adapted from a previously developed measure of level of contact report of mental illness.[23] Since its initial creation, a number of

Key points

- Negative and stigmatising views towards those living with dementia develop during adolescent years.
- One way of reducing the stigma associated with dementia is through contact with people living with dementia. There is currently no validated tool that measures extent and quality of contact.
- The adolescent level of contact dementia scale (ALoCDs) was developed and tested with 934 adolescents aged between 13 and 18 years.
- The scale was found to be a valid and reliable tool enabling assessment of direct and indirect contact with dementia.

TABLE 1 The demographics of participants included in the exploratory factor analysis (n = 422)

	n (Valid %)
Gender	
Male	204 (48.9)
Female	213 (51.1)
Age	
13	96 (23.0)
14	133 (31.9)
15	107 (25.7)
16	21 (5.0)
17	51 (12.2)
18	9 (2.2)
Ethnicity	
White British	327 (83.6)
British (not-specified)	31 (7.9)
White European	8 (2.0)
White (not-specified)	7 (1.8)
British Asian	6 (1.5)
Other	12 (3.1)
School	
A	39 (9.2)
B	320 (75.8)
C	63 (14.9)
D	0 (0)
E	0 (0)
Have you ever heard of dementia?	
Yes	399 (95.0)
No	21 (5.0)
Would you like to learn more about dementia?	
Yes	123 (29.4)
No	162 (38.7)
Maybe	134 (32.0)
Do you currently live with someone with dementia?	
Yes	13 (3.1%)
No	406 (96.2%)

TABLE 2 Item descriptives for items in ALoCDs

Item no	Item wording	Mean	SD
1	I have come across people living with dementia	2.29	1.23
2	I have spent time with people living with dementia	1.85	1.26
3	I have spent time with a family friend who is living with dementia	1.56	1.06
4	I have spent time with a family member living with dementia	1.82	1.38
5	I have looked after someone living with dementia	1.38	0.88
6	I have watched TV shows or movies in which a character has dementia	2.25	1.06
7	I have come across adverts (eg, billboards, leaflets) about dementia in my community	2.33	1.07
8	I have come across people living with dementia on social media (eg, Twitter, Facebook)	1.71	0.95
9	I have searched for information on dementia on the internet	1.45	0.80
10	I have learnt about dementia in school	1.43	0.77
11	I have spoken to family or friends about dementia	2.08	1.19

Abbreviation: ALoCDs, adolescent level of contact dementia scale.

TABLE 3 Factor loadings for each item on the ALoCDs

Item no	Item wording	Direct contact	Indirect contact
1	I have come across people living with dementia	0.84	
2	I have spent time with people living with dementia	0.92	
3	I have spent time with a family friend who is living with dementia	0.78	
4	I have spent time with a family member living with dementia	0.88	
5	I have looked after someone living with dementia	0.78	
6	I have watched TV shows or movies in which a character has dementia		0.74
7	I have come across adverts (eg, billboards, leaflets) about dementia in my community		0.7
8	I have come across people living with dementia on social media (eg, Twitter, Facebook)		0.69
9	I have searched for information on dementia on the internet		0.66
10	I have learnt about dementia in school		0.44
11	I have spoken to family or friends about dementia	0.68	0.39

Abbreviation: ALoCDs, adolescent level of contact dementia scale.

studies have adapted and utilised the measure in a number of samples, including adolescents.[24-27]

Items from the existing level of contact questionnaire were altered to capture adolescents' level of contact with 'people living with dementia' rather than people with 'mental illness'. New items were drawn to reflect both direct contact with people with dementia, but also more passive contact with dementia (eg, through social media). The item response scale was converted from dichotomous to Likert. All items were independently reviewed and then discussed between the research team. The final items were reviewed by 10 adolescents and one secondary school teacher to ensure that the wording was appropriate, clear and meaningful.

The field version of the ALoCD questionnaire was composed of 11-items (see Table 2). The ALoCD requires participants to respond on a 5-point scale: 1 = Never, 2 = Rarely, 3 = Occasionally, 4 = A moderate amount, 5 = A great deal.

Demographic information (eg, age, gender and ethnicity) was also collected and is presented in Tables 1 and 4.

2.3 | Procedure

Nineteen schools were approached on the basis of previous interest in participating in dementia-related research,[27] of which five accepted to take part (26.3%). Head Teachers were provided an information sheet about the study, and consent was obtained. All Head Teachers acted 'in Loco parentis', however, they were also given the option to notify the parents or guardians about the research, giving them the opportunity to opt their child out of participation. A total of 947 students agreed to participate in the study.

TABLE 4 The demographics of participants included in the confirmatory factor analysis (n = 488)

	n (Valid %)
Gender	
Male	226 (46.3)
Female	262 (53.7)
Age	
13	105 (21.6)
14	86 (17.7)
15	93 (19.1)
16	119 (24.4)
17	79 (16.2)
18	5 (1.0)
Ethnicity	
White British	337 (76.2)
British (not-specified)	51 (11.5)
White European	6 (1.4)
White (not-specified)	18 (4.1)
British Asian	5 (1.1)
Other	25 (5.7)
School	
A	60 (12.3)
B	337 (69.1)
C	0 (0)
D	36 (7.4)
E	55 (11.3)
Have you ever heard of dementia?	
Yes	468 (96.1)
No	19 (3.9)
Would you like to learn more about dementia?	
Yes	163 (33.5)
No	169 (34.7)
Maybe	155 (31.8)
Do you currently live with someone with dementia?	
Yes	20 (4.1)
No	468 (95.9)

Each school was given the choice about how best to distribute the questionnaire; either electronically (Bristol Online Survey, 2016) or as a hard copy. 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 dentifiable information was collected.

2.4 | Data analysis

A total of 947 students participated in the study from five secondary schools. Due to the large sample size, missing data was not imputed but cases with missing data were deleted prior to analysis.

Using sample one of 446 adolescents, principal components analysis (PCA) using varimax rotation was conducted using SPSSv24 to explore the internal structure of the ALoCD scale and how a particular item might contribute to the constructs. Kaiser's measure of sampling adequacy (KMO) was used to establish sample adequacy. A value of 0.80 and above indicates a good sample size. Factors were retained on the basis of eigenvalues of one or above. Only items with loadings above 0.40 were retained based on recommendations by Field.[28] Internal reliability of the retained factors was assessed using Cronbach alphas, with an alpha of 0.80 indicating good reliability, 0.70 suggesting satisfactory reliability and 0.60 demonstrating poor reliability.[29]

A second sample of 488 adolescents was used to test the construct validity of the factors extracted using confirmatory factor analysis (CFA). CFA using AMOSv22 software was undertaken using maximum likelihood estimation. Guidelines for testing model fit followed guidance by Hooper et al[30]: a chi square to degrees of freedom ratio (CMIN/DF) of less than 2.00, the goodness of fit index (GFI) ≥0.90, CFI ≥0.90, SRMR <0.05 and the root mean square error of approximation (RMSEA) <0.05. Post hoc analysis was used to improve the model fit[31,32] by inspecting modification indices (MIs), standardized residuals (SRs) and item content. The internal reliability of the factors was examined using Cronbach alphas. For factors containing fewer than seven items, average inter-item correlations were calculated based on the recommendation of Briggs and Cheek.[33]

To demonstrate discriminant validity between the direct and indirect scales, independent *t* tests were conducted between adolescents who lived with a person with dementia and those who did not. The scales would demonstrate discriminant validity if mean scores on the direct contact scale were higher for the group lived with somebody with dementia, and no significant difference in indirect contact.

3 | RESULTS

3.1 | Study 1: Exploring the factor structure of the ALoCDs

To explore the factor structure of the ALoCDs, a sample of 446 adolescents was utilised. Sample descriptives are presented in Table 1.

The sample size was found to be adequate (KMO = 0.88) to perform PCA. PCA yielded a two factor solution with eigenvalues of above 1.0, whereby factor 1 explained 42.7% of the variance and factor 2 accounted for 16.6%. Items loaded onto each factor with a value of at least 4.00 in line with recommendations by Stevens.[34] In total, six items loaded onto factor 1 (direct contact with dementia), and five items loaded onto factor 2 (indirect contact with dementia). Cronbach's alpha analysis produced a score of 0.91 for factor 1, and 0.63 for factor 2, indicating adequate levels of internal consistency for both factors. However, as the two factors contained fewer than seven items, it recommended to explore internal reliability by calculating average inter item correlations with a range of 0.20 to 0.40 indicating good internal reliability.[33] The average inter-item correlation for factor 1 was 0.63 suggesting some items may be too closely

TABLE 5 Item descriptives for items in ALoCDs post-confirmatory factor analysis

Item no	Item wording	Mean	SD
1	I have come across people living with dementia	2.47	1.22
2	I have spent time with people living with dementia	2.05	1.37
3	I have spent time with a family friend who is living with dementia	1.61	1.09
4	I have spent time with a family member living with dementia	2.01	1.43
5	I have looked after someone living with dementia	1.48	1.02
6	I have watched TV shows or movies in which a character has dementia	2.49	1.11
7	I have come across adverts (eg, billboards, leaflets) about dementia in my community	2.53	1.12
8	I have come across people living with dementia on social media (eg, Twitter, Facebook)	1.82	1.02
10	I have learnt about dementia in school	1.44	0.71
	Direct Contact Scale Pre CFA	11.84	6.01
	Direct Contact Scale Post CFA	9.62	5.13
	Indirect Contact Scale Pre CFA	9.82	3.24
	Indirect Contact Scale Post CFA	8.28	2.76

Abbreviation: CFA, confirmatory factor analysis.

related. The average inter-item correlation for factor 2 was 0.29 which is within the optimum range for good internal reliability. Item descriptives are presented in Table 2 and factor loadings are presented in Table 3.

To confirm the structure of the ALoCDs, a parallel analysis of 1000 data sets using a 95% cut-off was conducted as recommended by O'Connor (2000). Parallel analysis creates data sets with the same number of cases and variables as the actual dataset, filled with random numbers. An EFA is then performed on each data set, and any factors within the actual data set with eigenvalues that exceed those that emerge in 95% of the data sets of random numbers are defined as not having arisen due to chance variation within the data. The first five eigenvalues (and % of variance accounted for) extracted for 95% of the simulated data sets were equal to or less than 1.26 (1.14%), 1.19 (1.09%), 1.13 (1.03%), 1.08 (0.98%) and 0.99 (0.90%). In the actual data set, only the two eigenvalues of 4.70 which explained 42.68% of the variance, and 1.82 which explained 16.55% of the variance, exceeded chance values, suggesting that two factors underlie the data.

3.2 | Study 2: Testing the validity of the factor structure

3.2.1 | Construct validity

On a sample of 488 adolescents (sample description can be found in Table 4 and item descriptives can be found in Table 5), confirmatory factor analysis was used to test a two-factor model using maximum likelihood estimation. The initial CFA showed data did not fit the model well (χ^2 [89] = 198.49, $P < .001$; CMIN/DF = 4.62; GFI = 0.93,

CFI = 0.93, SRMR = 0.76 and RMSEA = 0.09), thus post hoc model fitting was conducted. This resulted in the removal of two items (items 9 'I have searched for information on dementia on the internet' and 11 'I have spoken to family or friends about dementia'), one from each factor, on the basis of large MIs (above 10), and SRs >±2.58, and assessment of item content. This revised model (containing 9 items – five in factor one and four in factor two) was found to fit the data satisfactorily (χ^2 [43] = 49.95, $P < .03$; CMIN/DF = 1.92; GFI = 0.99, CFI = 0.99, SRMR = 0.04 and RMSEA = 0.04).

3.2.2 | Internal reliability of new factors

Cronbach's alpha analysis produced a score of $\alpha = .89$ for factor 1, and $\alpha = .62$ for factor 2, indicating adequate levels of internal consistency for both factors. The average inter-item correlation for factor 1 was 0.62 and 0.28 for factor 2.

3.2.3 | Discriminant validity

Independent t tests were conducted to assess discriminant validity. Those living with someone with dementia had a significantly higher mean score (M = 18.40, SD = 4.73) on the direct contact scale (t = 8.35 [1, 468], $P < .001$) compared to those that did not live with someone who had dementia (M = 9.65, SD = 3.17). There was no statistically significant difference in mean scores between those living with someone with dementia (M = 9.25, SD = 4.80) and those not living with someone with dementia (M = 8.22, SD = 2.72) with regards to indirect contact (t = 1.98, P = .06).

4 | DISCUSSION

The reduction of stigma associated with dementia is a global priority and one method of achieving this is through increased dementia awareness and contact with people living with dementia. There are a growing number of initiatives for young people aiming to foster positive attitudes towards people living with dementia; such as 'Adopt a care home'[35] and 'Dementia Detectives'.[35] In order to evaluate the impact of such initiatives on dementia knowledge and attitudes, extraneous variables such as level of contact with people living with dementia need to be measured. The aim of this study was to develop and validate a new scale assessing the level of direct and indirect contact adolescents have had with dementia.

The Adolescent Level of Contact with Dementia scale (ALoCDs) consists of nine items measuring direct and indirect contact with dementia. The results of the study suggest that the direct contact sub-scale had better internal reliability, construct validity and discriminant validity compared to the indirect sub-scale. The high average inter item correlation for the direct contact scale (0.62) was above the optimum range recommended by Briggs and Cheek,[33] indicating that this subscale could be reduced further. Further work is required to assess the criterion validity of the scale and its relationship with dementia knowledge and attitudes.

To our knowledge, this is the first study to validate an adolescent level of contact dementia scale. The scale enables assessment of whether contact with dementia has been direct (eg, living with a person with dementia) or indirect (watching a TV show about dementia), and the extent of this contact. Given the current spotlight on dementia friendly generations, this scale will be a useful evaluation tool when assessing the impact of dementia friendly initiatives. Dementia education and awareness initiatives differ in terms of contact strategies for example the 'Adopt a Care Home' scheme involves direct contact with people living with dementia whereas 'Dementia Detectives' involves indirect contact through classroom-based education and videos of people living with dementia. Direct contact strategies may be costly with regards to time and finance, yet indirect contact strategies whilst cheaper may fail to have a significant impact on attitude and behaviour change.

5 | CONCLUSION

While the scale has a number of practical uses, further tests of reliability and validity are warranted. Initial validation of the scale suggests that tool is adequately reliable and psychometrically sound, whilst acceptable for use with adolescents. A key strength of the scale is that it addresses an adolescent's level of contact on a continuum rather than a dichotomous variable. This enables an assessment of the extent of contact as opposed to simply establishing if there has been exposure. Although the study has led to the production of a psychometrically strong scale, it is worth noting that whilst the sample of adolescents recruited for this study was large (N = 947), the sample was relatively homogenous with regards to ethnicity and age.

The ALoCDs can be used by researchers, educators and practitioners working to improve dementia awareness. The initial validation suggests a psychometrically sound scale but further research needs to be undertaken to fully explore its practical uses and limitations.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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