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Contextualizing Adolescent's Experiences of Dementia in England

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ABSTRACT

Adolescents represent an under-researched group that may already have experiences of dementia. In this study, we aimed to capture adolescents' level of contact (frequency) and quality of contact (whether experiences were positive or negative) with people living with the condition. In this cross-sectional study, 1,371 adolescents (aged 11–18 years old) across England were recruited. Descriptive statistics, cross-tabulations, and regressions were employed to explore the association between socio-demographic factors and the frequency and quality of dementia contact in adolescents. Over 64% of adolescents had come across people living with dementia, while over a quarter of adolescents had looked after someone living with the condition. The level of contact and quality of contact differed significantly between ethnic and religious groups. Stakeholders should work closely with different communities and schools, and take into consideration the nuances of cultural and region-specific resources in the community when seeking to raise dementia awareness in adolescents.

KEYWORDS


Quality of contact; level of contact with dementia; students; schools

Background

There is an estimated 55.2 million people living with dementia globally (Nichols et al., 2022). With aging populations across the world, there will be a greater number of people likely to be affected by the condition in the future. Dementia is not a normal part of aging, and leads to an irreversible decline in cognition and functioning (World Health Organization, 2023). Dementia has in recent years been acknowledged as a public health priority both in the UK and internationally (Ebert et al., 2020; World Health Organization, 2012).

Young people are often neglected in dementia strategies and policy, potentially due to the perceived contrast between the two groups. Yet, young people are not immune from the impact of dementia (Algar & Windle, 2023; Masterson-Algar et al., 2023; Santini et al., 2020; Venters & Jones, 2021). For

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example, there is a growing number of adolescent grandchildren (under the age of 21 years) of people living with dementia (Celdrán et al., 2011). There are also an estimated 40,000 people with young onset dementia who may have a young person under the age of 25 living with them in England (National Children's Bureau [online]. Young people caring for adults with dementia in England, 2016). Moreover, these young people are not just relatives of people with dementia but form an important part of their care and support network (Kates et al., 2023). However, establishing the extent to which young people care for people with dementia is difficult, because there are no national survey figures. Self-identified samples of young people may not see themselves as carers (or their actions as care) and thus are underrepresented in figures. One prior study has highlighted that nearly a quarter of adolescents have provided some form of care for someone with dementia in the past (23.2%, $n = 901$; 13–18-year olds) (Farina, Hughes, Griffiths, et al., 2020). However, these previous studies are limited due to their homogenous sample, with different factors likely to influence who adopts a caring role. For example, cultural differences are likely to influence expectations of care, and who is ultimately more likely to adopt a caring role (Botsford et al., 2011; Mukadam et al., 2011).

Dementia does not typically feature in the curriculum in England so adolescents obtain their knowledge from elsewhere (Farina, 2020). For some, this may be through spending time with someone with dementia as demonstrated by prior research in England where 45.8% of adolescents ($n = 901$) have spent time with someone with dementia (Farina, Hughes, Griffiths, et al., 2020), and for others, this is via TV or teachings from parents/grandparents (Cahill et al., 2015; Z. Felc & Felc, 2021; Olsen et al., 2020; Parveen, Farina, et al., 2020). However, these experiences have yet to be formally contextualized (Farina, Hughes, Jones, et al., 2020). While we have some limited understanding of the frequency of contact with dementia in adolescents, the quality of this experience is yet to be explored quantitatively. That is, whether different experiences of dementia are perceived to be positive or negative. Since adolescents have the highest rate of media use than any other age group (Goodyear et al., 2018; Livingstone & Third, 2017), it is reasonable to suspect that media (i.e., indirect contact) may be one way that adolescents form experiences of dementia. However, some evidence suggests that portrayals of dementia are usually negative (Evans, 2018; Zeilig, 2015). Understanding whether adolescents perceive information presented by the media as generally positive or negative is important since this can establish a social reality which influences an individual's perception, beliefs, and behaviors toward individuals (e.g., those living with dementia) according to the Cultivation theory (Romer et al., 2014).

There are also limitations in our understanding of how adolescents from different socio-demographic contexts experience dementia since prior research has been limited by small sample sizes (e.g., median sample size of

330 reported in a scoping review, Hassan et al., 2023b) and relatively homogenous adolescent groups (e.g., Isaac et al., 2017). Empirically, males and females differ in their level of contact with dementia, with female adolescents generally reporting more contact with dementia than males (Farina, 2020; Hassan et al., 2023a). It is therefore expected that there are socio-demographic differences in the level of contact with dementia. This is likely linked to differences in socialization, personal experiences, and societal expectations (e.g., gender norms and caregiving differences amongst different ethnic and religious groups) (Chung & Rimal, 2016, Naz et al., 2022). This is supported by the social role theory (Eagly, 1997) where gender differences in caregiving arise from socialization expectations of males and females. Social identity theory (Tajfel et al., 1971) also highlights how ethnic identity can influence social experience.

Generating a more accurate picture of adolescents' experiences (level of contact with dementia and quality of contact with dementia) of dementia is important to inform policymakers about what support and guidance are needed for young people and where to target resources. In this study, we aim to explore adolescents' experiences of dementia and any associations with their socio-demographic characteristics. A novel component of this study includes the inclusion effort of different socio-demographic groups including level of deprivation, as well as the inclusion of perceived positivity of experiences with dementia.

Methods

Study design

This study is derived from a cross-sectional study on dementia attitudes. The data was collected between February 2023 and April 2023 across six regions of England (Bedfordshire, Devon, East Sussex, Hertfordshire, Leicestershire, and West Midlands).

Ethics

The study was approved (ER/BSMS9PCH/1) by the Brighton and Sussex Medical School Research Governance and Ethics Committee. School headteachers and other senior school staff were consulted on 1) appropriate safeguarding procedures, 2) opt-in versus opt-out consent procedures, 3) emotional support for adolescents, and 4) strict confidentiality procedures. The researcher obtained an enhanced Disclosures and Barring Service (DBS) certificate. Concerning consent procedures, gatekeepers sent an information sheet as well as an opt-in and opt-out consent form to parental guardians. Typical consent processes that are used for school-age children in England

were followed. This included that adolescents under the age of 13 (11 and 12-year-olds) were required to have opt-in consent from their parents to take part. All participants during the study also had to give their informed consent by completing a consent form to take part in the study, in addition to parental consent procedures.

Participants

The inclusion criteria for participants included, a) being aged 11–18 years old and agreeing to participate in the study, b) attending a secondary school setting in England, and c) obtaining parental consent (opt-in/opt-out). The exclusion criteria included adolescents who could not provide consent. The age range inclusion was limited to 18 years old to reflect standard education models.

Study procedure

In total, 305 unique schools were identified through publicly available information. School gatekeepers of these schools (e.g., Head Teachers) were sent an e-mail invitation to take part in the study. School gatekeepers were provided with a brief study overview, detailed study information sheet and consent procedures. Of the 305 schools contacted, 273 schools did not respond to the invitation, while 21 schools refused to participate. Reasons given were lack of capacity to support the study due to staff shortages, and time pressures resulting from a tight curriculum. In total, 11 schools initially consented to participate in the study. However, two of these schools later withdrew without providing a reason. As a result, nine schools took part in the study. Gatekeepers provided written informed consent to allow the research to occur within the school and facilitated the distribution of the survey either online (via Qualtrics) or by pen and paper. The questionnaire link (or paper copy) was disseminated to participants a week in advance of data collection. On the day of the study, all participants were required to complete a consent form if they wanted to partake in the study. The questionnaires were self-completion on a standard set of measures that included demographic information, level of contact with dementia, and experience of dementia. No personally identifiable information was collected.

All participants completed the questionnaire during school time with their teachers. Schools that completed the questionnaire online did so using school computers. All teachers were informed of the classes who were taking part in the study. The researcher was present for the data collection for the schools that completed the paper questionnaire version. The researcher collected the paper questionnaires on the same day the questionnaires were completed by participants. The questionnaire took approximately 10 minutes to complete.

Participants were presented with a debrief form at the end of the questionnaire and were entered into a prize draw to win vouchers (value of £20). Participants could withdraw from the study up to one month after their data had been collected.

Measures

Patient public involvement

People with lived experience of dementia ($n = 6$) and adolescents aged 12–15¹ years old ($n = 3$) were consulted to guide decisions about outcomes choices. The level of contact with dementia and the quality of contact with dementia. The panel were compensated (in monetary value) for their time.

Demographic variables. Age, sex, ethnicity, religion, and region. Dummy variables were created for each ethnicity with the largest ethnic groups entered into the regression models (Black, South Asian, and Mixed) except White British (largest ethnic group) which served as the comparison category. All other smaller ethnic groups (East Asian, Middle Eastern, other ethnic background) were grouped together to create “other ethnic group” category. All dummy variables were classified as 1 versus 0. Religion was dichotomized into 0 = no religion and 1 = all other religions. Ethnicity was dichotomized as 0 = all other ethnic backgrounds, and 1 = white British. The same dummy variable procedure was applied to religion with “no religion” serving as the comparison category. Jewish, Sikh, Buddhist, and other religions were grouped together to create one dummy variable. For region, we extracted the Index of Multiple Deprivation (IMD) of the Lower Layer Super Output Area (LSOA) geographic area in which the school is based to provide us with an indicator of the deprivation within the catchment area. Schools were dichotomized into those in the most deprived LSOAs (Ministry of Housing, Communities and Local Government, 2019), based on whether they were in the 50% least (0) or most deprived LSOAs (1) in England. Age was treated as a continuous variable in the regression models. Sex was dichotomous as 1 = female, and 0 = male.

Dependent variables

Adolescent Level of Contact of Dementia Questionnaire (ALOCD):

- ALOCD is a validated measure ($\alpha = .88$) on the level of contact (frequency of contact) adolescents have with dementia (Parveen, Griffiths, et al., 2020). The scale consists of 10 items rated on a 5-point Likert scale that ranges from “1 – Never” to “5 – A great deal” with five items relating to indirect contact with dementia (e.g., “I have watched TV shows or movies in which the character has dementia”), and five items relating to direct

contact with dementia (e.g., “I have looked after someone living with dementia”). ALOCD was dichotomized for the logistic regression into 0 = never and 1 = all other responses (rarely, occasionally, very often, and a great deal’). The ALOCD items as the outcome variable (1 = having some level of dementia contact) and demographic variables entered simultaneously together. Each statement was considered alone in the analysis to obtain the percentage of participants who had and had not had direct/indirect contact with dementia and capture frequency of the contact. ALOCD total score was calculated to assess the relationship between frequency of contact and demographic variables. As ALOCD total score was skewed, a simple Log10 transformation was performed. The Log10 transformed total score was used in the analyses.

Quality of contact with dementia:

- There are currently no existing validated measures that capture the quality of adolescents’ level of contact with dementia. For the study, we designed a 3-item survey to capture the quality of contact. Participants were asked to indicate whether their experience of dementia was “generally positive” or “generally negative” about three statements. An example statement from the questionnaire includes “My experience of looking after someone living with dementia is” Participants were asked to circle one answer from the 4-point Likert scale that ranged between 0 = I have not experienced, 1 = generally positive, 2 = generally negative, 3 = Don’t know. Cronbach’s alpha for the five items indicated good internal consistency within the present study ($\alpha = .70$). For this analysis, we wanted to quantify the participants who had indicated that they had experience with dementia, and whether this experience was positive or negative. For ease of interpretation, the variable was dichotomized as 0 = generally negative and 1 = generally positive for the regressions. The generally positive response was the comparator in the logistic regression model.

Data analysis

SPSS (version 26) (IBM, New York, USA) was used to analyze the data. Descriptive statistics, checks for normality and cross-tabulations were obtained. Weighting was applied to ALOCD dichotomous items to obtain 95% confidence intervals (CI) and prevalence estimates using the one-sample binominal non-parametric test. Prevalence estimates denote having had some level of contact with dementia (1). Cell-based weighting was used to independently calculated with two sex categories (male, female), two age categories (11–14 years old, 15–18 years old), and five ethnicity categories (White, Black,

South Asian, mixed ethnicity, other ethnicity), creating 20 cells. National adolescent demography were taken from the 2021 census (Office for National Statistics, 2023).

Multiple logistic and linear regressions were employed to assess the demographic variables associated with each item of “quality of contact with dementia” and the ALOCD items. Assumptions to run the regression were met (Durbin-Watson statistic values were all between 1.5 and 2.5, and plots and multicollinearity was checked with the VIF values less than 10). An alpha of 0.05 was used to denote statistical significance. Participants who had never heard of dementia or Alzheimer’s before were excluded from the study, to remove those who had not formed any opinions about the condition. *A priori* sample size of 1,200 participants (allowing 20% missing data) was needed to attain at least 80% power for 5% statistical significance to detect a small effect size.

Results

A total of 1,625 adolescents aged 11–18 years old were recruited. Eighty-three participants (6.1%) had never heard of either “dementia” or “Alzheimer’s disease” before. As such, these individuals were removed from the analysis. Following data cleaning procedures, 1,371 adolescents remained in the analysis. Out of 1,371 participants, 994 (72.5%) participants had a 100% questionnaire completion rate. On average, participants were 14 years old ($SD = 1.04$) and roughly an equal number of females (48.1%, $n = 660$) and males (51.9%, $n = 711$). 55.9% ($n = 767$) identified as White British followed by South Asian (22.2%, $n = 304$). Adolescents were predominantly from schools in regions that ranked amongst the 50% most deprived LSOAs (70.6%, $n = 959$). Nearly half of the adolescents identified as having no religious beliefs (48.0%, $n = 654$). See Table 1.

Level of contact with dementia

From 1,209 adolescents, weighted prevalence estimates demonstrated that 69% of adolescents ($n = 834$, 95% CIs .66 to .72) have come across people living with dementia. The most frequent affirmative responses were related to watching a TV show or movie about dementia ($n = 905$; .75, 95% CIs .73 to .78), and coming across adverts about dementia ($n = 903$; .75, 95% CIs .72 to .77). The least frequently reported experience of dementia was looking after someone with dementia ($n = 362$; .30, 95% CI .27 to .32). See Table 2.

When all demographic variables ($n = 11$) were entered simultaneously with a total ALOCD score ($m = 20.20$, $SD = 8.3$) as the dependent variable, the regression model was statistically significant, $F(11,1155) = 8.37$, $p < .001$. The adjusted R square suggested the model explained 7% of the

Table 1. Demographics and descriptive statistics.

Demographics		Valid %	M ± SD	N
Region				1371
	Bedfordshire	52.2%		716
	Leicestershire	5.9%		81
	East Sussex	23.2%		318
	Hertfordshire	6.9%		94
	Devon	10.6%		146
	West Midlands	1.2%		16
				1371
School	School 1	33.0%		452
	School 2	16.1%		221
	School 3	3.1%		43
	School 4	8.4%		115
	School 5	6.9%		94
	School 6	10.6%		146
	School 7	14.8%		203
	School 8	5.9%		81
	School 9	1.2%		16
				1371
Sex	Female	48.1%		660
	Male	51.9%		711
			14.28 ± 1.04	1366
Age	11	1.1%		15
	12	0.7%		9
	13	20.4%		278
	14	38.1%		521
	15	28%		382
	16	11.1%		152
	17	0.1%		2
	18	0.5%		7
				1371
Ethnicity	White	55.9%		767
	Black	5.1%		70
	South Asian	22.2%		304
	East Asian	2%		28
	Middle Eastern	1.5%		21
	Mixed or multiple ethnic backgrounds	7.3%		100
	Other	2.3%		31
	I do not want to answer	3.6%		50
				1363
Religion	No religion	48%		654
	Christian	20.2%		275
	Buddhist	0.5%		7
	Hindu	7.6%		103
	Jewish	0.5%		7
	Muslim	14.2%		195
	Sikh	1.4%		19
	Other religion	0.6%		8
	I do not want to answer	7%		95

variance. Being female was associated with higher levels of contact with dementia ($p < .001$), whilst Black and mixed ethnic background adolescents were associated with lower levels of contact with dementia ($p < .001$ and $p = .01$, respectively) when compared with to white adolescents. Those who identified as Christian were associated with more contact than those who identified as non-religious ($p = .03$). There were no other significant factors in the model ($p > .05$). See Table 3. Although there was some variability between items, similar associations were

Table 2. Level of contact percentage breakdown of responses.

ALOCOD items	Response						One sample binominal test prevalence estimate			
	Never	Rarely	Occasionally	A moderate amount	A great deal	N	Missing	Yes (1)	Prevalence Weighted	95% CI Weighted
I have come across people living with dementia	35.5% (n = 429)	28.5% (n = 345)	20.3% (n = 246)	8.8% (n = 106)	6.9% (n = 83)	1209	162	.65 (n = 780)	.69	.66-.72
I have spent time with people living with dementia	54.3% (n = 656)	18.5% (n = 223)	11.6% (n = 140)	8.1% (n = 98)	7.5% (n = 90)	1207	164	.46 (n = 511)	.52	.49-.55
I have spent time with a family friend who is living with dementia	67.6% (n = 814)	16.0% (n = 193)	7.7% (n = 93)	4.1% (n = 49)	4.6% (n = 56)	1205	166	.32 (n = 391)	.36	.33-.38
I have spent time with a family member living with dementia	58.5% (n = 706)	14.6% (n = 176)	10% (n = 121)	8.6% (n = 104)	8.2% (n = 99)	1206	165	.42 (n = 500)	.48	.45-.51
I have looked after someone living with dementia	73.4% (n = 884)	12.0% (n = 144)	5.8% (n = 70)	4.2% (n = 51)	4.6% (n = 56)	1205	166	.27 (n = 321)	.30	.27-.32
I have watched TV shows or movies in which the character has dementia	26.4% (n = 318)	32.3% (n = 388)	23.5% (n = 284)	10.5% (n = 127)	7.4% (n = 89)	1206	165	.74 (n = 888)	.75	.73-.78
I have come across adverts about dementia	28.8% (n = 347)	28.6% (n = 344)	26.8% (n = 323)	11.2% (n = 135)	4.6% (n = 55)	1204	167	.71 (n = 857)	.75	.72-.77
I have come across people living with dementia on social media	33.1% (n = 398)	29.0% (n = 350)	22.8% (n = 275)	11% (n = 133)	4.1% (n = 50)	1206	165	.67 (n = 808)	.69	.66-.71
I have searched for information on dementia on the internet	54.1% (n = 651)	23.8% (n = 287)	14.8% (n = 178)	5.1% (n = 62)	2.2% (n = 27)	1205	166	.46 (n = 554)	.46	.44-.49
I have spoken with family or friends about dementia	46.3% (n = 559)	17.9% (n = 216)	19.1% (n = 231)	10.8% (n = 130)	5.9% (n = 71)	1207	164	.54 (n = 648)	.58	.55-.61

ALOCOD (Adolescents level of contact with dementia). The percentage frequencies denotes valid percent. Each item was dichotomized as yes (1) versus never (0). One sample binominal test prevalence estimate for "Yes" (1) is the unweighted proportion. Prevalence estimate and 95% CI is weighted.

Table 3. Multiple linear regression for ALOCD total score.

Multiple linear regression ALOCD (n = 1155)				
	R	R ²	Adjusted R ²	F
	.27	.07	.07	8.37
Variables	B	β	p	CI
Religion (0 = No religion)				
Religion (1 = All other religions)	.01	.02	.51	-.02–.05
Religion (1 = Christian)	.03	.07	.03*	.00–.06
Religion (1 = hindu)	-.01	-.01	.76	-.06–.05
Religion (1 = Muslim)	-.03	-.07	.14	-.08–.01
Ethnicity (0 = White)				
Ethnicity (1 = Black)	-.10	-.12	<.001***	-.15 – -.05
Ethnicity (1 = South Asian)	-.04	-.09	.07	-.08–.00
Ethnicity (1 = Mixed)	-.05	-.08	.01*	-.09 – -.02
Ethnicity (1 = All other ethnic groups)	-.01	-.02	.56	-.05–.03
Region (0 = Least deprived)				
Region (1 = Most deprived)	.00	.01	.77	-.02–.03
Sex (0 = Male)				
Sex (1 = female)	.07	.20	<.001***	.05–.09
Age	.01	.03	.25	-.00–.02

Outcome variable: ALOCD (Adolescent Level of Contact with Dementia) total score. β = standardized beta coefficient. Regression model summary indicated by R, R², adjusted R², and F values for ALOCD total score.

reported in models in which individual items of the ALOCD were the dependent variables. See Appendix A.

Adolescent's quality of contact with dementia

Of those who had previous experience with people with dementia, the majority of people who spent time with someone with dementia felt it was generally a positive experience (90.8%, $n = 394$). Similar positive experiences were held for people who looked after someone with dementia (82.3%, $n = 214$). However, far fewer had positive experiences when speaking to family and friends about dementia (47.0%, $n = 255$). See Appendix B.

Across the logistic regression models, age was the only factor to be consistently associated with quality of contact with dementia, with older ages being associated with generally more negative experiences. Females were associated with generally more positive experiences of spending time with people with dementia than males (OR = 2.81, $p = .01$) and in their experience looking after someone living with dementia (OR = 3.27, $p < .01$). While non-White British Ethnic groups were associated with positive experiences of looking after someone living with dementia (OR = 2.62, $p = .04$) and talking to family and friends about dementia (OR = 1.67, $p = .02$). Religious adolescents were associated with generally more negative experiences when talking to family and friends about dementia (OR = .58, $p = .01$). See Table 4.

Table 4. Multivariate logistic regressions for socio-demographic variables associated with positive experience of dementia.

Experience of dementia items (1 = positive experience)	Demographics	B	<i>p</i>	Exp(B)	95% CI for EXP(B)
When I have spent time with people with dementia my experience has been: $\chi^2 = 21.54$ (6, 413), $p < .01$	Sex (1 = female)	1.03	.01*	2.81	1.34–5.88
	Age	-.35	.03*	.70	.51–.97
	Religion (1 = religious)	.46	.32	1.58	.65–3.83
	Ethnicity (1 = nonwhite British)	.45	.33	1.56	.64–3.79
	Region (1 = most deprived)	-.64	.16	.53	.22–1.28
	ALOCDC (contact frequency)	-2.44	.07	.95	.01–1.26
My experience of looking after someone living with dementia: $\chi^2 = 26.38$ (6, 249), $p < .001$	Sex (1 = female)	1.19	<.01**	3.27	1.48–7.24
	Age	-.40	.01*	.67	.49–.91
	Religion (1 = religious)	-.33	.49	.72	.28–1.85
	Ethnicity (1 = nonwhite British)	.96	.04*	2.62	1.03–6.70
	Region (1 = most deprived)	-.56	.18	.57	.25–1.29
	ALOCDC (contact frequency)	-2.17	.11	.11	.01–1.57
When I have heard family or friends talk about dementia it is: $\chi^2 = 20.55$ (6, 523), $p < .01$	Sex (1 = female)	-.11	.56	.90	.63–1.28
	Age	-.19	.03*	.83	.70–.98
	Religion (1 = religious)	-.54	.01*	.58	.39–.88
	Ethnicity (1 = nonwhite British)	.51	.02*	1.67	1.08–2.56
	Region (1 = most deprived)	-.26	.18	.77	.53–1.13
	ALOCDC (contact frequency)	-.85	.15	.43	.13–1.37

Outcome variable: Experience of dementia items. χ^2 = Chi-square statistic for logistic regression. Statistical significance: * = $p < .05$; ** = $p < .01$; *** $p < 0.001$. Dichotomous variables are coded as 0 versus 1. *B* = unstandardized beta coefficient; Exp(B) = odds ratio; CI = confidence interval (lower – upper bound) [95%].

Discussion

Understanding the level and quality of contact with dementia in young people is essential to inform policy and support programs for this population. At present, there is little understanding of what these experiences look like, with prior data limited to relatively homogenous samples and one geographic location in England. To our knowledge, this is the largest and most diverse sample of adolescents from England to date to report on their experiences of dementia.

Our findings highlight that nearly half of the young people in our survey (46.0%) have spent time with someone with dementia in the past. Perhaps more significantly, over a quarter have looked after someone with dementia in the past (26.6%). While these findings are in line with those reported previously (i.e., 23% have provided some form of care, $n = 901$) (Farina, Hughes, Griffiths, et al., 2020), it does appear to be far higher than the 1% reported in the National Children’s Bureau survey ($n = 51$ young people identified from a total of 4,954 carers of all ages) (National Children’s Bureau, 2016). We should recognize that within our study, the item uses the term “looked after” rather than “care.” This distinction is important because we would argue that both reflect care, but the former is less stigmatizing and may also better capture the concept of “supervision.” This could be useful in determining key demographics for initiatives that aim to raise awareness of dementia or that such individuals must be provided with support in caring for someone with dementia.

We further demonstrate that there are demographic differences across the outcome measures, in line with prior findings. In terms of sex differences, females had significantly more contact with dementia than males (Cheston et al., 2019; Farina, Hughes, Griffiths, et al., 2020; B. Felc & Felc, 2021; Perion et al., 2021). Females also indicated that their direct experience of dementia was more positive than males, potentially reflecting better quality experiences (Hassan et al., 2023a). However, it does not explain why adolescent females are having more contact with people with dementia than adolescent males. Aside from the social and cultural norms relating to females having a larger share of caregiving responsibilities within the family over the lifespan (Falzarano et al., 2022; Kane et al., 2021), females may also have greater involvement in relationship-building activities socially within the family context (Gracia et al., 2022; Hilbrecht et al., 2008). This may lead to more frequent interactions with individuals with dementia. This theory is supported by our cross-tabulations that demonstrated that not only did females look after someone with dementia more so than males, but they also spent more time with a family member with dementia. However, we cannot confirm whether this is the case since we do not have information on the context in which participants are interacting with people with dementia (e.g., social functions or home life).

Older adolescents were associated with more dementia contact than younger adolescents. This finding is perhaps expected, as older adolescents have lived longer and so had more opportunities to be exposed to these experiences. Interestingly, older adults also reported having a generally less positive experience in their interactions with dementia, which potentially indicates that older adolescents may experience contact with dementia in a different context to how younger adolescents experience contact with dementia. Moreover, older adolescents may have greater involvement in caregiving responsibilities which may contribute to a more negative overall experience (Kavanaugh et al., 2016). Being able to compare the number of hours of care against these experiences would help us explore this relationship.

There did not appear to be any consistent role of religion in contact with dementia, with only Christian adolescents having significantly higher contact than non-religious adolescents. Religion may act as a facilitator for community activities that lead to interactions with a diverse range of community members (Dunbar, 2020), including people with dementia. For example, this could include religious groups hosting community activities for religious occasions (e.g., Easter church service and Diwali). However, we are unable to determine if this is the case as this information was not collected. Nevertheless, it is unclear why Christian adolescents, and not Muslim and Hindu adolescents, were associated with higher dementia contact. There may be cultural influences that may mean some religions openly discuss dementia more than others. Thus, adolescents may not realize they have come into contact with someone with dementia. A similar pattern was also reported with ethnicity,

with only Black and mixed ethnic adolescents, but not South Asian, having statistically significantly less contact with dementia compared to White adolescents. Further consideration is needed about the religious and cultural differences in the expectations for caring for someone with dementia (Botsford et al., 2011).

Our data also confirm previous findings that adolescents have had more indirect contact with dementia than direct contact, as adolescents get most of their information about dementia through the internet, film and media (Farina, Hughes, Griffiths, et al., 2020; Hwang et al., 2013). Given that young people have the highest rate of media use than any other age (Goodyear et al., 2018; Livingstone & Third, 2017), it is reasonable to expect that media may have a key role in the way adolescents access information about dementia and perceive the condition. Over 74% of the adolescents had watched TV shows or movies with a character who has dementia. A prior survey conducted in England of 11–14-year-olds found that 84% of adolescents had cited media as their main source of information on dementia (Baker et al., 2018), referring to the “dementors” in Harry Potter repeatedly (Cowley, 2005). Cultivation theory suggests that the media’s representation of a given topic can shape a person’s perceptions, attitudes, and beliefs (Shrum, 2017). While we did not examine the association between adolescent’s dementia attitudes and their experience of dementia in the media, it is certainly a point of interest for future work. We recommend stakeholders consider how young people will perceive dementia content when devising dementia awareness content. Policymakers and researchers could work together to ensure TV and film producers provide some form of counter-education or training on stigmatized groups to ensure the representation of dementia is more accurate, and fairer. Mass media campaigns might also prove to be a viable option to reduce prejudice (Clement et al., 2013).

There are limitations to consider for this study. First, the cross-sectional nature of the study limits what causal inferences we can make about the data with statistical associations. Future work should aim to explore this longitudinally. Second, while the strength of this study includes a relatively larger and more diverse sample compared to previous studies, the findings are still not wholly representative of adolescents across all of England despite efforts to include different school types and various socio-demographics. Third, there are currently no validated questionnaires on the experience of dementia that capture the quality of contact for this age group. Future work may aim to optimize and validate the concept of contact quality. The items did display good internal consistency nevertheless ($\alpha = .70$). Lastly, dichotomizing variables help us provide a clearer message. However, it may oversimplify the data. Although not all experiences can be adequately captured quantitatively or dichotomously, not all categories within a demographic variable have

a sufficient sample size to be able to provide a statistical comparison. The cross-tabulations do provide small assistance in providing some context to the associations.

Conclusion

This study provides an understanding of the level of contact with dementia and quality of contact with dementia across various socio-demographic groups in adolescents, which is an important context needed to help identify who might need the most support. Our findings hope to encourage stakeholders and policymakers to be mindful of young people in their public health efforts.

Note

1. We use “adolescents” when describing our sample in recognition of people’s developmental milestones, and to provide additional specificity (i.e., “adolescents” usually reflect people aged 10–19 years old, “young people” usually refer to people aged 10–24 years old).

Contribution to the field

- Generating a more accurate picture of adolescents’ level of contact with dementia and quality of contact with dementia in England.
- A novel component of this study includes the inclusion effort of different socio-demographic groups including level of deprivation.
- Our study addresses an important population gap by recruiting over 1300 adolescents from nine schools across six regions of England.
- Dementia quality of contact in adolescents is yet to be formally contextualized quantitatively.
- Patient public involvement input through an intergenerational panel of those with lived experience of dementia and adolescents.

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Author contributions

EH formulated and prepared the draft manuscript under the supervision of NF and NT. Both EH and NF contributed to the design of the study, planned analysis and planned output of the research. BH contributed to the recruitment efforts of participants. EH carried out the analysis and drafted the manuscript. NF, BH and NT reviewed and revised the manuscript. All authors have read and approved the final manuscript. The conducted research and analysis plan were not pre-registered.

Availability of data and materials

The datasets generated during and/or analyzed during the current study are not publicly available due ethical restrictions relating to underage participants. Data can be requested directly from the corresponding author upon reasonable request.

Ethics approval

The Brighton and Sussex Medical School Ethics Research and Governance committee granted ethical approval for data collection of this study (ethics approval code: ER/BSMS9PCH/1). Guardian/parental informed consent was obtained.

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