

What is taught about dementia in secondary schools? A survey of schools in Sussex, England (Innovative Practice).

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Abstract

Local dementia education initiatives exist in schools but it is unclear what the wider uptake of such programmes are. A self-created survey was sent to staff in a number of secondary schools (teaching ages 11-16) across Sussex, England. Sixty schools responded to the survey (response rate = 58%). While the majority of schools expressed an interest in including some form of dementia education within their school in the future, only nine schools (15%) currently had dementia education embedded within their curriculum. Despite government calls to reduce stigma and improve attitudes towards dementia, it seems very little is being taught in secondary schools on the topic.

Keywords

adolescents, curriculum, dementia, education, schools, children

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Introduction

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

Educating people about dementia is an important step in reducing stigma (Mukadam & Livingston, 2012). The school education system may be one such way to provide all members of society with this knowledge, and thus reduce stigma towards dementia. From the academic literature there is very little information about what secondary schools currently teach about dementia and its benefits to their students. It is however known that a variety of localised dementia education initiatives do exist across England (Atkinson & Bray, 2013; Di Bona & Kennedy, 2015; Nazir & Bangash, 2015; Parveen, Robins, Griffiths, & Oyeboode, 2015; Rylance & Pendleton, 2015). In addition, online resources from organisations such the Alzheimer's Society do provide free content for schools to access (Alzheimer's Society, 2017). At present it is unclear about the broader uptake of these dementia education initiatives.

The lack of information of what is taught about dementia in schools within England occurs in context of a rapid shift of provision from schools directly controlled by local councils to those outside of it (West & Bailey, 2013). This has been largely due to the introduction of academies, which amongst other things, allow schools not to follow the national curriculum (Department for Education, 2015). There are now over 2,000 secondary school academies for pupils aged 11-18 in England alone, which is set to rise (Department for Education, 2016). As such, there are a growing number of schools that have additional flexibility in what can be taught as long as it fits within the remit of providing a

'broad and balanced curriculum' (Department for Education, 2015). Formal evaluation of what secondary schools are teaching about dementia is the first step in identifying whether there is a need to further promote dementia in schools. This survey sets out to explore whether secondary schools (that cater exclusively to children aged 11-16), across a wide geographic area (Sussex, in South East England), include dementia education within their curriculum. Importantly, this survey also seeks to identify whether there is an interest in implementing dementia education initiatives in the future.

Methods

The study received ethical approval from the Brighton and Sussex Medical School Research Governance and Ethics Committee (16/022/BAN).

Participants

Respondents were required to be staff working at secondary schools in Sussex, England. Schools were required to teach children at a secondary education level (children aged 11-16). Schools that cater exclusively to special needs students or did not teach students between this age range (e.g. further education) were not included. There were no other exclusion criteria based on academic achievement, funding stream, or intake policy of the school.

Procedure

The survey was initially targeted at members of the senior leadership team (e.g. head teachers, deputy heads), however, they could delegate the survey to another member of staff if they felt they would be better able to answer the questions. Respondents were identified through word-of-mouth, contacting administrators at schools or searching schools' websites for contact information. Members of the senior leadership team in each school were initially emailed and lack of response was followed-up by a phone call. No incentives were provided, but all respondents were offered the opportunity to receive a summary of findings for the study.

All respondents were provided the same information about the study prior to participation. Consent was obtained through virtue of completion.

Materials

The survey was designed and piloted with a deputy-head at a local secondary school. The survey was primarily distributed using the Bristol Online Survey (BOS; <https://www.onlinesurveys.ac.uk/>) tool, however, respondents could complete the survey over the phone with a researcher if preferred. It was composed of both open and closed-ended questions about dementia education initiatives within the staff's school during the previous academic year (2015/2016). The survey was circulated between October 2016 and January 2017.

The survey was broadly divided into two sections, what was being taught about dementia in schools, and whether there was interest in implementing dementia education in the future. The survey took approximately 5 minutes to complete. In cases where the respondent was unable to answer the primary outcome ('Is dementia education embedded into your school's curriculum?') they were asked to identify whether another member of staff had that knowledge. Those that responded 'Not Sure' were only included in the final analysis if no other suitable staff member could be identified.

Supplementary information about schools were obtained from freely available information on the Department of Education website (Department for Education, 2017). All information was correct as of January 2017.

Analysis Plan

Descriptive data (e.g. frequencies) were calculated. Response rates were compared between schools that completed the survey and those that did not complete the survey. A series of Pearson's chi-squared tests using the conventional p-value threshold of 0.05 were also conducted to determine whether key school characteristics predicted whether the school were more likely to include dementia

within their curriculum. These characteristics included the type of school (e.g. maintained by local authority, academy), last rating they received from Ofsted (the organisation responsible for inspecting and regulating services for children) and whether the school had a selective intake policy (e.g. schools that have specific entry requirements for students). Statistical analyses were completed using IBM SPSS Statistics for Windows, version 23 (IBM Corp., 2015).

Schools in which multiple members of staff responded to the survey, the response from the most senior member of staff was included for analysis, the associated data of duplicate school responses were excluded.

Verbatim quotes were also analysed to provide additional context about what was being taught about dementia in the schools. A Conventional Content Analysis (Hsieh & Shannon, 2005) was conducted on open-ended questions regarding why staff felt they would, or would not, be willing to consider including some form of dementia education at their school. This analysis describes the content of the interviews rather than being aimed at developing a theory. Two researchers (NF & YF) independently read the first 20 responses and highlighted key words that appear to capture concepts, these were then developed into a coding framework. The two researchers discussed differences between codes until they came to a consensus. The two researchers then continued to code the rest of the responses. Coding was subsequently checked between researchers, and any new codes identified were discussed. Codes were then later grouped into themes.

Results

One hundred and four schools were approached to complete the survey. Following the removal of 5 responses (4 duplicates, 1 missing critical data), there were a total of 60 valid responses (Response rate = 57.7%).

There was no significant difference between characteristics of schools that completed the survey and those that did not ($p > 0.05$) (Table 1.). Staff that responded to the survey, on behalf of the school, were

most frequently Head of Department (n=20, 33.3%), followed by Deputy Head (n=11, 18.3%) and Assistant Head (n=9, 15.0%).

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Table 1. A comparison of characteristics between schools that completed the survey and schools that did not.

	Completed Survey (n=60)	Did not complete survey (n=44)	χ^2 (p-value)
Geographic Region			0.93 (p=0.63)
East Sussex	23	14	
West Sussex	27	24	
Brighton & Hove	10	6	
Last Ofsted Rating*			2.02 (p=0.57)
Outstanding	7	7	
Good	26	16	
Satisfactory	9	7	
Inadequate	0	1	
School type			0.39 (p=0.82)
Independent	16	11	
Academy	23	15	
Maintained	21	18	
School gender intake			0.39 (p= 0.82)
Boys	2	2	
Girls	5	5	
Mixed	53	37	
Intake policy**			2.69 (p=0.10)
Selective	4	0	
Non-selective/ Comprehensive	52	36	

*There was no information available on the Last Ofsted Rating in 31 schools. **There was no information available about intake policy in 12 schools.

Dementia education in the curriculum

Nine schools (15.0%) reported having dementia education embedded into the school's curriculum. Of these schools, it was commonly reported that dementia was being taught within Personal, Social and Health Education or similar (e.g. 'Life Skills', 'Learning about life'), though usually as part of a broader topic (e.g. mental health, aging, discrimination). These class based lessons occurred across all ages. A single school, included trips to care homes to support learning.

Ofsted rating ($X^2(2, N=42) = 2.02, p=0.36$), type of school ($X^2(4, N=60) = 7.08, p=0.13$) and intake policy ($X^2(2, N=56) = 0.94, p=0.63$), did not predict whether a school included dementia within their curriculum.

Eleven schools (18.3%) reported that they engaged in some form of dementia education, albeit not embedded within the curriculum. For example, dementia was reported to be taught by some schools during Health and Social Care lessons, a non-compulsory subject. Three schools highlighted that they were involved in fundraising activities that included dementia charities. Only two schools of these 11 schools had their students visit people with dementia. In the first, students first met with the carers of people with dementia to get a better understanding of the disease, and then performed 'music, drama and poetry' to the people with dementia on a regular basis. This occurred once a month across age groups. In the second school, students attended '...the annual Alzheimer Carol Service to take part in readings'.

Only a single school (1.7%) reported that they promoted online resources about dementia to their students. Three schools (5.0%) reported that they did something for Dementia Awareness Week.

Including dementia education in the future

The majority of respondents ($n=44, 73.3%$) were interested in including some form of dementia education within their school in the future, whilst three schools (5.0%) reported that they were not interested. When asked what were the best periods to teach about dementia, Personal, Social and Health Education was most frequently reported ($n=37, 61.7%$), followed by assembly ($n=21, 35.0%$) and form time ($n=17, 28.3%$). Only two respondents felt dementia was best taught as part of

extracurricular activities. Year 10 (age 14-15) was deemed as the best year group to teach dementia (n=39, 65.0%), followed by Year 11 (n=33, 55.0%) and then Year 9 (n=30, 50.0%).

Content analysis revealed four themes ('Perceived Importance', 'Practicalities', 'Experience with Dementia', and 'Interest in Dementia') were associated with whether a school would be interested in including a dementia education initiative.

In schools that were interested in teaching dementia in the future, the practicalities of implementation were commonly highlighted (n=24, 61.5%). Specifically, a number of respondents commented on how dementia education would best 'fit' within existing lessons and topics. However, many acknowledged that a lack of time and resources were a limiting factor; 'We would like to do more of it, but it is hard squeezing it into the curriculum...' The practicalities of implementing dementia education was the only theme to arise in responses in schools that were not interested in including dementia education in the future (n=3, 100.0%). One respondent explained, '[We are a] very small school that does not follow traditional format...' Another respondent identified that time was a driving factor for not to include some form of dementia education, 'This is difficult due to time constraints...'

A commonly held view was that it was important to teach about dementia from a societal perspective. For example, one respondent said, 'We like to try to cover as many important social issues as we can and this is certainly important.' No responses fit under this theme within schools that were not interested in including dementia education in the future.

A somewhat smaller theme was some staff expressed a general interest to teach dementia (n=10, 25.6%) (e.g. 'I would love to include dementia education in our PSHE [Personal, Social and Health Education] programme.'), though this is not always within their control, 'I would but not really my call'.

Previous experience of people with dementia was also identified as a theme related to respondents' interest in dementia education (n=7, 17.9%). Some described that their students might have experience with the disease; 'Because the children may have people in their families with

dementia...’ However, there were also respondents that highlighted their own experiences of dementia as a reason why they want to include dementia education.

Discussion

This survey highlighted that there is little being taught about dementia within secondary schools in Sussex (England), and that it is very rarely embedded within the curriculum. The survey however indicates that many schools have an appetite for including some form of dementia education programme within their schools in the future.

Secondary schools that responded to this survey in Sussex (England) overwhelmingly did not include dementia education within their curriculum, and those that did often did so as part of broader topics in Personal, Social and Health Education. A larger proportion of secondary schools included dementia outside of the curriculum, however, was surprising to find that the majority did not use Dementia Awareness Week as a means to stimulate conversation about the condition. It was positive that several schools did get their students to engage with people with dementia. Previous evidence suggests that getting adolescents to meet people with dementia (e.g. intergenerational programs) may be an effective method of improving knowledge and attitude of dementia (Atkinson & Bray, 2013) but also benefit the person with dementia (George, 2011).

The lack of widespread inclusion of dementia education was not due to a lack of interest or perceived importance on the topic. Many respondents identified places in which dementia education would best fit despite having limited time and resources. There were often views that dementia is an important topic and they understood that it could affect their students directly.

The presence of free online resources in terms of educational materials and children directed content, in the present sample, also appears to be underutilised. The lack of uptake may be for many reasons, possibly due to a lack of awareness or confidence to utilise them. Efforts by the Alzheimer’s Society to accredit resources for their use across Northern Ireland (Alzheimer’s Society, 2016) is an example of a positive step to encourage the adoption of such dementia education initiatives. However, there is

further need for evidence based education programmes, as there is often a lack of transparency with regards to their development process and outcomes.

A key limitation of this study was the modest response rate from schools. Previous researchers have asserted that there is a minimum response rate needed (e.g. 50%; Rea & Parker, 2014), though there is no consensus on this threshold. Response rates from organisations are often low (on average 35.7%), and therefore it has been proposed that it is more important that the methodology and findings are transparent (Baruch & Holtom, 2008). Non-response bias can be particularly problematic. This survey has identified that the characteristics of the schools did not predict whether schools responded to the survey. Except for the presence of local initiatives, there is no apparent reason why these findings here would not reflect the broader national picture. However, as this study did not collect data nationally, caution should be taken from making this assumption.

Another limitation of these findings is that the staff member answering the survey may not have had a sufficient overview of what was being taught within the school. In an effort to get the most accurate data, members of the senior leadership team were initially approached, but were encouraged to pass on the survey to other members of staff if they felt they did not have sufficient knowledge about what their school taught about dementia. It is possible that some staff, despite prompts did not have a full overview of what was being taught within their school. It is positive that only two respondents were unsure whether dementia was embedded within their school's curriculum.

Despite the existence of dementia education initiatives within the England (Atkinson & Bray, 2013; Di Bona & Kennedy, 2015; Nazir & Bangash, 2015; Parveen et al., 2015; Rylance & Pendleton, 2015) alongside the availability of free education resources online (Alzheimer's Society, 2017), secondary schools in Sussex (England) largely do not utilise them. Interest from staff to include some form of dementia education in the future is a positive indication that something could be implemented. Future research needs to not only investigate the barriers for schools to uptake such dementia programmes, but also ensure there is a clear evidence base for the benefits of providing dementia education to secondary school children.

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Conflict of interest statement

None declared.

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