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Abstract

The development of dementia friendly communities is a current global and national priority for the UK. As a response to policy, there have been a number of dementia awareness initiatives disseminated with the aim of reducing the stigma associated with a diagnosis of dementia. The inclusion of adolescents in such initiatives in imperative in order to sustain dementia friendly communities. With this is mind, the aim of this study was to establish the dementia education needs of adolescents and effective dissemination strategies to convey key messages. A total of 42 adolescents aged 12 to 18 years participated in eight focus group discussions. Key themes to emerge from discussions included: the importance of dementia awareness, topics of interest within dementia, preferred methods of learning, the inclusion of the person living with dementia and the use of social media. The findings of the study will enable the development of appropriate dementia awareness initiatives for adolescents and thus facilitate the sustainability of dementia friendly communities.

KEY WORDS:

Dementia friendly; Dementia education; Secondary schools; Students; Stigma; adolescents

What do adolescents perceive to be key features of an effective dementia education and awareness initiative?

Introduction

There are approximately 46 million people living with dementia worldwide, with a societal and economic cost of $818 billion. Due to an increasingly ageing population, dementia is now a global (WHO/ADI, 2009, 2012, G8 Dementia Summit, 2013) and a national priority in the United Kingdom (National Dementia Strategy, 2009, Prime Minister's Challenge, 2015).

The stigma associated with dementia has been receiving increasing attention with a key aspect of the UK's national dementia strategy focusing on reducing the stigma associated with the condition. Often those living with the condition are socially constructed as the 'living dead' and evoke a significant negative emotional response (Behuniak, 2011). Jolley and Benbow (2000) also highlight the stigma associated with dementia and suggest that dementia arouses fear before sympathy. Werner et al's (2014) literature review of 48 studies found that people with dementia are perceived by the public as unpredictable and difficult to communicate with and should be institutionalised. Kitwood (1997) proposed that a biomedical view was a contributory factor in the stigma associated with dementia due to the focus on the person's deficits. Scodellaro and Pini (2011) oppose this view and state that the negative influence of the biomedical model of dementia is debatable and varies between cultures. They argue that the stigma associated with dementia is not dissimilar to the stigma associated with older age (ageism) for example incompetence with regards to decision making.

There is a growing body of literature focused upon reducing ageism amongst young people. Bousfield and Hutchinson's (2010) report from a study including 55 students aged 16-25 years that the quality of contact with older people was of more importance in changing young people's attitudes than frequency of contact. O'Connor and McFadden (2012) suggest that people living with dementia may be more vulnerable to ageism as they trigger death related thoughts in young people leading to anxiety. Indeed, findings from a survey by the Alzheimer's Society (2007) suggest that adults of all ages fear dementia more than cancer, heart disease and stroke. In O'Connor and McFadden's (2012) study of 240 participants aged between 17 and 30 years, negative attitudes about ageing were positively associated with anxiety about death, suggesting a reduction in anxiety about death could reduce ageism in young people. Werner et al's study (2017) of 460 students aged between 14-15 years suggests that adolescents hold low levels of stigmatising beliefs towards people living with dementia. With evidence suggesting that stereotypes are formed over a lifetime (Riley et al, 2015), anti-stigma educational interventions should be targeted at a young age.

The importance of reducing the stigma associated with dementia is highlighted by a report by the Alzheimer's Disease International (2014) which found that the main barrier for accessing care and services for people with dementia and families is stigma, which prevented open discussions, led to erroneous beliefs that people living with dementia could not be helped, and led to social isolation and a poorer quality of life. Earlier work by Vernooij-Dassen et al (2005) had also highlighted the negative impact of stigma on the care of people living with dementia and their families, whilst it has been found that stigma impacts on all levels of service delivery from seeking help to prioritisation of resources from governments (Benbow & Jolley, 2012) suggesting the reduction of stigma is imperative in improving the quality of life for people living with dementia and their families.

As stigma develops during the lifespan, it is therefore important to address these negative attitudes early. Education, protest against inequalities and contact with people living with dementia have all been proposed as strategies to reduce stigma (Mukadam &Livingstone, 2012). Despite this, a recent survey found that of the 60 schools approached in Sussex (England), only nine schools had dementia education embedded into their curriculum

(Farina, 2017). In recent years there have been a number of dementia awareness initiatives aimed at young people and delivered in schools (Di Bona, Kennedy & Mountain, 2017; Atkinson & Bray, 2013; Nazir & Bangash, 2015; Parveen, Robins, Griffiths, & Oyebode, 2015; Rylance & Pendleton, 2015) and focused on improving awareness of dementia. The initiatives report receiving positive feedback from students, however there is little evidence to suggest impact on knowledge and attitude change. Importantly, in order for such initiatives to have a significant impact on attitude and behaviour change, they need to be co-designed by researchers with teachers and students, in order to meet the needs of the recipients they are aimed at (Taylor et al, 2013).

In order to co-design dementia awareness and education initiatives for young people, exploring the perspectives and educational needs of adolescents is important. The aim of this study was therefore to explore what adolescents perceived an educational programme on dementia needed to cover and the best methods to convey important messages.

Method

Study design

A qualitative methodology using focus groups was utilised to explore what features of a dementia education/awareness initiative adolescents perceived as important. Focus groups were considered an ideal methodology with adolescents as they would enable an exploration of a broad topic and allow participants to build on one another's ideas (Bryman, 2015).

Participants/Setting

Originally six focus groups were conducted in three schools and colleges in the North of England. To allow for geographical variability and to ensure data robustness (Bryman, 2015) a further two focus groups were conducted in one school in the South of England. A total of 42 adolescents participated in the focus groups with 3 to 7 participants per focus group. The majority of the students were female (76%) and were aged 12 to 18 years. With regards to ethnic diversity, the sample was mainly white British (66.6%), followed by British south Asian (29%), one student identified as ‘Asian/African’ and one student as Black British.

Procedure

Prior to data collection, ethical approval was sought and received from University ethics committees. Schools and colleges were approached via an introductory letter to the head teacher describing the purpose of the project and stating there would be a follow up to establish interest after two weeks. Of the three secondary schools and two sixth form colleges approached in the North of England, one secondary school and two colleges participated in the study. Once the head teacher confirmed the willingness of the school to participate, the heads of key stages 3 (age 11 to 14 years) and 4 (age 14 to 16 years) were introduced to the research team. The heads then disseminated the project information sheets to all form tutors. Students were randomly selected from a list provided by the form tutors to participate in the focus groups. Those selected were sent a letter, an information sheet and information for their parents or guardians. Parents were given an ‘opt out’ option whereby if they objected to their child participating in the research, they were given two weeks to notify the school and the research team. No parent chose to opt their child out of the process. Of the 60 students randomly selected, 42 agreed to participate in a focus group. Each school/college hosted two focus groups, which were facilitated by two researchers (either SP and SS or SP and AG). Prior to the discussion, each participant was given information about the project and informed consent was taken. Students completed a short demographic questionnaire containing questions pertaining to their age, gender, ethnicity, whether they had heard of dementia, if they knew anyone with dementia and whether this person was a family members, friend or other. Focus groups were audio recorded and transcribed verbatim. The length of focus groups ranged from 35 to 97 minutes.

For the additional two focus groups held in a single school in the South of England, similar procedures were followed to those held in the North of England. Notable difference include; the Deputy Head teacher selecting students based on a range of characteristics (e.g., age, gender, attainment), whilst all parents of all students "opted-in" to the research. The focus groups were run within the school with two researchers (NF and LJH).

Data analysis

Data was analysed using NVIVO v11 following Thematic analysis guidelines proposed by Clarke and Braun (2012). Thematic analysis was utilised due to the flexibility of the approach and the approach not being theoretically bound. Each transcript was repeatedly read and inductively coded. A series of codes was used to assign a conceptual label to sections of the transcripts. Further analysis allowed the identification of commonalities and contrasts and resulted in a more complex coding framework. The codes and definitions were discussed between the research team (SP, SS and AG) to facilitate data interpretation and key themes were developed.

Findings

Five key themes emerged from the data including: the importance of dementia awareness, topics of interest within dementia, methods of learning, the perspective of the person living with dementia and use of social media. Additional quotes illustrating themes are presented in Table 1.

The importance of dementia awareness

The majority of students perceived themselves to have very little knowledge of dementia and expressed an interest in learning more. Students discussed that there was more awareness of other illnesses and conditions and much media attention was given to other illnesses such as cancer. They thought a media driven campaign was required to improve dementia awareness. The facilitators mentioned Dementia Friends, a soap story focused on dementia and an Alzheimer’s Society TV advert, however only a minority of students were aware of these current campaigns. This suggests current public awareness campaigns have had a limited reach on a younger demographic and adverts should be screened during programmes that appeal to adolescents. Ten of the students had personal experience of dementia, that is their grand-parents had been diagnosed with dementia. They discussed how prior knowledge of dementia would have reduced the negative impact they had experienced observing grandparents living with dementia. They felt they would have been more prepared for the experience and would have been able to help family members if they had been more aware of the condition.

> *“In 2011 I sadly lost my grandad to dementia, but I never, because I was only 5 when it happened, I never really knew actually what kind of happened. When we used to go around there he used to like be playing the piano, he’d play table tennis with us and then it just kind of seemed over the course of a few weeks he kind of stopped doing those things and just got a bit more down in a way. Like, obviously I was so young I never really knew what went on during that. And I think it would be nice to teach children, obviously not so young, but teach children about what it is.”*
>
> (Focus group 7)

Topics of interest within dementia

As students felt they knew very little about dementia, they all expressed an interest in gaining a deeper understanding of the signs and symptoms associated with dementia. Many perceived dementia to be related to memory loss and older people, which they defined as those over the age of 60 years. A few students were aware of cases where younger people in their 40s had been diagnosed with dementia. An awareness of signs and symptoms was viewed as being important as it was related to being able to seek support early for family members. Students were interested in learning about the different types of dementia and confusion existed with regards to the difference between Alzheimer’s Disease and dementia. Four students also wanted to understand the prevalence of dementia in the general population.

The majority of students were also very keen to learn about the causes and risk factors of dementia and this was related to being motivated to reduce their own risk of developing dementia in the future. Seven students expressed an interest in wanting to know more about how to approach and communicate with a person with dementia. This was associated with their fear that their ignorance would offend the person with dementia or they may be perceived as intrusive. Students perceived that if they were able to effectively communicate with people with dementia, they would be able to support the person better. Students who had personal experience of dementia also stated that they would like to know more about available support for the person with dementia and family members.

> *“Its just like good knowledge to have, like just in case it comes about, then you know about it, and you don’t sound like ignorant, like you don’t care, like if you know about it, there’s more of a chance you can help someone”*
>
> (Focus group 2)

Methods of learning

Unsurprisingly, students tended to have a preference for interactive activity based learning over traditional lecturing. Interactive activities were perceived to lead to learning with a sustainable impact. Students also stated that such activities should have a novel element that would not be the norm in class room based activities to be memorable. Although students acknowledged that a dementia awareness initiative would require some ‘teaching’ to convey facts and figures, they felt room for discussion was important and would allow students to form their own opinions.

“I think if you get taught it and then you do an activity then that like reinforces it like then you defiantly understand it, but just them talking it just, it just goes out of the mind usually”

(Focus group 2)

The majority of students also perceived themselves to learn more effectively when working in small groups. This was related to anxiety caused when needing to come up with answers as an individual and judgement from teachers if they were unable to provide a correct answer. The group meant shared responsibility for answering questions and facilitating each other’s learning. However, a caveat to working in small groups was that students felt they could only work in small groups with people they already knew in order to feel comfortable and motivated to engage with learning about dementia.

Seven students suggested use of video clips to deliver key messages as audio/visual techniques helped them learn more effectively. Other suggestions included “simulation based learning” (an artificial scenario created to allow students to gain insight into the world from the perspective of the person living with dementia) which students had experienced as part of alcohol awareness week and also through work experience where students could spend time with people with dementia and scientists.

The perspective of person living with dementia

The idea of including the person with dementia in an awareness initiative in a school setting led to much debate. Most students agreed that incorporating the perspective of the person living with dementia was imperative to effective learning. It was felt that hearing directly from a person living with dementia would have a direct emotional impact on students and this would facilitate a deeper understanding of dementia and foster empathy. Students would receive a first-hand perspective of living with dementia and it would provide opportunities for asking questions and discussion.

Despite the acknowledgement of the importance of the perspective of the person living with dementia, students debated the method of contact with the person. Some students felt that a person with dementia would be incapable of delivering a lesson on dementia in school. Students' perceptions had an impact on their willingness to have direct contact with the person with dementia, with some assuming that the person would be 'very old' and it would be a negative experience for them; particularly because the person may become forgetful and confused and as a result very frightened in a classroom setting. They were apprehensive of how their peers would behave around the person with dementia and did not feel comfortable with the person being around students who misbehaved.

> *"P5: I dunno, if they keep repeating themselves, like us 14 year olds might not understand and might laugh that they've just said that, but it wouldn't be funny*
>
> *P3: yeah because if you're being mocked for what they've got then that would make you feel ashamed*
>
> *P1: yeah could lower their self esteem."*
>
> (Focus group 4)

Some students suggested video clips of people talking about their experiences of living with dementia would be a more suitable method of including the perspective of the person living with dementia. The majority of students agreed this would be a 'safer' method whereby students would gain a deeper understanding but the person with dementia would not be subjected to an uncomfortable situation. However some students thought that they would not be able to ask people living with dementia questions and discuss ideas. Facilitators asked students if they would be willing to engage with people living with dementia via social media. All students were willing to interact with people living with dementia via social media; however interestingly, many did not believe that people with dementia were capable of using social media. This was related to assumptions that older people did not use social media and as dementia was perceived to be associated with older people, people with dementia would not be capable of using social media.

Use of social media

A number of students suggested using social media to ‘modernise’ learning and gave examples of where other lessons had used social media to facilitate learning. However students felt it would be impractical to incorporate use of social media within a classroom session on dementia. They felt their peers could not be trusted with social media during a lesson and strict supervision would be required. Some schools also had rules about not using mobile phones during lessons. Social media was perceived as an effective method of engaging with young people and raising awareness on a wider scale. Students suggested that the following social media platforms to engage with young people: Facebook, Instagram and Snapchat. Twitter was considered by some to be confusing and more of an ‘advertising’ platform. YouTube was a popular choice amongst students, with many stating they enjoyed watching videos. One group indicated they would be interested in helping the research team to set up a YouTube dementia channel.

> *“P4: We need supervision!*
>
> *P1: to make sure we’re on the right tracks and we’re posting and tweeting about dementia and not One Direction (Laughs)”*
>
> (Focus group 1)

Insert Table 1 about here

Discussion

The aim of the study was to explore the dementia related educational needs of adolescents and a number of key recommendations emerged from discussions with adolescents aged 12-18 years. By exploring and addressing the educational needs of young people in secondary schools we are better placed to prevent the development of stigmatising views as such views develop during the lifespan (Werner et al, 2017). Adolescents expressed an interest in learning more about dementia and perceived awareness of dementia to be important within their age group. A significant number of the students had some personal experience of dementia and wished they had been more prepared. As such, it is important to reflect upon the aims of existing localised dementia awareness initiatives for young people (Di Bona et al, 2017; Nazir & Bangash, 2015; Parveen et al, 2015; Rylance & Pendleton, 2015, Atkinson & Bray, 2013) and identify how best to implement them on a wider scale. Most students expressed a desire to learn more about the risk factors associated with dementia and how to reduce one's own risk. This has clear implications for prevention and public health work. The findings are in line with the recommendations proposed by Riley et al (2915) who proposed public dementia education should include information about symptoms, how people with dementia can maintain a normal life, continue to enjoy life and maintain their individuality.

The findings suggest that an effective method of dementia education delivery is allowing students to work in small groups with known people, with opportunities for discussion and key messages embodied within interactive activities. This is in line with a recent systematic review (Surr et al., 2017), which found that dementia training was effective in changing the attitudes of health care professionals when delivered in small face to face groups, with discussion and activity based learning rather than a reliance on written material. Students also suggested that the activities should be novel to have a significant impact which is in line with the ‘Adopt a Care Home’ scheme (Di Bona et al., 2017). Interestingly, although students could see the benefits of being taught by people with dementia, many were cautious about involving the person with dementia for their own wellbeing. A systematic review by Corrigan et al (2012) found that direct contact with those with a mental health condition reduced stigma amongst adults but education was more effective in reducing stigma amongst adolescents. This suggests that incorporating the perspective of people living with dementia via video clips and education may be sufficient in reducing stigma amongst adolescents, however it is worth noting that as the studies focused on mental health as opposed to dementia, the findings may not be applicable. Adolescents did not discuss the possibility of peer education/mentorship but it may be an element that could be incorporated into dementia education for adolescents.

Although the discussions with adolescents have led to key recommendations for designing dementia education and awareness initiatives, there are a number of limitations within the current study worth noting. The recommendations are based on a small sample of 42 adolescents of which the majority were female. The issue of social desirability is a concern when using a focus group methodology as adolescents may have not felt comfortable disclosing a lack of interest in dementia amongst their peers. In addition, it was difficult for students to discuss topics for an awareness initiative as they had very little knowledge of dementia. The study did not include the perspective of teachers or people living with dementia, who could provide further insight into important topics and teaching modalities. Future dementia awareness initiatives aimed at students should be co-designed with adolescents, teachers and people with dementia. Importantly, there is a need for a transparency in terms of the development and benefits of dementia awareness initiatives. Further work is also required to establish specific misconceptions held by students and how best to overcome such prejudices.

In summary, the study has highlighted the need for specific dementia awareness initiatives aimed at adolescents, key messages for such initiatives to include, and how to deliver such messages.

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None to declare

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Table 1. Additional quotes illustrating key themes emerging from focus group discussions.

Theme	Quote
Importance of dementia awareness	“*like everything my friend learnt about dementia was from experience and her grandma having it so obviously with her not knowing anything before like watching the symptoms progress and stuff had a massive impact on her coz she didn’t have any idea what was going to happen so I think if she were educated about it when she were younger then she could have, obviously it still would have made her really upset but I think she would have been able to brace herself and like expect it coming so prepare herself emotionally”*
Topics of interest within dementia	“The risk factors and the common knowledge about it, what you can do to prevent it and what you can do to keep yourself safe from it or stuff”
Methods of learning	“Sometimes with teachers you may feel a little anxious because they may think you're a bit stupid or something, but when it's your peers you're alright cause they'll like laugh at you but they're like "actually no I don't understand that either"
Perspective of person living with dementia	“I think if there was a person in my class teaching us, if it was a dementia person talking to us about how it is, I'd feel like "oh I'm a bit more interested because now I understand the real perspective". Because obviously we don't have dementia so we don't really have 100% understanding on how it is.”
Use of Social media	“Like the classes should be more modernised, because as a generation we are getting more into like social media rather than just sitting down at a desk and writing things, cause that's not how we learn anymore”.