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Initial evaluation of a university dementia awareness initiative.

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Abstract

Purpose: This paper describes a study which explored the knowledge and attitudes of university students towards people living with dementia, and developed and tested a dementia awareness workshop, Dementia Detectives: University edition, designed to improve knowledge and foster positive attitudes to dementia in students.

Design/methodology/approach: Dementia Detectives: University edition was launched during Dementia Awareness Week and five workshops were delivered to university students. Forty-two participants attended and completed a knowledge and attitude measure before and after the workshop, as well as rating the workshop with regards to satisfaction, relevance, understanding and whether they would recommend the workshop to friends.

Findings: Students perceived living with dementia to be a negative and stigmatised experience. The workshop scored highly in terms of satisfaction, relevance and understanding and all students stated they would recommend the workshop to others. Paired t-tests found significant improvements in self-assessed dementia knowledge.

Research Limitations: This was a pilot evaluation and further testing with larger samples is required.

Practical implications: The workshop meets the requirements for tier 1 dementia education and training as outlined in the Dementia Core Skills and Knowledge Framework published by the Department of Health.

Social implications: The workshop has the potential to increase knowledge, change attitudes, improve empathy and contribute to the development of a dementia aware workforce through undergraduate education.

Originality/value: Dementia Detectives: University edition is a novel interactive method of dementia education and training.

Article Type: Research

Keywords: Dementia training; Attitudes; Stigma; Knowledge; Dementia awareness

Background

In 2015, there were 46.8 million people in the world living with dementia and this was predicted to increase to 131.5 million by 2050 (Alzheimer's Disease International, 2016). In the UK, there are currently 850,000 people living with dementia with numbers set to increase to 2 million by 2051 (Alzheimer's Society, 2015). The ageing world population with its implications for increases in numbers of people with dementia, has led dementia to become a global (G8 summit, 2013) and national priority (National Dementia Strategy, 2009; PM Challenge, 2012, 2015). Key features of the National Dementia Strategy in the UK are to address the stigma attached to dementia by raising public awareness and providing effective dementia education and training for health and social care professionals.

The term stigma originates from the late 16th century and is used to describe a state of disgrace marking an individual apart from others in a community (Goffman, 1968). Mukadam and Livingstone (2012) describe four major factors contributing to the stigma associated with mental illness including perceptions that: people with mental illness are dangerous, are personally responsible for succumbing to their illness, have a poor prognosis and that the illness causes a severe disruption of normal social interaction. Despite dementia being a neurological condition, it is often met with the same fear and misunderstanding as mental illnesses.

The basis for the stigma associated with dementia, such as lack of knowledge, has been well explored. A systematic review by Cahill et al (2015) identified 40 articles exploring public attitudes and knowledge of dementia, in the UK, America and Australia. The studies highlighted a moderate level of dementia knowledge, with a common misconception being the assumption that memory problems were a normal part of ageing. The studies highlighted public lack of clarity about the point at which memory problems were significant enough to indicate dementia. Vernooij-Dassen et al (2005) highlight that prompt recognition

of symptoms may aid a timely diagnosis of dementia. The authors estimated that there was typically a delay of 30 months between the person and relatives recognising the symptoms of dementia and seeking a medical diagnosis. Yet the stigma associated with dementia may prevent people from using post-diagnostic support and as a result people may only turn to health care services at crisis point, which is more costly for the National Health Service. Timely diagnosis could be improved through public awareness campaigns.

The increasing recognition of the stigma associated with dementia and its impact on those living with the condition and family members (Bamford et al, 2014) has led to political drivers for the development of public dementia awareness programmes such as the Alzheimer's Society's national Dementia Friends campaign and the formation of the Dementia Action Alliance to develop Dementia Friendly Communities. It is believed that by improving the understanding of dementia, the stigma surrounding the condition can be reduced. The Dementia Friends programme has received a great deal of attention but evidence of impact to date is limited.

Baillie et al. (2015) suggested that student nurses usually have limited contact with people living with dementia, and may hold the same stigmatised views of dementia as the general public. They evaluated the impact of Dementia Friends on 418 student nurses and reported a positive reaction to the programme and an improvement in knowledge. Mitchell et al. (2016) also reported on the impact of Dementia Friends on 322 undergraduate nursing students. They reported 40.79% of the nursing students stated 'very good' improvements in their knowledge. One recent study by Adefila et al. (2015) reported on a training programme 'My Shoes' which aimed to change attitudes and develop empathy for people living with dementia. The virtual reality, experiential learning programme was delivered to students of health professions and was found to change the way students perceived people with dementia and consequently also changed care practices. The literature suggests that much dementia

awareness training has been aimed at trainee health care professionals. Further dementia awareness work is required with non-health care professional students in order to build and sustain a dementia friendly younger generation.

Dementia Detectives: University Edition

Dementia Detectives was originally developed as an awareness initiative for secondary school students aged 14 to 16 years (Parveen et al., 2015). The hour-long dementia awareness workshop received positive feedback from schools and gained a large following of over a thousand people on social media. The new version for university students described here was developed and launched as part of Dementia Awareness Week in 2016. The aim of Dementia Detectives is to foster positive person-centred attitudes towards those living with dementia amongst young people and encourage involvement in a dementia friendly community. The detective theme is incorporated into the workshop as a metaphor underlying the notion of dispelling the myths surrounding dementia and uncovering the truth, whilst working in teams. The workshop is delivered by a knowledgeable facilitator and involves a number of interactive activities. Dementia Detectives: University Edition retained the original aims and philosophy of Dementia Detectives but was redesigned to appeal to an older student audience. The current article describes the pilot phase of developing and implementing the University edition.

The first two levels of Kirkpatrick's (1984) four-level model for evaluation of training interventions was used to evaluate the impact of the workshop. This model has been widely utilised for evaluating the impact of training (Surr et al, 2017). The four levels are:

1. Reaction – learners' reaction to and satisfaction with, the workshop

2. Learning - the extent to which learning has occurred, including changes in knowledge and attitudes

3. Behaviour – extent to which behaviour has changed as a result of the workshop

4. Results – impact of training on outcomes for people with dementia and their families.

The aims and objectives of this pilot study were:

1. To test the feasibility and acceptability of delivering Dementia Detectives: University Edition at a university
2. To establish baseline attitudes and knowledge of dementia amongst university students
3. To use Kirkpatrick's model to evaluate the impact of Dementia Detectives: University edition across levels one and two (reaction and learning)

Method

Participants

The workshop was open to all students at a university in the North of England irrespective of degree/subject being studied or level of study (undergraduate or post graduate). The workshop was advertised through posters and leaflets displayed on the campus in the weeks prior to Dementia Awareness Week. Interested students were invited to sign up to one of five workshops scheduled during Dementia Awareness Week.

Evaluation methodology

Pre questionnaire: Students were asked to rate on a scale of 1 to 10 how much they felt they knew about dementia. A Dementia Knowledge Questionnaire consisting of 11 items rated on a 5-point Likert scale (strongly agree to strongly disagree) was developed to assess student perceptions of their levels of knowledge before the workshop took place. The items were based on the awareness level competencies outlined in the Dementia Core Skills and

Knowledge Framework (2015; see table 3 for details). This framework was commissioned and funded by the Department of Health and developed by Skills for Health and Health Education England. The purpose of the framework is to standardise dementia education and training for the health workforce by providing key competencies to be covered by training. The Framework is applicable to health care professionals and educational organisations which train students who will subsequently be employed in the health care sector. After completing this 11-item measure, students were asked to state their age, gender and subject of study.

Post questionnaire: Following the workshop, students were asked to complete a further copy of the Dementia Knowledge Questionnaire. In addition they were asked to use a 5-point Likert scale to rate their satisfaction with the workshop, how relevant they perceived it to be, their understanding of the materials, and their likelihood of recommending the workshop to peers. Students were also asked open ended question with regards to which features of the workshop they enjoyed the most and how the workshop could be improved.

Delivery of the workshop (procedure)

Prior to delivery of the workshop, ethical approval was sought and granted by the University ethics committee. Anonymity was ensured through the use of numerical codes to match pre and post questionnaires. At the beginning of the workshop, participants completed the time 1 questionnaire and were then split into five 'detective teams'. The activities of the workshop are outlined in table 1. Once the workshop was complete, students were asked to complete the post-workshop questionnaire, were given a list of further sources of information and support and encouraged to engage with the workshop's social media accounts (Dementia Detectives has an active Twitter and Facebook account).

Insert Table 1 about here

Data analysis

The data collected during Operation POD (see table 1) were analysed using thematic analysis (Clarke and Braun, 2014) to establish baseline attitudes and perceptions of dementia. Data collected during Operation Action were also analysed using thematic analysis to establish the impact of the workshop on participant behaviour. Questionnaire data were analysed using basic descriptive and paired t-tests. Open ended questions were analysed using content analysis (Elo & Kyngas, 2008).

Results

Sample

One hundred and fifty free tickets were made available for the 5 workshops and 105 students signed up to attend, with 42 attending the workshop. Thirty-two participants were female and 10 were male, with an age range from 18 to 58 years. Those attending the workshop were studying: clinical sciences (n = 9), nursing (n = 7), social work (n = 7), psychology (n = 6), pharmacy (n = 3), management (n = 3), engineering (n = 2), research (n = 3) and unknown (n = 2).

Attitudes

Responses to the question posed in Operation POD, 'What do you think of when you hear the word dementia?' were thematically analysed and organised into eight main themes.

Types of dementia

Many of the groups listed types of dementia, with Alzheimer's disease being the most common, followed by Vascular dementia and Young Onset Dementia. One group recognised that dementia was an umbrella term for over one hundred types of dementia.

Signs and symptoms

All groups associated dementia with memory problems, which was the most commonly cited symptom. This was described as: *'forgetfulness'*, '*memory loss'*, *'living in the past;* and *'not being able to recognise people'*. Other perceived signs and symptoms were associated with cognitive decline, communication and decision-making problems including *'confusion'; 'unaware of surroundings', 'repetitive speech', 'loss of vocab '* and *'regression'*. Physical symptoms such as *'incontinence', 'weight loss'* and *'loss of motor skills',* along with psychological and behavioural expressions such as *'depression', 'changes in personality', 'paranoia'* and *'hallucinations', 'violence', 'wandering',* and *'agitation'* were also listed by the groups as signs and symptoms.

Causes of dementia

The majority of groups attributed a biological cause for dementia, suggesting *'neurons lose connections', 'brain deterioration', 'amyloid beta plaques'* and *'tangles'*. Two of the groups also suggested that there was a possible genetic link, using the terms *'risk gene'* and *'deterministic gene'*. In addition to attributing a biological cause, almost all groups believed that dementia was caused by *'old age'* along with co-morbidities and life style choice.

Disease timeline

There was common agreement that dementia was a *'progressive'* condition, which caused people to *'deteriorate'* and *'degenerate'* over time. Despite disagreement on the time frame in which this occurred, some suggesting it was *'slow'* and others suggesting it was *'fast'*, it was clear that participants considered dementia to be progressive. Terms such as *'care', 'assisted living', 'care home', 'hospital', 'palliative care'* and '*death*' were often used to describe the later stages of dementia.

Experience of living with dementia

All the groups considered the experience of living with dementia to be negative, with terms such as: *'sufferer', 'stressful', 'frustration', 'vulnerable', 'loss of self,; 'worry', 'distress', 'drain'* and *'traumatic'* commonly used. Many also considered dementia to be associated with an increased risk of *'social isolation', 'reduced relationship'* and an *'increased risk of harm'*. None of the groups suggested any positive aspects to living with dementia. For many, their negative perceptions led to a stigma being attached to those living with the condition, with many groups suggesting people were: *'hidden', 'under-rated' and 'confined'*.

Emotional impact

All of the groups mentioned the emotional impact that dementia might have on the person living with it. Many of the words they used had negative connotations, such as *'fear', 'denial', 'anxiety'* and *'anger'*.

Impact on others

Participants readily talked about the impact that dementia might have on both the person and their wider family with key phrases such as *'hard work, 'supervision'* and *'frightening to the family'* being used.

What helps?

While the groups had mainly negative perceptions about dementia, some indicated: *'getting enough support', 'receiving treatment to slow down symptoms', 'treating people with dignity', 'developing coping mechanisms', 'getting enough sleep'* and *'getting the right diet'* might help.

Impact of Dementia Detectives: University Edition

Reaction

Ratings on the 5-point Likert scale for satisfaction, relevance, ease of understanding and recommendation to others, were found to range between 4 and 5 (i.e. satisfied to very satisfied). The mean scores for participant satisfaction and relevance were 4.55 (SD = 0.50), there was a mean score of 4.75 for understanding (SD = 0.44) and a mean score of 4.70 (SD = 0.47) for recommendation. Participants indicated that the main positive aspects of the workshop were: interactive activities, group work and the informative aspect (see Table 2). Six participants suggested ways that the workshop could be improved, including: further information on types and causes of dementia, statistics on dementia prevalence, a question and answer session at the end and an information pack for participants to take away.

Insert Table 2 about here

Learning

Participants' ratings of their perceived knowledge of dementia increased from before (M = 4.44, SD = 1.96) to after the workshop (M = 7.83, SD = 1.46). A paired t -test revealed a significant increase in self-assessed knowledge after the workshop (t (41) = -13.30, p < .001). Further paired t-tests on each knowledge item revealed significant improvements (see table 3). The largest change was for the item 'I can give people advice on how they can live well with dementia'.

Insert Table 3 about here

Behaviour

In the final workshop activity participants were asked what 'What can you do to support someone living with dementia?' Responses were divided into four main themes:

Attitudinal behaviour

Students' talked about changing their attitude towards people living with dementia and reported they would be '*more considerate'*, '*caring*' and '*empathetic*'. '*Keeping calm'*, '*having patience*' and trying to understand the person by '*putting themselves in their shoes'* were strategies they suggested using to achieve this. Students also said that '*not jumping to conclusions*' or '*taking things too personally'* would help them to react more positively. Other actions included: '*not talking down to people*' or '*becoming easily annoyed*'. One group said they would '*not mock somebody living with dementia*'.

Practical behaviour

All of the groups listed at least one practical action they would do to assist someone living with dementia. Responses ranged from broad actions, such as raising awareness about dementia, to simple actions like helping someone with their shopping or on public transport. There was a consensus that these actions could be achieved by talking to the person to find out how they could help and providing assistance where possible. This required students to get to know people living with dementia in their community. The students' suggestions about how they would do this included '*listening to their wants and needs*', '*giving them choice*', '*providing reassurance*', '*talking at a slow pace*', '*repeating questions*', '*being consistent*' and '*providing routine*', '*smiling*' and '*being polite and friendly*'. A clear message from students was that people living with dementia should be facilitated to live as independently as possible. They also suggested that the responsibility to help should be shared among friends and family members with a clear care plan to be drawn up.

Social environment

A number of groups suggested changes to the person's social environment could support someone living with dementia. They were conscious about the risk of social isolation, suggesting '*regular conversation*' and '*interaction with others*'. Stimulating and challenging activities such as '*talking about the past*', '*looking at photo albums and memorabilia*' were

suggested as a way to facilitate this. Many felt '*learning about a person's background was essential*'. Informing neighbours that someone has dementia was mentioned as a good way to ensure they did not become socially isolated.

Physical environment

Some groups thought ensuring people lived in a safe environment was essential to enabling them to live well with dementia. They suggested '*regular risk assessments*' and adaptations to environment should be carried out. Making '*clear signs and instructions'* were specific examples of how they could improve the physical environment.

Discussion

The purpose of this pilot study was to establish the knowledge and attitudes of university students with regards to dementia, to test the feasibility and acceptability of a dementia awareness workshop and to evaluate the impact of the workshop on knowledge. Workshop participants had some pre-existing knowledge of dementia, recognising it as a neurological condition with cognitive, psychological and physical symptoms. However negative stereotypes and attitudes were evident. Students voiced two specific misconceptions: dementia was perceived to occur only in old age and people living with dementia were thought to be aggressive. Participants expressed very negative perceptions of life with dementia, believing that people with dementia have a very poor quality of life and that it is not possible to live well with dementia. They also associated significant stigma with dementia.

This suggests dementia awareness programmes should focus on challenging these misconceptions, and particularly promote living well with dementia in order to reduce the stigma associated with the condition. Within the current study, once the facilitator established the attitudes of the group during the 'warm up' activity (Operation POD), specific

examples were used during the workshop to challenge these views. This demonstrates the flexible nature of the workshop, but also highlights that it is important for a facilitator to have experience/knowledge of dementia.

The workshop was well received by students and scored very highly on the 4 satisfaction questions. The students were particularly positive about the interactive activities and group work and the detective theme worked well. Based on participant feedback, the workshop will be adapted to include further information on prevalence and causes of dementia. It is important when tackling stigma and prejudice to offer direct contact with the stigmatised group where possible. Direct contact with people with dementia is an evidence-based method of reducing stigma with a number of anti-prejudice campaigns being based on this approach (Corrigan et al, 2012). To achieve this, we recommend the workshop is co-delivered, where possible, with a person living with dementia. Where this is not possible, a video maybe used instead. Within Dementia Detectives, the video was very well received.

The before and after measures revealed that learning had occurred with significant self-reported improvements in knowledge. Participants also indicated a range of behaviours and actions they would be willing to perform to support a person living with dementia in the community. It should be noted that although participants were able to give examples of how they could change their behaviour, this does not indicate behaviour change, therefore information about the actual impact on behaviour is limited and challenging to ascertain. Despite initial data suggesting a positive impact, further evaluation with a larger sample of students and longer follow-up is required, using validated measures of knowledge and attitudes. Further thought with regards to how the fourth level of Kirkpatrick's evaluation model, i.e. the impact on people with dementia themselves, could be addressed is also required. The challenge of measuring impact on people living with dementia is pertinent to all dementia awareness initiatives and is not exclusive to the current workshop.

Although initial evidence suggests that the workshop had a positive impact on student knowledge and attitudes, only 42 of 105 registered students attended. However it should be noted that delivering the workshops during Dementia Awareness Week limited the availability of students, as many had already left campus for the summer break. This highlights some disadvantages for student populations of tying dementia awareness initiatives to the designated national Dementia Awareness Week. This also explains the high level of initial interest (105) and high level of attrition before attendance. It was not possible to deliver the workshops prior to Dementia Awareness Week due to the university hosting a range of other activities for students and staff. This highlights the importance of the context of the University calendar in influencing success of this type of cross-campus initiative.

The workshop was aimed at all university students but mainly attracted students from disciplines related to health (psychology, clinical sciences and nursing). A key recommendation of the Dementia Core Knowledge and Skills Framework is that tier one dementia education (dementia awareness programmes) should be incorporated into the undergraduate curricula of undergraduate degree programmes within the health and social care field. This would thus address a key priority of the National Dementia Strategy (2015), to provide effective training and education to health and social care professionals. The current workshop meets the required learning outcomes for a tier 1 dementia awareness training package. The lower levels of interest from other fields suggest further active engagement is required prior to delivering dementia awareness workshops. The workshop was promoted for only one week prior to dementia awareness week using passive engagement strategies (posters) and more active engagement strategies might draw in a wider range of students.

In conclusion, preliminary data suggests Dementia Detectives: University edition is acceptable to university students, and has a significant positive impact on knowledge and attitudes. It has the potential to be adapted and delivered as part of undergraduate health

related degree programmes, thus contributing to the development of a knowledgeable and competent dementia workforce and a dementia friendly society.

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Table 1. An outline of Dementia Detectives: University Edition activities

Activity name	Length of activity (minutes)	Activity outline
Operation POD (Perceptions of Dementia)	5 minutes	Each team is asked to write down what they thought of when they heard the word dementia. This provided a baseline assessment of participants' attitudes and provided the facilitator with specific misconceptions (for example 'people with dementia are aggressive') to address in the remainder of the workshop.
Living with dementia	5 minutes	Participants are asked to watch a video of a person with young onset Alzheimer's disease discussing how she lives well with dementia and what facilitates this. This was presented early in the workshop so that the person was featured before the condition (a key objective of the workshop). The participants discuss their thoughts on the video.
Dementia busted	10 minutes	A short talk on the signs and symptoms of dementia (with the facilitator stressing that each person's experience with dementia is unique), types and causes of dementia, the process of diagnosis, activities that support people to live well with dementia, and risk factors.
Operation HACK	5 minutes	Each team is presented with an encrypted message which they have to decipher as a team to reveal key messages such as 'dementia is not the same as ageing'
The power of words	5 minutes	A short session on positive imagery and language in dementia (for example avoiding terms such as demented, dementia victim, dementia sufferer) and presentation of the 'Dementia Empowerment and Engagement Project' guidelines on appropriate language.
The Case of Joy Jones	20 minutes	Within this case study, a fictional person living with dementia (Joy Jones) is described as behaving aggressively and the teams are asked to discuss potential explanations for Joy's behaviour. Each team is given a clue representing a different aspect of the biopsychosocial model; for example, to represent the health aspect of the model the team was presented with the clue 'Joy suffers from migraines'. After discussion, the participants were presented with the full biopsychosocial model to demonstrate that Joy's behaviour may not be due to dementia alone but that her unique experience could be explained by the interaction of neurological impairment with a range of other factors.
Operation 'In Their Shoes'.	5 minutes	The purpose of the activity was to encourage empathy for people with dementia. Participants were asked to

		close their eyes whilst the facilitator read a scenario in which a student at university had to navigate various stressful situations on campus on their first day. The participants were asked how this situation would make them feel and the facilitator linked this to how people with dementia may experience similar emotions during their day.
Operation Action	5 minutes	Participants watched an Alzheimer's Society video showing a person with dementia navigating their day and illustrating how members in the community performed small actions to empower and enable the person to be independent. The video was followed by participants writing down actions they would be willing to perform to support a person with dementia.

Table 2. Summary of workshop aspects participants highlighted as being positive

What was the best bit of Dementia Detectives: University edition	Number of times mentioned
Interactive activities	13
Informative	9
Group work	7
Real life scenarios/videos	7
Engaging/interesting	5
Positive messages	5
Accessible	4
Useful for application	3
Range of activities/ learning materials	2
In their shoes activity (empathy)	2
Good length	1
Good method to raise dementia awareness	1
Friendly presenters	1
Broad range of information	1

Table 3. Pre and post workshop scores on knowledge items

Knowledge item	Pre workshop Mean (SD)	Post workshop Mean (SD)	t	df	p
How much do you feel you know about dementia?	4.44 (1.96)	7.83 (1.46)	-13.24	35	.001
I would be able to explain to someone else what is meant by the term 'dementia'	3.57 (0.94)	4.57 (0.50)	-6.26	41	.001
I don't know what the prevalence of dementia in the UK population is	3.66 (1.27)	2.77 (1.28)	3.49	40	.001
I would be able to recognise the signs of dementia in a person	3.12 (1.00)	4.29 (0.60)	-6.59	40	.001
I am unsure as to what people can do to reduce their risk of developing dementia	3.54 (1.10)	1.90 (0.97)	7.72	40	.001
I would be able to explain why early diagnosis of dementia is important	3.05 (1.13)	4.31 (0.60)	-7.55	41	.001
I can give people with dementia advice on how they can live well with dementia	2.45 (1.13)	4.33 (0.57)	-10.39	41	.001
I would be able to give others reasons why it is important to recognise the person with dementia as a unique individual	3.38 (1.27)	4.60 (0.50)	-6.35	41	.001
I am not sure what the impact of dementia is on a person and their family	3.02 (1.16)	1.74 (0.77)	7.22	41	.001
I don't have the skills I need to use to be able to communicate effectively and compassionately with people who have dementia	3.36 (1.08)	1.83 (0.76)	9.28	41	.001
I understand reasons why a person with dementia may show signs of distress	3.79 (1.02)	4.69 (0.47)	-5.82	41	.001
I know where and how to signpost people, families and carers to dementia advice, support and information if they need it	2.88 (1.23)	4.19 (0.74)	-6.45	41	.001