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Title: **Adopt a Care Home: an intergenerational initiative bringing children into care homes**

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The authors confirm that there is no conflict of interest.

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Adopt a Care Home: an intergenerational initiative bringing children into care homes

Abstract

Dementia friendly communities, in which people living with dementia actively participate and those around them are educated about dementia, may improve the wellbeing of those living with dementia and reduce the associated stigma. The Adopt a Care Home scheme aims to contribute towards this by teaching schoolchildren about dementia and linking them with people living with dementia in a local care home. Forty-one children, ten people living with dementia and eight school / care home staff participated in a mixed methods (questionnaires, observations, interviews and focus groups) evaluation to assess the scheme's feasibility and impact. Data were analysed statistically and thematically. The scheme was successfully implemented, increased children's dementia awareness and appeared enjoyable for most participants. Findings, therefore, demonstrate the scheme's potential to contribute towards dementia friendly communities by increasing children's knowledge and understanding of dementia and engaging people living with dementia in an enjoyable activity, increasing their social inclusion.

Adopt a Care Home: an intergenerational initiative bringing children into care homes

Introduction

Up to two thirds of residents in care homes live with dementia in the United Kingdom, making up a large proportion of the 850,000 people estimated to have the condition (Alzheimer's Society, 2014a). Enabling people with dementia to 'live well' in care homes with an improved quality of life is a national priority (Alzheimer's Society, 2013a, Department of Health 2009). To improve quality of life, National Institute for Health and Care Excellence guidelines recommend older people in care homes are provided with opportunities to maintain and develop social relationships, engage in leisure activities and contribute to their community (National Institute for Health and Care Excellence, 2013).

However, these opportunities are often unavailable and people living with dementia do not always receive high quality care (Care Quality Commission, 2014; Owen & Meyer, 2012). To address these and other shortcomings in dementia care in England, a National Dementia Challenge was established which had as one of its aims to improve quality in care homes for people living with dementia and increase their connection to their local community (Department of Health, 2012, 2015, 2016). The challenge encouraged the development of dementia friendly communities, where people living with dementia are empowered to contribute to and be included within society, to improve their wellbeing and reduce stigma associated with dementia (Alzheimer's Society 2013b; Department of Health, 2012, 2015, 2016). Similar initiatives are ongoing across the world, sharing a common goal to increase understanding around dementia in order to reduce stigma and social isolation for

those with the condition (Alzheimer's Australia, 2013; Alzheimer's Disease International, 2012).

Intergenerational initiatives

Intergenerational initiatives, where children interact with people living with dementia, may contribute to dementia friendly communities in three ways. Firstly, educating children about dementia may reduce stigma (Alzheimer's Society 2014b; Alzheimer's Disease International, 2012; Department of Health 2016). Secondly, engaging people living with dementia in an activity where they are helping children learn may contribute to their wellbeing, provide a sense of purpose and increase social contact (Galbraith, Larkin, Moorhouse & Oomen, 2015). Lastly, intergenerational initiatives may increase the social inclusion of care home residents, thus offering a positive, sustainable way of drawing on the community to achieve benefits for people living with dementia, children and wider society, at very little additional cost.

Despite their potential, the practice of and research into intergenerational initiatives involving people living with dementia is limited (Galbraith et al., 2015). In England, a few dementia awareness initiatives involving children have been established and received mostly positive feedback in terms of increasing children's knowledge about dementia, although their evaluation has been limited (Nazir & Bangash 2015; Parveen, Robins, Griffiths & Oyebode, 2015; Rylance & Pendleton 2015). A larger initiative, involving nineteen schools found a number of positive outcomes, including children's increased dementia awareness, knowledge of how to help people living with dementia, reduced stigma and fear and increased awareness and appreciation

of unpaid carers (Atkinson & Bray, 2013). A larger scale scheme to educate children about dementia in Australia is being implemented, but has not yet finished its evaluation (Baker et al., 2017). However, none of these schemes has focussed on providing immediate benefit for people living with dementia.

Other intergenerational initiatives have focussed more on benefits for people living with dementia. These have involved people living with dementia and children engaging in a diverse range of activities together, including art, music, games, educational and mentoring activities (Galbraith et al., 2015). Many benefits for people living with dementia have been reported, including: improved wellbeing or mood (Chung 2009; George 2011;Jarrott & Bruno 2003; 2007; McNair & Moore, 2010); reduced stress (George 2011; Jarrot & Bruno, 2007); increased social interaction and activity (George 2011; Jarrott & Bruno 2007) and improved sense of purpose, growth, confidence or pride (George 2011; Jarrott & Bruno 2007; Skropeta, Colvin & Sladen, 2014; Whitehouse & Whitehouse, 2005). However, there is a lack of certainty around generalizability from these studies because effect sizes are generally small, or reported inconsistently across participants or outcome measures (George 2011; Skropeta et al. 2014). These studies also have limitations to their methods: many have small sample sizes (George 2011; Skropeta et al., 2014) or have no control group with which to compare the effects of the scheme (Chung 2009; Skropeta et al,. 2014).

Whilst both sets of schemes demonstrate potential benefits, only the minority have been evaluated for the impact on both people living with dementia and children,. A

number of challenges to practical implementation have been reported, including concerns from carers of both participant groups about potential negative impacts of participation and difficulties encountered in selecting appropriate activities to facilitate collaborative engagement from all (Jarrott & Bruno 2003; 2007). Further research into the outcomes and implementation of intergenerational initiatives is indicated to increase confidence that outcomes are positive, understanding of the impact of contextual factors and to inform development of evidence based best practice guidelines (Galbraith et al., 2015).

A new intergenerational initiative: the Adopt a Care Home scheme

The Adopt a Care Home scheme was devised by an English city council as part of its aim to become a dementia friendly community (Channel 4 News, 2015; Wallace & Horner, 2014). It aims to increase children's dementia awareness and improve wellbeing and community participation for people living with dementia in care homes (Wallace & Horner, 2014). The scheme involves teaching schoolchildren about dementia and linking them to people living with dementia in care homes. Schools and care homes deliver the scheme in partnership, adhering to a flexible "specification" that allows content and format of school and care home based sessions to be adapted to local circumstances (Wallace & Horner, 2014). Usually the scheme consists of a year group of children receiving one school term of regular lessons focussed on dementia, as part of their personal and social health education. These lessons focus on educating children about dementia, explaining what it is and how it affects people who live with it, using case studies and experiential games as well as more formal teaching of facts. As many children as practicable participate in

a few intergenerational sessions within a care home, completing lifestory books with people living with dementia, chatting and sharing refreshments. Generally children are aged nine or ten and care home residents have mild to moderately severe dementia (with some verbal communication). The scheme was piloted with one school / care home partnership in a city in the north of England and evaluated. The teachers taught themselves about dementia, under the guidance of the city council.

Aims

1. Does the Adopt a Care Home scheme increase primary schoolchildren's awareness and knowledge of dementia?
2. Does the Adopt a Care Home scheme engage (interest / provide enjoyment for) people living with dementia in care homes?
3. Can the Adopt a Care Home Scheme be delivered safely and feasibly by a school / care home partnership?

Method

Study design

This evaluation was completed to study a single intergenerational initiative in its real life context, without changing practice, thus suiting a case study design (Yin, 2014). Mixed methods were selected as considered most appropriate for research into complex interventions that are not well described or understood in terms of benefits, best methods of evaluation and processes and mechanisms of delivery (National

Institute of Health Research School for Social Care Research, 2013; Yin, 2014). Methods were chosen pragmatically, to integrate within the four months of scheme delivery and strike the optimal balance between gaining high quality data and minimal intrusion and burden for those participating in and delivering the initiative.

Participants

Participants came from one school and their partnered care home, which agreed to be the pilot site for the Adopt a Care Home scheme. There were three groups of participants:

1. *People living with dementia.* Ten people living with dementia were purposively selected by care home staff, on the basis of being likely to enjoy interaction with children and unlikely to be disruptive. All were white British, four men and six women, with an age range of seventy to ninety. Three of the ten were described by the staff as having mild, five as having moderate and two as having severe dementia.
2. *Children*. One year group of children, 41 children, aged nine or ten, was chosen by the school as the most appropriate to take part in the scheme. A subsample of sixteen were purposefully selected by the school to visit the care home, on the basis of having demonstrated most interest in dementia. Of the sixteen, nine were girls and seven boys, eleven were white British and five from a mix of other ethnic backgrounds. Thirteen of these also participated in a focus group.
3. *Staff*. Two care home managers and two class teachers were responsible for delivering the scheme and participated in interviews. A number of other staff were involved in its delivery, four care home support workers were

purposively selected by their managers to participate in interviews for reasons of convenience of availability whilst trying to represent a range of opinions on the scheme. The total staff group of eight consisted of five women and three men, all white British.

Data collection

Four methods employed.

1. Questionnaires. Questionnaires were selected as a quick and inexpensive established method of gaining information about people's subject knowledge (De Vaus, 2001). The dementia awareness questionnaire (Alzheimer's Society, 2014b) devised for children was chosen as the most appropriate off the shelf measure available and was administered by teachers in class (pre- and post-curriculum). It is a twelve item questionnaire, combining multiple choice and open questions, see table one. Answers scored one point if accurate, half a point if partially accurate and zero points if inaccurate.

2. Non-participant observations. Non- participant observations have been proposed as an effective method for gathering data about wellbeing, affect and scheme experience in people living with dementia (George 2011, Snyder, Ryden, Shaver, Wang, Savik et al. 1998; University of Bradford, 2008). No suitable existing measure was found, so the first author devised a new one to structure data collection, with the content informed by existing dementia observation measures (e.g. Snyder et al.,1998; University of Bradford, 2008). The one page tool had the following headings (and prompts): facial expression, eye gaze (focussed on task / other person/ where?), speech (initiation, responses, content), body language (positioning, relaxed / tense, hands, feet), behaviour

(wandering, seated, responsive to task, sharing items, note taking), other. The two researchers observed half the participants each, focussing their time on one group of people living with dementia and children at a time, aiming to allocate equal time to each group but also allowing some time to observe the session as a whole. Researchers discussed the observations both in advance and at the end of each session to improve consistency of data recording.

3 Semi-structured interviews. A topic guide was devised by the first author to capture staff perceptions on the scheme, its implementation and impact. It consisted of eight questions about positive and negative aspects of the scheme, experiences of participation for participants and facilitators, also suggestions for scheme improvement. In order to increase acceptability and convenience of interviews, the four care home support staff were interviewed individually. The two teachers were interviewed together by two researchers and the two care home managers together by one researcher. Notes were taken during all interviews, the manager and teacher interviews were audio recorded and transcribed.

4 Focus group. Focus groups have been recommended as a method for gaining data from participants, like children, who might be intimidated if interviewed alone, they also allow representation of opinion from a range of people and the development of ideas between them (Carter & Henderson, 2005). A topic guide was devised by the first author to capture children's opinions on scheme participation and attitudes towards people living with dementia. The group was facilitated by two researchers. Ground rules were explained and reinforced at regular intervals. To enhance communication, children were sometimes asked to express their opinion by choosing the most appropriate of three face cards – smiley, neutral and sad. The focus group was audio recorded and transcribed.

Ethics, consent, safeguarding and data management procedures

This evaluation was granted ethical approval following university and local authority ethics committee review. It was also approved by the NHS Trust managing the care home and the school's board of governors. National NHS ethics approval was not considered necessary as this study was deemed to be a service evaluation which did not change clinical care.

Consent was a multistage process. In advance of the scheme / evaluation written information and opportunities for face to face or telephone discussion were provided to people living with dementia, their family carers, children, their parents / guardians and staff. This included an information event for potential participants in the care home. All participants and relatives were asked to inform care home, school or research staff if they or their relative wished to opt out of the scheme / evaluation. All had the option to continue with the scheme participation without taking part in the evaluation. Immediately prior to intergenerational sessions, both children and people living with dementia were introduced to the researchers and asked if they remained willing to participate and have researchers write notes about their observations. Verbal consent was recorded in writing by researchers.

Further consent was sought for participation in the evaluation interviews and focus groups. Child friendly participant information sheets and consent forms were provided to children who had visited the care home (and their parents / guardians) inviting them to participate in a focus group. Consent forms were signed by parents

and children. All staff invited to participate in interviews were given participant information sheets and signed consent forms prior to participation.

Safeguarding of participants remained the responsibility of the school, for children and care home, for people living with dementia. Purposive sampling of both children and people living with dementia for participation in care home visits reduced the risk to both parties. Sufficient staffing was in place to provide support to any participants who needed it.

Data was anonymised at source, with the exception of audio recordings which were anonymised after transcription. All data was stored securely following University data management procedures.

Data analysis

Quantitative. Responses to the dementia awareness questionnaire were entered onto an excel spreadsheet and checked for accuracy. Descriptive statistics and Wilcoxon rank tests were performed to assess for statistically significant differences in response to questions pre- and post-curriculum using IBM SPSS statistics version 19 (IBM Corp., 2010). The questionnaires were also reviewed by hand to look for any patterns such as similar incorrect answers.

Qualitative. All information recorded on observation sheets, transcriptions, notes and researchers' reflections were entered into nViVo qualitative data analysis software version 10 (QSR International 2012), coded and categorised. Thematic analysis was carried out (Guest, MacQueen & Namey, 2012). This involved

researchers reading transcripts and notes, ascribing codes, categories and then themes to the data. They then checked these against the data, looking for evidence of themes, categories and codes being confirmed or disconfirmed, to ensure trustworthiness and credibility (Mays & Pope, 2000).

Results

Dementia awareness questionnaire (Alzheimer's Society, 2014b)

Dementia knowledge and awareness was very low amongst children before their participation in the scheme (mean 2/11) and still low (mean 4/11) but statistically significantly higher ($p<0.01$) post curriculum. Most questions were answered correctly by more children post-curriculum than pre-curriculum, with a statistically significant difference on five out of eleven questions (See Table 1). The exceptions were no difference in numbers correctly identifying that most carers are not paid by the government or correctly naming a famous person with dementia. However, pre-curriculum, twenty-one children incorrectly named seven celebrities they thought had dementia, whereas post curriculum only four did.

INSERT TABLE 1

Qualitative findings

Findings from non-participant observations, interviews and focus group were analysed thematically. Four themes emerged: “expectations and first impressions”, “lifestory booklets”, “interactions” and “reflections and lasting impact”.

Expectations and first impressions. Participants (people living with dementia, children and staff) had varying expectations and first impressions of the scheme. Teachers reported knowing little about dementia prior to participation and had spent time educating themselves about dementia and preparing to share their personal experiences prior to teaching the children. Care home staff had positive expectations of scheme participation, many remembered previous times when children had visited the care homes and how this had generally been enjoyed by people living with dementia. They had put in steps to maximise the likelihood of the scheme being a positive experience for all participants, through careful selection of care home participants, staff education and increasing staffing for the first visit by the children. Mostly children reported that they had worries prior to visiting the care home, focussed around the potential of people living with dementia becoming angry and frightening, especially if they were “asked something they didn’t understand”. On arrival, children were mostly quiet, looking around the room anxiously, often avoiding eye contact with people living with dementia. One said: “I were a bit quiet, but once I got used to it I started asking questions”. Once sat down, most brightened quickly, smiling and talking to people living with dementia. Similarly, a few people living with dementia initially looked anxious or uncertain when children arrived, looking to staff for reassurance. Most brightened when children approached, making eye contact, leaning in and smiling. A few had less of a reaction, but none negative. Prior to the start of the second visit, some said they were looking forward to being with the

children again, one bringing a card he had drawn ready to show. When the children arrived, there were less signs of worry or nervousness on either side. Some people living with dementia clearly remembered the children from the first week, with many faces lighting up.

Interactions. The majority of interactions between children and people living with dementia were positive, with numerous observations of both adults and children with smiling faces, making eye contact and engaging in lively conversations and laughter. Amongst the ten people living with dementia there were four patterns of interaction. Four responded to children's questions independently, discussing their childhood, family, work and other aspects of their earlier life appropriately and initiated appropriate conversation back. Two, whilst giving appropriate responses, were brief and quiet, not initiating or sustaining conversation with children. Two chatted extensively but sometimes became confused or spoke off topic. Two did not engage with the children but sat smiling at them. Amongst all those who spoke with the children there were occasions when they struggled to answer the children's questions, finding it difficult to understand what or why they were being asked, or being unable to recall the detail. When this happened, some laughed it off, some turned to staff for help or sometimes staff intervened spontaneously, either to rephrase the question or to provide the person living with dementia some form of memory prompt. In one instance, a woman with dementia took the initiative to ask the child to repeat or rephrase the question for her. Some of the people living with dementia referred directly to their memory problems - a few spoke about their sadness at forgetting things, and apologised to the children when they couldn't answer their questions. By contrast, a few who looked happy and relaxed for most of

the session did not refer directly to their difficulties. Instead they occasionally looked worried or concerned, with their change of demeanour occurring when they couldn't answer the children's question or they were unsure if their response was correct.

In line with observational data, care home staff all agreed that most people living with dementia enjoyed the interaction with children, with one stating "they like having them here". They had been surprised at the extent of the positive impact on one person about whom they stated "Usually he is extremely restless and can get quite agitated, spending most of his time trying to …escape from the care home…" but instead had remained seated and "…had engaged much more than usual…". They were keen to highlight that participants' ability to engage in the session had not related to severity of dementia. They also indicated that there had sometimes been subtle changes in people's behaviour, reporting that even one of the less vocal people had loved seeing and spending time with the children, even though this had not been clear to researchers.

Most children had positive facial expressions, made eye contact and initiated and responded to conversation with people living with dementia appropriately. Two had minimal interaction although appeared to be listening, concentrating to conversation, and could be more actively engaged with staff facilitation. Two others occasionally looked bored, confused or frustrated. One of these initially looked very unhappy and avoided eye contact with anyone in the room, but with teacher support participated more. Most children adapted their communication styles without prompting, for instance, leaning in when they spoke or increasing their volume, speed or clarity of speech. None shouted. However, when communication difficulties were encountered that could not be so easily rectified, children had differing responses. Some

rephrased questions, others looked puzzled and looked to or spoke instead to staff member. On one occasion, a person living with dementia put his hand on a child's arm (which appeared, to the researcher and care staff, a gesture of warmth). This made the child appear quite uncomfortable and the care staff member quickly placed herself between the pair, holding the man with dementia's hand herself.

Lifestory booklets. Care home managers chose a shortened version of a lifestory booklet used in routine practice, to encourage conversation between children and people living with dementia and at the same time reinforce children's literacy skills. Opinions on lifestory books were divided. Some children stating they were useful in guiding their questions, others preferring listening and chatting more spontaneously. Two reported "hating" the reading and writing involved in the books . Researchers' observations were similar, noting some children talking more freely during a refreshment break, others more engaged when using the books. Teachers both appreciated the direction the books provided, but mostly preferred pupil-led, project-based work which better illuminated children's learning.

Reflections and lasting impact. Most children reported that learning about dementia had been interesting, visiting the care home enjoyable and that they would like to continue visiting. One stated it had been "nice to visit, to find out what help they needed and to be able to help them". Another said "people with dementia were like normal people, funny and told jokes". None wished they had not taken part in the learning, though one wished he had stayed in the classroom playing dementia learning games instead of having to walk to the care home. Similarly, teachers felt all children had benefitted from learning about dementia and most had looked forward

to the weekly dementia teaching, whether in school or in the care home. In terms of children's factual knowledge acquisition, many were able to describe signs and symptoms of dementia, knew there were many types of dementia and that there is no cure. However, there was more uncertainty about dementia's cause, with one child asking "Can you catch it? Is it a virus?" Children also asked the researchers which of the adults at the care home had dementia, having been uncertain who was staff. Despite factual uncertainties, there was unanimous agreement when one child stated "You should treat people with dementia with kindness". It was also widely accepted that if you saw someone in the supermarket who seemed confused or muddled about what they were doing, "You should not rush them or get angry but offer to help them as they might have dementia". The teachers stated that it was this kind of attitudinal learning that they felt was more important than learning facts about dementia and had been the focus of teaching.

Participating in the scheme had impact beyond the children, as they reported talking to their families about dementia, finding out they had relatives with dementia or working in dementia care. The teachers said that not only had the scheme been fully supported by all children's parents, but it had led to many families discussing dementia for the first time. The other impact, described by the teachers was how talking about dementia had an emotional impact on both the children and the teachers. One described how the children had concentrated quietly on a video about dementia, and how they had discussed their feelings and been concerned and sympathetic towards the teacher after she shared her personal experiences of family members with dementia. The teacher considered that studying dementia had "strengthened class bonds", with pupils generally more involved and interested in their learning.

Staff felt overall the scheme had gone well, were glad they had tried it and planned to continue with it. Care home staff stated "…it was really positive for the children, for service users and for the staff…". When describing the impact on service users one stated "She said, "I've loved it", it improved her wellbeing and she got a lot out of it…" In terms of the scheme's wider impact, one said "To bring people in and have a look at what we do…takes away the stigma." One member of staff felt staff needed more preparation and expressed concerns about safeguarding as you could not be sure what people living with dementia would talk about, stating "some people have stuff in their past that would be a bit off limits." He did though acknowledge that this had not been problematic. Most of the staff interviewed had suggestions for future activities that could be incorporated into the scheme. These included: people living with dementia becoming pen pals with the children, going to school fairs, concerts, assemblies and for a Christmas lunch; children visiting the care home for other lessons, such as craft activities, storytelling or history; or a child-led presentation based project, sharing photos, reminiscence and sports activities (for example, carpet bowls).

Discussion

Children's knowledge and awareness of dementia increased when they participated in the Adopt a Care Home scheme. Scheme participation appeared to be an enjoyable experience for the majority of children and people living with dementia. No wholly negative experiences were reported or observed. There were wider impacts as children discussed their dementia learning with their families and class bonds

strengthened. The school and care home implemented the scheme safely, within the intended time frame and plan to continue. This suggests the Adopt a Care Home scheme and other intergenerational initiatives have the potential to contribute towards both increasing knowledge and understanding of dementia in children and engaging people living with dementia in an enjoyable, social activity that brings the community into the care home.

Impact for people living with dementia

Most people living with dementia were observed to be engaged and interacting with children. Staff reported that scheme participation was, for most, an enjoyable experience. Levels of engagement varied between people being fairly passive, watching children or responding with additional support, to initiating conversation and appearing animated and far more engaged than in other care home-led activities. Levels of engagement did not appear to correspond to severity of dementia. These findings are broadly consistent with those from other intergenerational schemes (Chung 2009; Galbraith et al., 2015; George, 2011; Jarrott & Bruno 2003; 2007).

Children's knowledge and awareness of dementia

Children's baseline factual knowledge about dementia was minimal but increased through scheme participation, consistent with findings from previous studies (Atkinson & Bray 2013; Nazir & Bangash 2015; Parveen et al., 2015; Rylance & Pendleton, 2015). However, there was wide variation between individuals and generally, knowledge and understanding of dementia remained limited after a school

term of teaching. This could be because: the dementia awareness curriculum was not in sufficient depth; that teachers did not focus on teaching dementia facts; or that the topic of dementia is too complex to teach children about effectively in one school term. However, it could also be because the questions on the chosen questionnaire did not fully capture children's knowledge and awareness of dementia.

From the focus groups it was evident was that those children who had visited the care home exhibited sympathetic attitudes and increased confidence in relation to dementia, consistent with previous studies (Atkinson & Bray, 2013; Galbraith et al., 2015). Prior to scheme participation only one child reported knowing someone with dementia. This increased both with children reporting knowing the people they had met in the care home and also through having discovered relatives of theirs had dementia. This is consistent with previous suggestions that children generally have limited contact with people living with dementia either as they do not know anyone with dementia or because adults deliberately limit their contact with them (Celdran, Triado & Villar, 2011; Chung, 2009; Galbraith et al., 2015;Jarrott & Bruno 2007; Sakai, Carpenter & Rieger, 2012). It also suggests the scheme had wider impact beyond the participating children in terms of increasing communication about dementia within their families. Another unintentional scheme benefit was teachers reporting the scheme's positive influence on the personal development of children, as bonds between the class grew as they discussed emotionally challenging issues. Both of these findings are consistent with those found previously (Atkinson & Bray, 2013). These wider impact findings are relevant given that the purpose of increasing dementia awareness is to reduce the stigma associated with dementia and make society more dementia friendly (Alzheimer's Disease International, 2012; Alzheimer's Society, 2013b; Department of Health, 2009; 2012, 2015, 2016). They suggest

intergenerational initiatives could contribute to making communities more dementia friendly.

Safety and feasibility

The scheme was implemented successfully and safely within agreed timeframes. No participants became upset or distressed during this study whereas this could have been a possibility, given that others have reported that meeting people with dementia can be distressing for children (Sakai, et al., 2012). Perhaps this scheme's success was due to skilful preparation and facilitation by both school and care home staff. Indeed the one episode of potentially inappropriate touching of a child by a person with dementia was managed firmly but sensitively by a member of care home staff without causing any evident distress. However, during the care home visits, there were times when some children or people living with dementia became less engaged and required input from staff to re-engage them in the activity, which was not always successful. To a certain extent this is to be expected given the participants and that others have described intergenerational schemes as very challenging to implement (Atkinson & Bray 2013; Galbraith et al., 2015; Jarrott & Bruno 2003; 2007). Sessions appeared mostly well planned and facilitated. One staff member, however, suggested communication about and preparation of care home sessions could have been improved. Researchers noted variation in the quality of facilitation, although it was mostly very high. The chosen activity, the lifestory booklet, was positively received by many, but a minority of children and people with dementia may have benefitted more from other activities. Staff suggested a number of other suitable activities for the scheme. Other documented intergenerational

projects have included a variety of activities similar to these, including reminiscence, Montessori based education, games, creative and literacy based activities (Atkinson & Bray, 2013;Galbraith et al., 2015).

Limitations

Our evaluation was brief, pragmatic and subject to time, resource and environmental constraints. As such, it had a number of limitations that impact on the reliability and validity of findings. Its sample size was small and largely determined for reasons of convenience. In terms of data collection, the questionnaire did not relate specifically to the information the children were taught in school, nor was it designed for self-completion by primary school children. This may partly explain why so many children left questions unanswered. The focus group was too large and the observations and interviews sometimes too short to capture in depth opinions from all participants or fully capture their experiences. Not all participants were asked about their experiences of participating, Significantly, people living with dementia and children who did not attend the care home were not asked for their opinions on the scheme.

Implications for practice

There are three main recommendations for further implementation of this or similar intergenerational initiatives. Firstly, the development of a resource pack for teachers containing all the age appropriate materials they need to teach children about dementia, including sufficient training for themselves. This would reduce teachers' burden and ensure a high quality age appropriate dementia curriculum. Options

include training as a Dementia Friends champion (Alzheimer's Society, 2013b), or from care home staff, and collating existing resources,including those used in this scheme, the Dementia Resource Suite for schools (Alzheimer's Society, 2014b), those collated by Atkinson and Bray (2013) and in development by Kids 4 Dementia (Baker et al., 2017). Secondly, having a designated individual responsible for organising and facilitating contact between the schoolchildren and people living with dementia. Other successful intergenerational schemes have reported having someone in this role (Chung 2009; George 2011; Jarrott & Bruno, 2007). This could be a volunteer or member of health or education staff who works closely with school teachers and care home staff to understand the needs, capabilities and aims of people living with dementia and children to plan and facilitate activities and sessions accordingly.

Thirdly, the collation of a toolbox of intergenerational activities for use in the care home. All of the activities suggested by staff participating in this scheme and reported in accounts of similar intergenerational initiatives, could be included. Some of these activities would require more long term connections between the school and care home which might help foster community links and a sense of belonging to the local community among participants. Indeed, one previous intergenerational study found that longer term projects enabled intergenerational relationships to better develop (George, 2011).

Implications for future research

Firstly, future research should aim to clarify more formally the potential benefits of intergenerational initiatives for children, people living with dementia and their

potential to contribute towards a dementia friendly society. Specifically, do intergenerational initiatives contribute to the wellbeing of people living with dementia and enable them to feel more connected to their local community? Also, do they lead to long term positive attitudinal and behavioural change in children and others in their community? In order to address these questions, a more in-depth robust and long term evaluation of intergenerational initiatives on a larger and more varied sample (i.e. multisite) would be required. Secondly, future research should focus on assessing the experience and effects of intergenerational initiatives for all participants. For instance, this could be achieved through interviewing people living with dementia directly, using appropriate enhanced communication techniques, and asking them to complete appropriate, standardised measures, rather than collect proxy opinions. To better gather data from children, an improved dementia knowledge and awareness questionnaire and smaller focus groups could be used. Establishing the importance and influence of care home visits on the children is recommended, this could be assessed by interviewing children who did not visit the care home and comparing their post curriculum dementia awareness questionnaire responses with those who did. Long term follow up of children would be required to assess the lasting impact of the scheme.

Conclusion

The Adopt a Care Home scheme, an example of an intergenerational initiative, was implemented safely by the participating school and care home. It successfully increased children's dementia awareness and engaged people living with dementia in a social and enjoyable activity. It had wider impacts in terms of increased family discussions about dementia and children's attitudinal changes. It is the only UK

based scheme we are aware of that exists to both increase dementia awareness in children and contribute to the wellbeing of people living with dementia who participate. The evaluation has contributed to a growing body of knowledge about the scope and potential benefits of intergenerational initiatives for people living with dementia and dementia awareness schemes for children. However, further scheme refinement and research is recommended. Findings suggest intergenerational initiatives have potential to contribute towards both increasing knowledge and understanding of dementia in children and engaging people living with dementia in an enjoyable, social activity that brings the community into the care home.

Table 1: Children's pre and post-curriculum scores on dementia awareness questionnaire

Questionnaire item	**Pre-curriculum score /40**	**Post-curriculum score / 40**
What is dementia?	5.5	25.00*
Name four types of dementia	.0	5.50*
You only get dementia if you are old	20.00	21.00
Dementia is curable	12.00	28.00*
Which of these means you are less likely to get dementia?	4.50	19.00*
It is not possible to live well with dementia	8.00	24.00*
Which of these is a sign of dementia?	9.00	16.50*
How many people have dementia in the UK?	7.00	14.00
What proportion of people in the UK with dementia know they have it?	11.00	17.00
Most carers are paid by the government	12.00	12.00
Name a famous person living with dementia	.00	.00
Total score /440	88.50 (mean questionnaire score 2.2 /11)	168.50* (mean questionnaire score 4.2/11)

* = statistically significant at $p<0.01$

Adopt a Care Home: an intergenerational initiative

References

Alzheimer's Australia. (2013) *Dementia Friendly Societies: the Way Forward.* Retreived from: http://www.fightdementia.org.au/common/files/NAT/Paper_31_web.pdf.

Alzheimer's Disease International. (2012) *World Alzheimer Report 2012: Overcoming the stigma of dementia.* London: Alzheimer's disease International

Alzheimer's Society. (2013a) *Outcomes of the James Lind Alliance Dementia priority setting partnership.* 2013. Retrieved from: http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2226

Alzheimer's Society. (2013b) *Building dementia-friendly communities: A priority for everyone.* Retrieved from: http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200436

Alzheimer's Society. (2014a) *Dementia UK: Update.* 2014. Retrieved from: https://www.alzheimers.org.uk/dementiauk1-136

Alzheimer's Society. (2014b) *Dementia Resource Suite for schools: Creating a dementia-friendly generation.* Retrieved from: http://www.sitra.org/news/dementia-resource-suite-for-schools/

Atkinson, T., & Bray, J. (2013) *Dementia Awareness & Intergenerational Exchange in Schools : A Pioneer Project supporting Dementia Friendly Communities Final report*. Association for Dementia Studies (University of Worcester) & Coventry & Warwickshire NHS Trust.UK

Baker, J.R., Jeon, Y-H., Goodenough, B., Low, L-F., Bryden, C., Hutchinson, K., & Richards,L. (2017 in press) What do Children Need to Know about Dementia? The Perspectives of Children and People with Personal Experience of Dementia. *International Psychogeriatrics*

Care Quality Comission. (2014) *The state of health care and adult social care in England 2013/2014 [*Internet]. HMSO; 2014. p. 1–82. Retrieved from: http://www.cqc.org.uk/sites/default/files/state-of-care-201314-full-report-1.1.pdf

Carter, S., & Henderson, L. (2005). Approaches to qualitative data collection in social science. Chapter 9 in Bowling, A & Ebrahim, Eds *Handbook of Health Research Methods.* Berkshire, UK: Open University Press.

Celdran, M., Triado, C., & Villar, F. (2011) "My Grandparent Has Dementia": How Adolescents Perceive Their Relationship With Grandparents With a Cognitive Impairment. *Journal of Applied Gerontology*, 30(3), pp.332–352.

Channel 4 News. (2015). Video, retrieved from: https://t.co/V9Y5ScP4QK

Chung, J.C.C. (2009) An intergenerational reminiscence programme for older adults with early dementia and youth volunteers: Values and challenges. *Scandinavian Journal of Caring Sciences*, 23(2), pp.259–264.

de Vaus,D.A. (2001).*Surveys in Social Research*. London, UK: Routledge.

Department of Health. (2009) *Living well with dementia : Dementia: A National Dementia Strategy*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Department of Health. (2012) *Prime Minister ' s challenge on dementia: Delivering major improvements in dementia care and research by 2015*, Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf.

Department of Health. (2015) *Prime Minister ' s challenge on dementia 2020.* Retrieved from: https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020.

Department of Health. (2016) *Prime Minister ' s Challenge on Dementia 2020: Implementation Plan*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf

Galbraith B., Larkin H., Moorhouse A., & Oomen T. (2015) Intergenerational Programs for Persons With Dementia: A Scoping Review. *J Gerontol Soc Work 2015;58(4)* pp 357–78.

George, D.R. (2011) Intergenerational volunteering and quality of life: Mixed methods evaluation of a randomized control trial involving persons with mild to moderate dementia. *Qual Life Res. 20(7)* pp987–95

Guest, G., MacQueen K. M., & Namey, E. E. (2012). Introduction to Apllied Thematic Analysis. In *Applied Thematic Analysis*. Thousand Oaks, CA: SAGE Publications.

IBM Corp. Released (2010). *IBM SPSS Statistics for Windows, Version 19.0.* Armonk, NY: IBM Corp.

Jarrott, S.E., & Bruno, K. (2007). Shared Site Intergenerational Programs: A Case Study. *Journal of Applied Gerontology*, 26(3), pp.239–257.

Jarrott, S.E., & Bruno, K. (2003). Intergenerational activities involving persons with dementia: an observational assessment. *American journal of Alzheimer's disease and other dementias*, 18(1), pp.31–37.

Mays N., & Pope C. (2000) Assessing quality in qualitative research. *Bmj. 320 (7226),* pp50–52.

McNair,B., & Moore,K. (2010) The effects of intergenerational programs on individuals with Alzheimer's disease or dementia. *Annual in Therapeutic Recreation, 18* pp141-156

National Institute for Health and Care Excellence. (2013) *Mental wellbeing of older people in care homes.* Retrieved from: http://publications.nice.org.uk/mental-wellbeing-of-older-people-in-care-homes-qs50#close

Nazir,E., & Bangash, A. (2015) Awareness Raising in Schools. *The Journal of Dementia Care, 23 (2)* p14-15.

Owen T., & Meyer J. (2012) *My Home Life: promoting quality of life in care homes.* Retrieved from: http://www.jrf.org.uk/publications/my-home-life

Parveen, S., Robins, J., Griffiths, A.W., & Oyebode, J.R. (2015) Dementia Detectives: busting the myths. *The Journal of Dementia Care July/August 2015 Vol 23* pp12-13

QSR International Pty Ltd., (2012) *nViVo 10 qualitative data analysis software; version 10.* QSR

Rylance, R., & Pendleton, J. (2015) Awareness Raising in Schools. *The Journal of Dementia Care, 23 (2) p14-15*

Sakai, E.Y., Carpenter, B.D. & Rieger, R.E. (2012) What's Wrong with Grandma?": Depictions of Alzheimer's Disease in Children's Storybooks. *American Journal of Alzheimer's Disease and Other Dementias*, 27(8), pp.584–591.

Skropeta, C., Colvin, A., & Sladen, S. (2014) An evaluative study of the benefits of participating in intergenerational playgroups in aged care for older people. *BMC Geriatrics*, 14(1), p.109.

Snyder, M., Ryden, M.B., Shaver, P., Wang, J-J., Savik, K., Gross, C.R., & Pearson, V. (1998) The Apparent Emotion Rating Instrument. *Clinical Gerontologist*, 18(4), pp.17–29.

University of Bradford, (2008) *The Bradford Well-being Profile*, Retrieved from: http://www.bradford.ac.uk/health/media/healthmedia/Bradford-Well-Being-Profile-with-cover-(3).pdf.

Wallace,A., & Horner, K. (2014) *Adopt a Care Home (AaCH) & Dementia Awareness© Service Pilot.* Sheffield City Council.UK.

Whitehouse, P.J,. & Whitehouse, C.C. (2005). The intergenerational school: Integrating intergenerational approaches in the care of those with age-related cognitive challenges. *Australasian Journal on Ageing*, 24(SUPPL.1), pp.57–58.