The Kids4Dementia education program is effective in improving children’s attitudes towards dementia

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Abstract
Improving children’s understanding of people with dementia is essential for tackling societal stigma around dementia. Kids4Dementia is a teacher-led multimedia dementia education resource for 9–12 year olds (approximately 150 minutes duration). A non-randomised, wait-list-controlled, mixed-methods design examined whether Kids4Dementia was (1) efficacious in improving students’ attitudes towards people with dementia and (2) engaging and acceptable for
teachers and students. Students who completed Kids4Dementia (n = 136) showed improved scores on the Kids Insight into Dementia Survey, relative to the control school (n = 67), especially students who had not heard of dementia before (Time × Group × Dementia Familiarity interaction, \( F(1, 191) = 5.28, p = .023, \) partial \( \eta^2 = .027 \)). Qualitative reports indicated that the program was acceptable and engaging for teachers and students and corroborated improvement in student empathy and behavioural intentions towards people with dementia. The findings provide preliminary evidence for the efficacy of Kids4Dementia as an engaging, stakeholder-directed, curriculum-aligned dementia education program.

Keywords

attitudes, children, dementia, education, school

Introduction

Stigma is experienced by over 75% of people with dementia (Alzheimer’s Disease International, 2012). It contributes to social isolation and delays in seeking diagnosis and help (Alzheimer’s Disease International, 2012; World Health Organisation, 2012). Thus there is a critical need to improve dementia awareness and literacy across society (Alzheimer’s Disease International, 2012; World Health Organisation, 2012). Young people may be a key target for this education. Stereotypic beliefs peak in flexibility around 10–14 years of age (Alfieri, Ruble, & Higgins, 1996), and adolescents demonstrate greater responsiveness to anti-stigma education than adults (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). The current estimates are that one third of young people know someone with dementia (Alzheimer’s Society, 2015). These will only increase as the dementia prevalence rate is set to triple to 131.5 million worldwide by 2050 (Alzheimer’s Disease International, 2015). This means that more and more young people will be living with a grandparent or parent with dementia or connecting with people with dementia in their community. Yet, young people seem ill-prepared for these relationships or encounters. For example 62% of 8–17 year olds in a British government poll reported that they would like to help people with dementia but that a lack of understanding holds them back (Alzheimer’s Society, 2015). Parents may not initiate conversations about dementia due to low confidence in their own knowledge about dementia or a desire to “protect” their child from such information (Wolf et al., 2009). While several websites and storybooks are available to help young people with a relative with dementia (Sakai, Carpenter, & Rieger, 2012), they are not always used (Denny et al., 2012) and nor are the resources targeted towards young people who do not (yet) know someone with dementia.

School curricula are becoming increasingly focused on educating students to become active and informed citizens (Schulz, 2012). Dementia education through schools would inform all children regardless of their experience with people with dementia. Furthermore, young people may be more receptive to anti-stigma information when presented by a non-parental source (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004). The UK investigated a school-based dementia awareness initiative. A lead teacher at each of 22 participating schools incorporated dementia into the curriculum by way of dementia awareness lessons, aged care facility visits or dementia-themed art, drama and music projects. The initiative demonstrated an improvement in children’s attitudes regarding dementia,
with children’s confidence in meeting a person with dementia rising from 27 to 76% across one academic year (Atkinson & Bray, 2013).

While a promising start, the UK program required significant teacher investment and dementia knowledge. For there to be wide-reaching and sustainable adoption of the program across schools, a curriculum-based approach was needed to assume minimal demands on the teacher, in addition to ensuring standardised content developed in consultation with stakeholders.

We ran a qualitative inquiry to learn what young people think or understand about dementia and what people with personal experience of dementia would like young people to think or understand about the condition (Baker et al., under review). Based on this information, we created Kids4Dementia, a classroom-based education program, to improve dementia literacy in Australian schools. The program demands negligible preparation and resources and no prior knowledge on behalf of the teacher. Moreover, it was intentionally made available online to enable broad reach across metropolitan, regional and rural schools. This paper describes the program pilot, a critical first step in intervention development (Craig et al., 2008). In the school context of fixed curriculum objectives and limited time, program “fit” may be especially important for determining successful and continued roll-out of the program in schools. The study aims to determine (1) the program’s efficacy in improving students’ attitudes towards people with dementia and (2) the acceptability and teacher/student engagement with Kids4Dementia.

**Method**

**Setting**

The setting was three independent Christian primary schools in regional Australia, who were the first to express an interest in the program. None had engaged in any previous dementia-related education.

**Design**

The study employed a waitlist-controlled, mixed-methods design in that two schools implemented Kids4Dementia in Term 1 of the 2016 school year (intervention group), whereas one school was assigned to “wait” and start the program in Term 2 (waitlist group). The allocation was non-randomised in that the group assignment was based on term preferences.

**Participants**

All students within the selected classes of the last two primary school years (typically 9–12 years old) were eligible to participate. In line with the University Human Ethics Committee approval (HC15748), the teacher distributed the Information and Consent form to the students’ parents. A total of 203 students (intervention group n = 136; waitlist group n = 67) provided verbal assent and written parental consent.

**Kids4Dementia program**

Kids4Dementia was developed by teachers, children, people with dementia, carers and academics. The program comprised a website supporting seven modules (see Table 1), linked by an
Table 1. Overview of the Kids4Dementia education: modules, activities and timings.

<table>
<thead>
<tr>
<th>Module</th>
<th>Format</th>
<th>Minute</th>
<th>Activity</th>
<th>Minute</th>
<th>Total time (minute)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is dementia?</td>
<td>Animation: Ollie and Ruby try to work out why their grandfather is acting strange and discover that he has dementia.</td>
<td>3 + 5 minute discuss</td>
<td>Class discussion</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>2. What can we do?</td>
<td>Animation: Ollie works out how best to interact with and help his grandfather despite the frustrations sometimes.</td>
<td>3</td>
<td>Think-pair-share problem-solving scenarios</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>3. What happens in nursing homes?</td>
<td>Animation: Ollie learns how to make visits to his grandfather in the nursing home more fun.</td>
<td>3</td>
<td>Activity ideas worksheet^a</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>4. What causes dementia?</td>
<td>Animation: A short overview of what dementia is and how it affects different parts of the brain.</td>
<td>3</td>
<td>Online interactive brain with quiz</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>5. How can we keep our brains healthy?</td>
<td>Animation: Ruby illustrates five ways that we can keep our brains healthy.</td>
<td>3</td>
<td>Poster^a</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>6. How does it feel to have dementia?</td>
<td>Adult real-life videos: People with dementia tell us what annoys them most about living with dementia and what they would like people to know about dementia.</td>
<td>2 × 3 minute videos</td>
<td>Communicating a message role-play briefs</td>
<td>15</td>
<td>21</td>
</tr>
<tr>
<td>7. How does it feel for the family?</td>
<td>Child real-life videos: Children with a father or grandparent with dementia talk about what it is like and how it feels.</td>
<td>2 × 3 minute videos</td>
<td>Letter or poem worksheet^a</td>
<td>20</td>
<td>26</td>
</tr>
</tbody>
</table>

^aPossible to do as homework.
animated narrative of a 10-year-old boy, his 12-year-old sister and their Grandfather, who they noticed to be acting a little different to usual. The characters were likeable, credible and similar to the audience, elements known to be persuasive in reducing stigma (Morton & Campbell, 2008). The use of dramatized animation recognised that stigma reduction is mediated by entertainment value of an educational experience (Ritterfeld & Jin, 2006) and that storytelling is a reliable way to elicit empathy (Barraza & Zak, 2009; Castelán Cargile, 2016), an established motivator of prosocial behaviour in young people (Batson et al., 1995; Williams, O’Driscoll, & Moore, 2014). Further, storytelling, based around a family with which the target audience could identify, was anticipated to emphasise the message of personhood (Kitwood, 1997) – a key program learning outcome identified in our qualitative work with people with personal experience of dementia (Baker et al., under review). Humour also featured in the program to align with stakeholder requests to avoid a portrayal that dementia is all “doom and gloom” (Baker et al., under review). Two of the modules included film of adults with dementia and child relatives speaking about the condition, recognising that adding video-based contact to anti-stigma education significantly improves effectiveness (Chan, Mak, & Law, 2009; Reinke et al., 2004). Each module was accompanied by a class (or homework) activity, such as an interactive brain, role-play, or drawing; these mapped onto the state’s Personal Development, Health and Physical Education and other syllabus curricula. The learning outcomes (see supplementary Box S1) were informed by a literature review and our qualitative work with children in the community and people with personal experience of dementia (Baker et al., under review). Teachers delivered the program within class time. After the first introductory module, teachers chose the module order. Kids4Dementia was completed over a minimum of four weeks, and within one school term (10 weeks), and took about 150 minutes to complete (see Table 1).

**Waitlist control**

The control school engaged in no dementia curricula for the term that the intervention schools were implementing K4D (i.e. school-as-usual).

**Measures**

*Kids Insight into Dementia Survey.* Kids Insight into Dementia Survey (KIDS) is a reliable and valid measure that we developed of children’s attitudes towards people with dementia (Baker et al., 2017). Children read a vignette about a lady with dementia and rate how much they agree with 14 statements about people with dementia on a Likert scale ranging from “Agree a Lot” (5), “Don’t Know/Unsure” (3), “Disagree a Lot” (1). Items pertain to the Personhood of a person with dementia (e.g. “People with dementia have hobbies and interests”), Stigma (e.g. “You can “catch” dementia from other people”) and Dementia understanding (e.g. “Dementia is when something has gone wrong in your brain”). Scores are summed with negative items reverse scored. Higher scores indicate more positive attitudes toward people with dementia. The KIDS was researcher-administered and completed twice – at the start and end of Term 1 (pre- and post-K4D implementation for the intervention schools).

*Dementia familiarity.* Children checked however many of nine situations in which intimacy of contact with a person with dementia varies from “I’ve never observed a person like that” to “I live with a person like that” (Corrigan et al., 2005). The most intimate situation checked
was taken as the familiarity index. Children also indicated whether or not they had heard of “Alzheimer’s disease” or “Dementia”.

**Process evaluation.** Teachers recorded student attendance, module timings and feedback. One teacher from each of the two intervention schools participated in a 20-minute post-program interview with author JB. Open questions probed how well students engaged with and understood the program; what they liked best and least; particularly salient or novel learning content; acceptability of K4D; and suggested improvements. A representation (age and gender) of students from the intervention schools participated in post-program focus groups with the author JB (n = 19 across three groups), probing similar questions including how students might anticipate behaving with this new knowledge.

**Analyses.** A mixed repeated-measures analysis of variance was conducted in SPSS 24 (IBM Corporation, 2013), with measurement occasion as a within-groups factor and condition as a between-groups factor, to determine whether the intervention group showed significantly improved dementia attitudes compared to the control group. The control group only had one school, and schools typically chose to deliver the program by year group (i.e. all year classes combined); so we were unable to account for school or class cluster. However, significant baseline group differences (identified by independent T-tests or Chi-square, \( p < .05 \) – see Table 2) were entered as a covariate. The interviews and focus groups were audio recorded.

<table>
<thead>
<tr>
<th>Table 2. Sample characteristics and variable descriptives.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intervention group (n = 135) % (n) or M (SD)</strong></td>
</tr>
<tr>
<td>Gender: Female</td>
</tr>
<tr>
<td>Australian-born</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Not heard of either “Alzheimer’s Disease” and “dementia”</td>
</tr>
<tr>
<td>Highest level of contact:*</td>
</tr>
<tr>
<td>Never seen/seen in passing</td>
</tr>
<tr>
<td>Seen in media/books</td>
</tr>
<tr>
<td>Family friend/relative</td>
</tr>
<tr>
<td>KIDS Baseline Score (Time 1) (range 14–70)</td>
</tr>
<tr>
<td>KIDS Post Score (Time 2) (range 14–70)</td>
</tr>
</tbody>
</table>

*With a person with dementia (percentages do not add up to 100% exactly because of missing data).

\* \( p < .05 \)
transcribed and content analysed in NVivo 11, based on study aims (QSR International Pty Ltd, 2012).

The pilot was not designed to be statistically powered. However, post-hoc analyses using G*Power 3.1 (Erdfelder, Faul, Buchner, & Lang, 2009) revealed that the final sample of 195 students had 90% power to detect a small effect size, accounting for two groups, two measurement time points and a .683 correlation between Time 1 and Time 2 KIDS.

**Results**

**Sample descriptives**

Of the 203 participating students, 195 provided both Time 1 and Time 2 data – sample characteristics are presented in Table 2. The only significant group difference was that a significantly smaller proportion of the intervention group had heard of dementia, relative to the control group.

**The effect of Kids4Dementia on children’s attitudes towards people with dementia**

The KIDS (Time 1 and Time 2) met all data assumptions of independence, normality and equality of covariance and error variances. Given the baseline group difference, students’ familiarity with the word “dementia” was entered into the model. There was a significant main effect of Time, \(F(1, 191) = 37.56, p < .001, \) partial \(\eta^2 = .164\), and a significant Time × Group interaction, \(F(1, 191) = 23.89, p < .001, \) partial \(\eta^2 = .111\). These were qualified by a significant Time × Group × Familiarity interaction, \(F(1, 191) = 5.28, p = .023, \) partial \(\eta^2 = .027\).

Figure 1 illustrates the three-way interaction, via inspection of the groups familiar versus not familiar with the word dementia (n = 127 and 68, respectively). For children who had

![Figure 1. Students’ scores on the Kids Insight into Dementia Survey from pre- to post- Kids4Dementia (range 14–70), as a function of intervention versus control group and whether or not students had heard of “Dementia” or “Alzheimer’s Disease”. (a) Children who had heard of the words “Dementia” or “Alzheimer’s disease”. (b) Children who had not heard of the words “Dementia” or “Alzheimer’s disease”.](image)
heard of dementia, both K4D and control groups showed an improvement in dementia attitudes from pre- to post-K4D (pairwise comparisons, \( p < .001 \) and \( p = .005 \), respectively). A significant Time × Group interaction indicated that this improvement over time was significantly greater for the K4D group than the control group, \( F(1, 125) = 6.23, p = .014 \), partial \( \eta^2 = .047 \). For children who had not heard of dementia, the control group showed a small non-significant deterioration in attitude over time, whereas the K4D group showed a significant improvement in dementia attitudes (\( p < .001 \)), evident in a significant Time × Group interaction \( F(1, 66) = 17.14, p < .001 \), partial \( \eta^2 = 2.06 \).

**Qualitative findings**

Was Kids4Dementia acceptable and engaging? **Student attendance.** Students participated in Kids4Dementia as part of normal school classes. Between 86.5 and 91.6% of students were present for each module (see Table 2).

**Design and medium.** Teachers said that Kids4Dementia “flowed well” and that they “…really liked the way the lessons were planned out, simple, easy to follow.” Students responded positively to the animations and videos, and most activities received an enthusiastic mention as a part that was liked best, typically because it was “fun” (e.g. the brain game or poster) or because it “made you think about it a lot” (e.g. the letter writing). The offer of research team support was never utilised. When the project team contacted teachers to see how they were progressing, the teachers had no questions and said that everything was okay.

**Content.** Teachers said that they would recommend Kids4Dementia to other teachers, that students enjoyed the program and that some were asking to continue with it next year. One teacher discussed that “It’s really good to learn something not usually taught in schools”, whereas another commented that “there wasn’t anything that wasn’t relevant or boring”. Teachers identified that the only thing that students wanted to know that the program left unanswered was who develops dementia and whether it is hereditary.

Several students made comments akin to, “At the start, I had no idea what dementia was. I didn’t even know it was a thing”. Thus the topic novelty seemed especially engaging, but with content still pitched appropriately; for example, “…when teachers explain something I don’t always understand… but the videos, that made it more interesting and I, like, got everything they were talking about.”

Teachers did not observe any student distress and rather described students as keen to participate in the dementia conversations and (where appropriate) share personal experiences about knowing a relative with dementia.

**Did Kids4Dementia improve children’s attitudes towards people with dementia?** **Improved understanding and empathy.** As noted, students appeared to start from a low baseline of dementia knowledge. Program content that stood out for the students was the occurrence of younger-onset dementia “when I heard that you could get it [dementia] in your 30s I was really astonished” and that the condition is not contagious. Another notable learning outcome for students was that “it was nice to know about the brain…I just thought it was one big thing…but there was lots of different parts.” This seemed especially important as a way to
understand how people with dementia can have interests and still “do” things despite perhaps demonstrating difficulties in other life aspects:

I thought, how do people with dementia do stuff, because they forget everything, but later in the program I found out that only parts of their brain stop working, so they can still remember some things, and how to walk and stuff like that.

Teachers endorsed an increase in students’ empathy and described how the activity where a message had to be communicated without saying certain words (Module 6), “really hit home just how frustrating communication can be for people with dementia”, and that the videos of the children speaking emotionally about having a relative with dementia (Module 7) had “a significant impact on the children”. Students agreed that “those kids on the video, I really feel for them”. Students also noted “positives”:

It doesn’t mean that you can’t have fun… If there’s a really funny joke that you love hearing, they might say it and say it. And if they forget that they already got you chocolate, they might give it to you again.

Behavioural intentions. Students were adamant that they would behave quite differently now if they were to meet a person with dementia. One boy said, “I wouldn’t have known what to do, I’d probably get all scared... now I’d help them and I wouldn’t treat them like they’re a little kid, I’d treat them like you’d treat a normal human being.” This positive impact was described for family relationships also. One girl said, “I knew he [my grandad] has it and what to do but I didn’t know there was so much you could do that would help him feel better about himself.” For some students, this new knowledge was shared with parents. One boy asserted that “I, for once, got to teach my parents something... they only knew the name of it... they knew that it was a memory loss thing, but they didn’t know anything else about it.” The students seemed to grasp the big picture of the program; for example, at the end of one focus group, a girl thanked the researcher for the program reasoning that “if you didn’t do it, people would probably just walk past someone with dementia”.

Discussion

The pilot findings suggest that Kids4Dementia is acceptable and engaging for both teachers and students and that teachers were able to deliver the program independently. Efficacy of Kids4Dementia in improving children’s attitudes towards people with dementia was demonstrated by improved scores on the KIDS for students who participated in Kids4Dementia, in comparison to students at a control school who engaged in no dementia curricula. The attitude improvement was particularly pronounced for students who had not heard of dementia (a medium effect size of .45), in comparison to children who had heard of dementia (a small effect size of .22). Whether someone has heard of dementia is a crude measure, but it makes sense that children starting from lower baseline knowledge about dementia will be more responsive to an education program about dementia than children with prior knowledge about the condition.

However, children in the control group who had heard of dementia showed a significant improvement in attitudes towards people with dementia despite having not yet received the
Kids4Dementia intervention. This was an unexpected finding. We reason that after completing the pre-questionnaire about dementia and perhaps motivated by some experience with dementia (implied by having heard of the condition), students went home and independently sought out further information about dementia. The control group consisted of one school of 67 students, whereas the intervention group consisted of two schools of a combined 136 students. The inequality in sample size was a design limitation due to complications in recruiting a fourth school to participate. However, there is consistent evidence that a difference in group size does not have a significant impact on determining intervention effectiveness (e.g. Hutchins, Brown, Mayberry, & Sollecito, 2015).

Indeed, qualitative reports supported the quantitative improvements in students’ knowledge; for instance that the brain consists of different parts, that you cannot “catch” dementia and that people in their 30s can develop dementia. The qualitative reports also supported augmented empathy for people with dementia and their relatives, which is an important catalyst for prosocial behaviour (Batson et al., 1995; Williams et al., 2014).

Whilst a survey measure of attitude change cannot assess real behaviour change, students made several remarks suggestive that Kids4Dementia could have a positive impact on children’s conduct with people with dementia, both in the community and at home. Certainly, student feedback that Kids4Dementia sparked conversations about dementia with parents introduces a potentially novel way to increase adult dementia literacy.

The key prerequisite for scaling-up an intervention is that it is efficacious (Milat et al., 2016), and the study findings testify to this. Schools have many competing demands for additional curricula activities, and the standout translational strength of Kids4Dementia is that it aligns with curriculum outcomes and systems. However, independent schools (in which Kids4Dementia was piloted) are typically more resourced than state schools. Thus, the next goal is to assess generalisability of these promising findings across state and rural schools, employing a more rigorous design that allows for randomisation, clustering and longer-term follow-up. In anticipation of the reduced resources of state schools, we will trial whether reducing the “dose” of Kids4Dementia to a teacher’s choice of five (instead of seven) modules can still maintain effectiveness. Moreover, based on these pilot findings, we will incorporate a genetic component into the program. Originally, genetics were excluded from Kids4Dementia for concern that it may be too complex or sensitive an issue for students. However to include genetic information in the program is consistent with the wishes of people with dementia and their relatives, to be open and honest about the condition (Baker et al., under review; Svanberg, Stott, & Spector, 2010). Contextual opportunities and constraints are likely to change as scaling up proceeds, and teacher interviews at the state schools can identify facilitators to their school running the program yearly, against competing priorities.

In summary, the findings provide preliminary evidence for the efficacy of Kids4Dementia in what could be a world first in terms of a brief, engaging and acceptable dementia education program that is curriculum-aligned and stakeholder-directed.

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