

Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes

Running title: personal experience of dementia and attitudes

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Background: it is unclear how attitudes towards people with dementia are formed and whether, for instance, increased contact with people with dementia, either through work or personal experience alters attitudes. This study used a validated questionnaire (the Approaches to Dementia Questionnaire or ADQ) to examine whether having experience of dementia (either as a result of work, or by being affected by dementia) is associated with differences in attitudes towards dementia.

Methods: a modified version of the ADQ was completed by 2,201 participants, either on-line or in written form. Participants also recorded their age, gender and ethnicity as well as whether they worked with people with dementia, or had been personally affected by dementia.

Results: increased contact with people with dementia was associated with increases in both total ADQ scores and across both sub-scales reflecting more positive person-centred attitudes toward dementia. The highest levels of increase were found amongst non-white participants.

Conclusions: this study is, we believe, the first attempt to look systematically at whether greater contact with people with dementia is associated with changes in attitudes. The results strongly support the contention that increased contact with people with dementia leads to more person-centred attitudes, and by inference, less stigmatising views.

Keywords: dementia; Alzheimer's disease; community care; stigma; attitudes; social support.

Background

A key element of government policy within the United Kingdom (UK) and elsewhere has been to build dementia-friendly communities, and to reduce the stigma that people with dementia face (Department of Health, 2012). In order for these aims to be achieved, public attitudes towards people with dementia need to become more person-centred. However, it is unclear how attitudes towards people with dementia are formed and whether, for instance, increased contact with people with dementia, either through work or personal experience alters attitudes.

Previously research in this area has typically focussed on attitudes of professionals working with individuals living with dementia (e.g., Kokkonen *et al.*, 2014; Leung *et al.*, 2013; Lintern, 2001) or on attitudes to mental ill-health across the general population. For instance, nursing staff working within institutional care who have received training typically show more positive attitudes about people living with dementia (e.g., Leung *et al.*, 2013). Where wider surveys of the attitudes of the general public toward dementia have been undertaken (e.g., McParland *et al.*, 2012), results suggest the general public has, at best, a fair to moderate knowledge about dementia, but there are often misconceptions, such as believing dementia to be a normal part of ageing. Research into attitudes toward dementia often tends to focus on specific issues such as screening for dementia (Bond *et al.*, 2010), euthanasia (Williams *et al.*, 2007) or artificial feeding (Bryon, de Casterlé & Gastmans, 2008), rather than on wider issues. Moreover, these surveys often do not use validated scales (Cahill *et al.*, 2015), or directly compare attitudes across settings, populations, or over time.

In the wider mental health literature, increased levels of contact have been associated with a positive impact on attitudes and a reduction of stigma (London and

Evans-Lacko, 2010; Couture and Penn, 2003; Clement et al, 2015). While there is an assumption that increased contact with people with dementia will break down barriers, improve attitudes and help to overcome stigma, not all research findings suggest such contact has positive outcomes. One consistent finding is that exposure to dementia increases people's concerns that they, themselves, may develop dementia. These concerns have been termed "*dementia worry*" (Kessler *et al.*, 2012), with the degree of exposure to dementia having a substantial effect on the level of dementia worry reported, (Kessler, Tempel & Wahl, 2014). For instance, either having a relative living with Alzheimer's disease (Cutler & Hodgson, 1996, 2001) or working with people affected by dementia (Kessler, Tempel & Wahl, 2014) both seem to be associated with increased concerns about developing dementia at some point in the future. Moreover, individuals who have relatives with dementia not only tend to report more concerns regarding their own potential development of the disease (Corner & Bond, 2004), but engage in more symptom-seeking behaviour (Hodgson, Cutler & Livingston, 1999).

What is not clear is whether experience of dementia, either through personal experience, or through working with people with dementia, in addition to increasing dementia worry also changes person-centred attitudes towards dementia. In a previous study we reported data from a survey relating to public attitudes in Bristol and South Gloucestershire towards dementia (Cheston, Hancock and White, 2016). In that report we deliberately excluded data from participants who worked with people with dementia in order to ensure that our analysis was representative of the broader population. In the current analysis of the survey data, we instead examined whether experience of dementia, either through worked in dementia care, or being affected by dementia, is associated with different attitudes towards dementia.

Methods

Design. This cross-sectional study used a modified ADQ to collect data over a seven-month period.

Measure. The ADQ and modifications to this questionnaire for this study have been described in detail elsewhere (Cheston, Hancock and White, 2016). Briefly, it is 19-item scale with total scores ranging from 19 to 95. The ADQ is made up of two subscales: ‘*Hope*’ (8 items indicative of a sense of optimism or pessimism about the abilities and the future of the person affected by dementia); and ‘*Recognition of Personhood*’ (RoP) (11 items reflecting the extent to which people have a person-centred understanding of dementia or recognise people affected by dementia as unique individuals with the same value as any other person). Higher scores indicate more positive attitudes towards people with dementia. Each item uses a 5-point Likert scale to measure agreement or disagreement toward the statement. Modification of wording to six questions was made in order to be consistent with contemporary language in dementia care (see Cheston, Hancock and White, 2016 for adaptations).

Ethics. Ethical approval was granted by the University of the West of England (UWE REC REF No: HAS/15/04/147), with Avon and Wiltshire Mental Health Partnership NHS Trust hosting the online survey. Participants were informed the study was being carried out by Bristol Health Partners.

Participants. In all, 2,201 people completed the survey (online, 1,865; paper, 337). Participants were asked to provide general background information on their age, gender, and ethnicity. Participants were also asked to identify their contact with people with dementia in two ways: whether they worked with people with dementia; and whether they had been personally affected by dementia.

Procedure. The distribution of the survey has been described in more detail elsewhere (Cheston, Hancock and White, 2016). Briefly, the survey was available online, and in paper format for those without access to, or unable to use a computer (Sommer & Sommer, 2001). Data from online questionnaires were downloaded into Excel, with responses collected on paper forms being manually entered. Both datasets were aggregated before being transferred to SPSS for analysis (IBM Corp., 2013).

Statistical analysis. A series of exploratory and main analyses were conducted. Exploratory analysis using chi-square was used to establish differences between people who had and had not worked with people with dementia. For the main analyses, Welch's *t*-test analyses (which do not assume equal variances, Derrick, Toher & White, 2016) were performed on the data to explore differences in ADQ scores between the two populations. Cohen's *d* was used to quantify effect size. Some commentators suggest *d* values should only be reported where the effect is significant (e.g., $p < 0.05$), while others argue if sample sizes are quite large then having an indication of the effect size is useful. We therefore elected to report effect sizes in both cases. Ellis (2010) gives broad rules of thumb for the interpretation of *d* as follows; $d < 0.1$ indicates a trivial effect, $0.1 < d < 0.3$ a small effect, $0.3 < d < 0.5$ a moderate effect, $0.5 < d < 0.8$ a medium effect, $0.8 < d < 1.3$ as large, and $d > 1.3$ a very large effect.

Results

ADQ internal reliability. The altered scale demonstrated good internal reliability with a Cronbach's Alpha of 0.86 (95% Confidence Interval (CI) 0.85 – 0.87), and Alphas of 0.77 (95% CI 0.76 – 0.79) for the Hope and 0.84 (95% CI 0.83 – 0.85) RoP sub-scales respectively.

Representativeness check. A series of chi-squared analyses were carried out to explore whether there were differences between participant sub-samples. Results indicated participants who worked with people with dementia were more likely to be women than men ($\chi^2(1) = 17.77, p < 0.001$), aged under 64 years ($\chi^2(1) = 16.83, p < 0.001$) and white ($\chi^2(1) = 15.90, p < 0.001$). Participants who had been affected by dementia were more likely to be white, $\chi^2(1) = 45.53, p < 0.001$.

Analysis One: Is increased contact with people with dementia associated with person-centred attitudes? In order to analyse the combined impact of increased levels of contact with people with dementia, a compound variable was created with four categories: working with and affected by dementia; not working with people with dementia, but personally affected by dementia; working with people with dementia, but not affected by dementia; and neither working with people with dementia, nor affected by dementia. Outliers were identified using the outlier-labelling rule (Hoaglin, Iglewicz & Tukey, 1986). While we recognise that opinion is divided as to how to treat outliers, for the purpose of this analysis, they were removed. Levene's test indicated the assumption of homogeneity of variance was breached for each of the three one-way ANOVA analyses that were carried out on the ADQ data. For this reason, Welch's *F*, which is known to be robust for heteroskedastic comparisons on unequal samples sizes, was used. Data screening did not identify any potentially influential observations that could compromise statistical conclusions.

INSERT TABLE 1 ABOUT HERE

Hope. There was a significant interaction between conditions, $F(3, 1140) = 112.35, p < 0.001$. Post-hoc analysis using the Games-Howell test indicated that compared to participants who had neither personal experience of dementia, nor had worked in this area, then both experience of dementia (mean difference = 1.04 (95% CI 0.22, 1.86),

$p < 0.006$) and working with people with dementia (mean difference = 4.606 (3.85, 5.36), $p < 0.001$) had significantly increased scores on the Hope sub-scale. Where participants had worked with people with dementia, then having personal experience of dementia did not significantly add to scores (mean difference = -0.61, (-1.34, 0.13), $p = 0.15$).

Recognition of Personhood (RoP). There was a significant interaction between conditions, $F(3, 1139) = 55.40$, $p < 0.001$. Post-hoc analysis indicated that both being affected by dementia (mean difference = 1.04 (0.30, 1.78), $p = 0.002$) and working with people with dementia (mean difference = 2.89 (2.23, 3.55), $p < 0.001$) had significantly increased RoP ADQ scores. However, where participants already worked with people with dementia, then personal experience of dementia did not significantly increase scores (mean difference = -0.29 (0.32, -0.89), $p = 0.61$).

Total ADQ score. There was a significant interaction between conditions, $F(3, 1143) = 118.43$, $p < 0.001$. Post-hoc analysis indicated that both working with people with dementia (mean difference = 7.60 (6.38, 8.82)) and being personally affected by dementia (mean difference = 2.07 (0.75, 3.39)), had both significantly increased total ADQ scores at the $p < 0.001$ level. However, as was the case with the sub-scale results, where participants worked with people with dementia, then being personally affected by dementia did not change total ADQ scores (mean difference = -0.91 (0.23, -2.04)).

INSERT TABLES 2, 3 and 4 ABOUT HERE

In order to explore the impact that demographic factors might have on participants' experiences of dementia, a series of separate two way ANOVAs were conducted comparing ADQ scores with the demographic variables of age, ethnicity and gender,

respectively. Supplementary *t*-tests were then carried out using Welch's *t*-test. The focus initially was on the interaction between demographic variables and the impact of working with people with dementia. We subsequently repeated the analysis but focussed instead on the impact of being personally affected by dementia.

Analysis Two: Does the experience of working with people affected by dementia have an impact on attitudes toward dementia within different populations?

Age. For the Hope dimension, the two-way interaction between age and work was significant, $F(1, 2064) = 4.748, p < 0.029$. A supplementary *t*-test showed there was a significant difference between Hope scores between those participants aged under 64 years who had worked with people with dementia and those who had not, $t(1876) = 17.46, p < 0.0001, d = 0.79$. However, for participants aged over 65 years, working with people with dementia did not significantly increase Hope scores, $t(64) = 1.71, p = 0.089, d = 0.32$.

In terms of RoP scores, the two-way interaction between working with people with dementia and age was not significant, $F(1, 2069) = 0.147, p = 0.701$. However, for total ADQ the interaction between age and working with people with dementia was significant, $F(1, 2069) = 5.01, p = 0.025$. Further analysis showed that for younger people, working with people with dementia increased total ADQ scores, $t(1827) = 17.81, p < 0.0001, d = 0.81$. However, for older participants, working with people with dementia did not significantly increase total ADQ scores, $t(69) = 1.79, p = 0.078, d = 0.29$.

Ethnicity. For the Hope dimension, the two way interaction between ethnicity and work was significant, $F(1, 2060) = 11.16, p < 0.001$. For white participants, there was a significant difference between those who had experience of working with people

with dementia, $t(1845) = 16.04, p < 0.001, d = 0.74$. For non-white participants, this difference was even stronger, $t(184) = 6.82, p < 0.001, d = 1.03$.

For the RoP scale, the two-way interaction between work and ethnicity was again significant, $F(1, 2065) = 18.56, p < 0.001$. The difference in RoP responses for white participants who had either worked or not worked with people with dementia was significant, $t(1796) = 10.22, p < 0.001, d = 0.47$. The same was true for non-white participants $t(163) = 6.73, p < 0.001, d = 1.00$.

Exploration of differences between participants from white and non-white backgrounds on the total ADQ score, demonstrated a two-way interaction between work and ethnicity, $F(1, 2065) = 24.23, p < 0.0001$. For white participants those who had worked with people with dementia scored at a significantly higher level than those who had not, $t(1833) = 15.89, p < 0.001, d = 0.73$. Once again, for non-white participants, working with people with dementia produced an even stronger increase in overall scores, $t(142) = 8.47, p < 0.001, d = 1.29$.

Gender. The two-way interaction between work and gender was not significant for Hope ($F(1, 2063) = 0.088, p = 0.767$), RoP ($F(1, 2068) = 2.445, p = 0.118$), or for the Total ADQ score ($F(1, 2068) = 0.59, p = 0.444$).

Analysis three: Does being affected by dementia have an impact on attitudes toward dementia within different populations?

Gender. The two-way interaction between gender and being affected by dementia was not significant for Hope, $F(1, 2065) = 2.58, p = 0.108$). However, there were significant interactions for both the RoP sub-scale ($F(1, 2070) = 5.15, p = 0.023$), and for the total ADQ score ($F(1, 2070) = 3.96, p = 0.047$). Further analysis using independent samples t-tests indicated that the RoP scores of male participants who

had been affected by dementia was significantly higher than the scores of male participants without this experience ($t(434) = 3.00, p = 0.003, d = 0.29$). However, this was not the case for female participants ($t(1622) = 1.10, p = 0.27, d = 0.05$). Similarly, being affected by dementia raised overall ADQ scores for male participants ($t(433) = 2.56, p = 0.011, d = 0.24$), but not for female participants ($t(1631) = 1.01, p = 0.31, d = 0.05$).

Age. The two-way interactions between age and being affected by dementia for the Hope ($F(1, 2066) = 0.13, p = 0.72$), and RoP subscales ($F(1, 2071) = 0.01, p = 0.93$), as well as for the total ADQ score ($F(1, 2071) = 0.16, p = 0.69$) were not significant.

Ethnicity. The two-way interactions between ethnicity and being affected by dementia for Hope was not significant, $F(1, 2062) = 0.72, p = 0.40$. However, the interactions for RoP ($F(1, 2067) = 13.05, p < 0.001$), and total ADQ score ($F(1, 2067) = 6.57, p = 0.01$) were significant. Subsequent analysis indicated that for white participants, being affected by dementia did not significantly improve either RoP scores ($t(1877) = 0.07, p = 0.95, d = 0.004$), or total ADQ scores ($t(1882) = 0.40, p = 0.69, d = 0.02$).

However, for non-white participants, being affected by dementia did significantly increase both RoP scores ($t(92) = 3.45, p < 0.001, d = 0.56$), and total ADQ scores ($t(75) = 2.01, p = 0.042, d = 0.35$).

Discussion

Given the impact of stigma on people who are living with dementia, it is important to understand how more person-centred attitudes can be fostered. The purpose of this paper was therefore to examine the impact of participants' experience of dementia on their attitudes towards dementia. Experience was defined in two broad ways: either working with people with dementia; or being personally affected by dementia. Our

findings indicated that participants who have worked with people who have dementia, or who have been personally affected by dementia scored higher across both ADQ sub-scales and the overall total score. This suggests contact with people with dementia acts to increase what Kitwood has conceptualised as a “*person-centred*” approach to dementia (Kitwood, 1997). At the same time, there wasn’t an additive effect - that is to say, both being affected by dementia and also working with people with dementia, did not cumulatively increase ADQ scores.

Exploring in more detail the impact of demographic factors on these changes indicated contact with people with dementia interacts most consistently with ethnicity. For non-white participants, working with people with dementia led to significant increases both in ADQ sub-scales and overall total score, while being personally affected by dementia led to significant increases in Recognition of Personhood (RoP) scores and total ADQ score. For white participants, these increases were either not significant or, where present, were weaker. These results need to be seen within the context of research elsewhere which indicates that attitudes of participants from non-white communities towards dementia are less positive (e.g. Sayegh and Knight, 2013). Our research suggests while this is generally the case, having experience of dementia, especially when this is gained as part of work, helps to reduce this disparity.

At the same time, these results need to be interpreted with caution, as the number of non-white participants in the sample was considerably less than the white participants. The comparatively positive attitudes found in non-White participants may have been due to our recruitment methods, which drew on out contacts with health and social services (Moriarty, Sharif & Robinson, 2011). Moreover, it is also clear that the strongest impact of increased levels of contact were evident amongst

those groups of participants who otherwise scored at the lowest levels: in other words, those groups of participants who, when not reporting contact with people with dementia scored at a low level, have the greatest potential to increase their scores. Thus non-white participants generally tended to have lower mean scores than white participants, while men typically scored at a lower level than women. This was the case both when comparisons were made between participants who had and had not worked with people with dementia, and participants who had and had not been personally affected by dementia. One exception to this was younger people (i.e., individuals aged under 64 years), who both consistently scored more highly than older people (i.e., individuals aged over 65 years), and also showed significantly higher increases on the Hope sub-scale and the total ADQ score as a result of working with people with dementia. These findings align with the large body of attitude research literature which argues that experience with, and exposure to an attitude object (e.g., person with dementia), enhances attitudes towards that object potentially through increased knowledge and awareness (Fishbein & Ajzen, 2010). As such the findings strengthen the case that building dementia-friendly communities and increasing opportunities for contact with people with dementia will lessen the stigma that is held towards the condition (Lin and Lewis, 2015).

A number of elements of our methodology need to be taken into account when interpreting this data. The extent to which participants in this study can be taken as being truly representative of the wider population is open to doubt: for instance, recruitment to the on-line survey took place largely through the Dementia Health Integration Team – an established local network within social care, the health service and the academic sector (Cheston, Hancock and White, 2016). Similarly, the paper survey was completed by participants who had attended dementia-related activities.

Therefore it is likely the participants in this study had an interest in dementia even if they had not worked in dementia care, or identified themselves as being affected by dementia. This may have impacted on the positive attitudes towards dementia found in non-white participants, which may not be typical of a wider sample. The recruitment process is also likely to have been associated with the comparatively few participants either aged over 65, or from non-white communities who completed the survey as these populations may not use, or have access to the internet in the same way as other populations (Estacio, Whittle & Protheroe, 2017). We also chose not to define more closely what was meant by the phrase “*personally affected by dementia*”.

While this means that the category was broad, there was also a degree of ambiguity or flexibility about who might have identified themselves in this way. As a result it includes participants who may have actually have very little contact with the person living with dementia as well as those who may have cared for relatives and friends over many years, and those who had, themselves, been diagnosed with dementia.. Potentially, then, the study could have been strengthened by using a more robust measure of level of contact.

Despite these limitations, this study is, we believe, the first attempt to look systematically at whether greater contact with people with dementia is associated with changes in attitudes. As the care of people with dementia is increasingly predicated on the development of dementia-friendly communities, in which the stigma that is sometimes associated with dementia is challenged, then it is important to understand what impact increased levels of contact with people with dementia has on attitudes. In this regard it is reassuring to find that while increased contact with people with dementia may result in greater dementia worry (Cutler & Hodgson, 1996, 2001;

Hodgson, Cutler & Livingston, 1999; Kessler, Tempel & Wahl, 2014), it is also associated with higher levels of person-centred beliefs and attitudes.

Conflicts of Interest: the Authors declare that there are no conflicts of interest.

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