# Understanding what Influences People's Attitudes towards Individuals with Dementia

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Manuscript word count: 3927

## Abstract

Stigmatisation of people with dementia is a problem that affects people's quality of life. This is an increasing problem due to the growing numbers of people diagnosed with dementia as indicated by dementia being the leading cause of death in the UK (Starr, 2017). Identifying the causes behind negative perceptions should help remove, or reduce, stigma. This study investigated how a person's age, familiarity, knowledge, or fear, of dementia influenced their attitudes towards people with dementia. Findings from 130 participants aged 18-64 years old showed that fear of dementia had a significant negative correlation with attitudes towards people with dementia. However, age, familiarity and knowledge, did not have a significant effect on participant's attitudes. Overall, regression analysis indicated that these predictor variables only explained 6% of variance in attitudes toward people with dementia. This indicates that interventions focused on reducing fear of dementia may have a positive effect on public attitudes towards people with dementia, but clearly there are more complex explanations that need to be sought to explain the current levels of stigma seen.

# Understanding what influences people's attitudes towards individuals with dementia

Dementia is an umbrella term for a set of symptoms such as memory loss, difficulties with problem-solving or language and is the leading cause of death in England and Wales (Starr, 2017). Dementia symptoms often get progressively worse over time and become severe enough to effect daily life. Someone with dementia may also experience changes to their mood or behaviour. These symptoms often accompany diseases that affect the brain. Alzheimer's disease is the most common cause of dementia (alz.co.uk, 2016). It is estimated that worldwide 46.8 million people have Alzheimer's or a dementia-related condition, with roughly 850,000 people in the UK living with dementia (alz.co.uk, 2016). Given the trend of an increasing ageing population, it is estimated that over 1 million people in the United Kingdom will be living with dementia by 2021 (Alzheimer's Society, 2012). Further, recent recommendations promote the principle or reduction in dementia risk through changes in lifestyle behaviours e.g. physical activity and weight reduction (Livingston et al., 2017). However, like many mental illnesses, negative perceptions and stigmatisation of the diagnosis of dementia are commonplace and this is likely to be obstructive to the efficacy of interventions aimed at behaviour change.

An example of the perception of dementia is seen in prior research, with "loss, failure and meaningless existence" used to describe those living with dementia (Harris &Keady, 2008). British media helps facilitate these perceptions with headlines such as "The living death of Alzheimer's" used when referring to the disease (Peel, 2014). The phenomenon of "dementia worry" (an emotional response to the perceived threat of a dementia diagnosis) is something that is evident within western middle-aged populations (Kessler, Bowen, Baer, Froelich & Wahl, 2012). The research suggests this perception influences individuals' responses to their own age-related cognitive changes, engagement in prevention behaviour as well as interactions

with people with dementia. Stigmatisation of dementia leads to people who may experience symptoms of dementia delaying seeking help and therefore early diagnosis (Clement et al., 2015). Specifically, stigma was identified as the fourth highest barrier to help-seeking. This is of concern because early diagnosis can slow down progression and help ensure people with dementia, and their families, receive appropriate care and support. The World Alzheimer's Report has said that people living with dementia are often subject to feelings of isolation and being hidden due to stigma (Batsch et al., 2012; Singleton et al., 2017). For people with dementia, social isolation has been shown to be linked to depression, anxiety and self-esteem (Burgener et al., 2015). Quality of life for people can be severely hindered without the appropriate treatment and care (Psota, 2015). What is less understood however, is what factors influence the level of stigma and negative perceptions about dementia that people hold.

Theory may help us understand negative attitudes towards people with dementia. For example, the Intergroup Contact Hypothesis (Pettigrew, 1998) suggests that prejudice is caused by low intergroup contact. Therefore, individuals who have had little contact with people with dementia may be more prejudiced towards them. Research investigating the emotional reactions and beliefs about dementia found that participants who knew someone with dementia, showed less negative reactions and more pro-social reactions towards dementia, than people who didn't know someone with dementia (von dem Knesebeck et al., 2014). In contrast, alternative research has indicated that increased dementia worry is associated with exposure to people with dementia (Kinzer & Suhr, 2016) and proximity to Alzheimer's is associated with greater fear (French, Floyd, Wilkins & Osato., 2012). Therefore, the influence of exposure to dementia on peoples' perspectives of dementia is unclear. Further, although there is extensive research into how increased familiarity is associated with positive attitudes towards people with mental illnesses generally, (Corrigan et al., 2001; Angermeyer & Dietrich, 2006; Arvaniti et al., 2009) there is little research into dementia specifically.

Alternatively, stigma has been described as a problem of knowledge, attitude and behaviour (Thornicroft et al., 2007). This again supports the Intergroup Contact Hypothesis, which states that prejudice is caused by generalisations about groups of people based on incorrect or incomplete information (Pettigrew, 1998). The theory would suggest that learning more about a category of people, should reduce prejudice and negative attitudes. Lee et al. (2010) investigated Korean American immigrants' knowledge of Alzheimer's disease. Findings showed that participants had very poor knowledge of the disease, specifically the causes, treatments and diagnoses, and believed Alzheimer's to be a form of insanity. Those participants who were less familiar with people with Alzheimer's, were more likely to have poorer knowledge than those with higher familiarity. Jang et al. (2010) found similar results, where participants who felt shameful about family members living with Alzheimer's disease were more likely to be less educated and less knowledgeable about the disease. These findings suggest that improving levels of understanding about dementia may help to reduce stigma but what is unclear whether this lack of knowledge is a specific factor at play within the UK.

Perhaps unsurprisingly, fear of dementia has been shown to effect attitudes towards people with dementia. People who fear developing dementia, or dementia related conditions, demonstrate more negative perceptions of people who live with dementia. It was shown that people who were more fearful of dementia, were more likely to think dementia resulted in a low quality of life (von Dem Knesebeck, 2014). Furthermore, increased fear of dementia was associated with more scepticism about the early detection of dementia, and less willingness to care for a family member with dementia. This is important because the problem with stigmatised attitudes in the public is that it may particularly induce fear in older populations. Indeed, it has been found that older participants not only fear developing dementia but show higher degrees of discomfort around friends or relatives with the condition (Corner & Bond, 2004; French et al, 2012). Alternatively, research has suggested that increased age may

positively influence attitudes towards people with dementia (von Dem Knesebeck et al., 2014; Kalaitzaki et al., 2012) with older respondents (aged 60 years and over) more likely to express positive reactions towards people with dementia than younger. Specifically, the research showed that increased age positively affected participant's emotional reactions towards people with Alzheimer's disease (Kalaitzaki et al., 2012). Although the causality of this relationship is uncertain it is perhaps a case of again returning to questions of familiarity.

In summary, a range of research has investigated the variables age, knowledge, familiarity and fear individually, but not collectively. Plus, much of this research has been conducted outside of the UK and concentrated on Alzheimer's specifically therefore, it is unclear whether similar patterns of influence may be apparent. Based on the past research however the following predictions are made:

- $H_1$: Older participants will have a more positive attitude towards people with dementia.
- $H_2$: The more knowledge a person has of dementia, the more positive attitude they will have.
- $H_3$: The more familiar a person is with dementia, the more positive attitude they will have towards people with dementia.
- $H_4$: The more fearful a person is of developing Alzheimer's disease, the more negative attitude they will have towards people with dementia.

## Methods

### Design

A correlational design was used with four predictor variables and one dependent variable. The four predictors were: age; knowledge of dementia; familiarity with dementia; and fear of developing Alzheimer's disease. A multiple regression analysis was carried out to find to what extent these factors could predict attitudes towards people dementia although being cross-sectional in design, causality will not be established.

**Participants**

An opportunistic sampling method was used to recruit 130 participants (13 males, 116 females and 1 identifying as “other”) aged 18-64 years (mean: 24, SD: 9.87). Participants were recruited from a range of sources: a University research participation scheme, local community social media pages, a dementia support group and dementia charity shop. The aim of this approach was to gain a sample with varied levels of familiarity and knowledge of dementia. Individuals with dementia were excluded from participation. All 130 participants provided complete data.

**Materials**

An online questionnaire was delivered via Qualtrics software (Qualtrics, Provo, UT, USA). Demographic details were obtained on age, gender and highest level of education.

To assess familiarity, a four-item measure was adopted. Participants were required to provide a "yes" or "no" response, which was then subsequently converted to a numerical figure with a higher amount indicative of more familiarity with individuals with dementia. An example item was "Have you ever spoken to someone with dementia?”. Scale reliability analysis was good ($\alpha$=.71).

Assessment of knowledge of dementia used the 30 item Alzheimer's Disease Knowledge Scale (ADKS) (Carpenter et al., 2009). Participants were required to provide a response of true or false. A correct response is given a value of 1 with a higher score indicating higher levels of knowledge. An example item is, "Poor nutrition can make the symptoms of Alzheimer’s disease worse." The Cronbach's alpha ($\alpha$=.52) indicates that participants did not respond in a consistent manner in relation to this measure, and therefore the subsequent analysis using the ADKS must be interpreted with caution.

To assess fear, the 30-item measure Fear of Developing Alzheimer's Disease Scale (FADS) was adopted (French et al., 2012). The scale reliability analysis was excellent (Cronbach's α=.93). Statements such as "The older I get, the more fearful I become that I may develop Alzheimer's disease" were presented with a 5-point Likert scale, where 1= never and 5 = always. Responses were summed to produce a score, where a higher score indicates a higher level of fear.

The 19-item attitudes towards people with dementia scale (McParland et al., 2012) was also adopted. Analysis confirmed the measure was reliable (α=.73). The measure is split into two sub-sections: general attitude and post-diagnosis attitude. The general attitude section includes 11 statements about people with dementia such as, "For people with really bad dementia life is not worth living" followed by 5-point Likert scale (1= strongly disagree and 5 = strongly agree). The post-diagnosis section contains two statements followed by 4 questions, each about people with dementia. It starts with questions about early diagnosis: "Just diagnosed - do you think they should...Continue to live alone?" This is followed by the same questions directed towards people who have been diagnosed a long time. Responses are converted to a numerical figure, with a higher score indicative of a more positive attitude towards people with dementia.

**Procedure**

Ethical approval of the research was attained by the University of Winchester ethics committee (ref: HSS/Psych/62036564) and complies with BPS Code of Ethics and Conduct (2009). A participation information sheet was provided containing relevant information about the study and participant requirements and rights. Informed consent was subsequently obtained from participants before they proceeded on to the questionnaire. All data was anonymised with participants allocated a random 4 digit number (which they could quote if wanting to

subsequently withdraw their data from the study). After completing the demographic section, participants then completed the rest of the questionnaire in the order: familiarity with dementia; knowledge of Alzheimer's disease; fear of developing Alzheimer's disease and attitude towards people with dementia. Upon completion, a debriefing page provided details of the study and recommended sources of support for anyone with concerns about dementia.

**Analysis**

Initial analysis was undertaken in order to assess normality of data variables. Table 1 shows the means and standard deviations of participants' age and scores of familiarity, knowledge, fear and overall attitude. Age was positively skewed and so where correlational analysis is presented, a Spearman's Rho is reported. However, in relation to the assessment of whether age, knowledge, familiarity or fear are predictive of attitudes towards people with dementia, a multiple regression was conducted as prior research has shown that this technique is robust to violations of normality (Bohrnstedt et al., 1971).

Table 1

*Descriptive data of study variables*

| | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|
| Age | 18 | 64 | 24.00 | 9.874 |
| Familiarity | 4 | 8 | 6.18 | 1.396 |
| Knowledge | 14 | 30 | 20.85 | 3.298 |
| Fear | 0 | 71 | 32.72 | 15.706 |
| Overall Attitude | 35 | 80 | 57.29 | 7.946 |

## Results

To assess the relationships between variables, a correlational analysis was conducted (see Table 2). As fear of developing Alzheimer's disease increased, attitudes towards people

with dementia decreased: $r$ = -.26, $p$ =.003. Interestingly, age was found to have a significant correlation with familiarity $r$ = -.21, $p$ = .017 and knowledge $r$ = .38, p < .001. Familiarity also had a significant correlation with knowledge $r$ = -.24, $p$ = .007 and fear $r$ = -.20, $p$ =.023.

Table 2

*Correlations Table of study variables*

| | Age | Familiarity | Knowledge | Fear | Overall Attitude |
|---|---|---|---|---|---|
| Age | - | | | | |
| Familiarity | -.21** | - | | | |
| Knowledge | .38** | -.24** | - | | |
| Fear | .03 | -.20* | .12 | - | |
| Overall Attitude | .03 | -.03 | .04 | -.26** | - |

N.B. ** p < .01, * p<.05

Using the enter method, the regression analysis yielded an adjusted $R^2$= .06 suggesting that the factors age, familiarity, knowledge and fear could explain 6% of variance in attitudes towards people with dementia. The ANOVA showed this model to be a significantly better at explaining the variance in the data than the mean, letting us reject the null hypothesis that there is no relationship predictor variables and overall attitudes: $F$(4, 125) = 2.9, $p$ = .03. However, Table 3 shows that only fear was found to be a significant predictor (standardised $\beta$ = -.26, $p$ < .001, CI [-.22, -.05]) of overall attitude towards people with dementia.

Table 3

*Regression Analysis of Variables Predicting Attitudes toward People with Dementia*

| | | Unstandardised Coefficients | | Standardised Coefficients | | | 95% Confidence Interval for B | |
|---|---|---|---|---|---|---|---|---|
| Model | | B | Std. Error | Beta | t | Sig. | Lower Bound | Upper Bound |
| 1 | (Constant) | 62.28 | 6.38 | | 9.76 | .00 | 49.65 | 74.90 |
| | Age | -.09 | .07 | -.11 | -1.22 | .22 | -.23 | .06 |
| | Familiarity | -.57 | .51 | -.10 | 1.12 | .27 | 1.59 | .44 |
| | Knowledge | .24 | .22 | .10 | 1.10 | .28 | -.19 | .68 |
| | Fear | -.13 | .04 | -.26 | 3.00 | .00 | -.22 | -.05 |

## Discussion

Previous research has suggested that the factors age, familiarity, knowledge and fear can affect attitudes towards people with dementia (Corrigan et al., 2001; Lee et al., 2010; von Dem Knesebeck, 2014). The results of this study indicate that collectively these factors only accounted for a small amount of variance in attitudes towards people with dementia, with fear being the only significant predictor. As hypothesised, the results show as an individual's fear of developing dementia increases, their attitudes towards individuals with dementia became more negative. However, contradictory to the other study hypotheses, no significant relationship was evident between age, familiarity and knowledge with attitudes towards people with dementia.

The results support suggestions that fear is a contributing factor to stigmatise attitudes towards people with dementia. Specifically, findings support research that found people more fearful of dementia were more likely to think that people with dementia had a low quality of

life (von Dem Knesebeck, 2014). The correlations indicated that as fear increased, familiarity with dementia decreased, which both could be an indication of avoidance behaviours as a result of fear, and that the more familiar a person is with dementia, the less fearful they will be of developing the condition. In all likelihood, the two factors/explanations may coincide with each other. This association supports previous research that found people who had contact with people with dementia, or had cared for a person with dementia, showed less fearful reactions (Laforce & McLean, 2005). But it also acts in contrast to French et al., 2012 which indicated that closer proximity to individuals with Alzheimer's was associated with greater fear. There is a possibility that the framing of the research towards dementia generally, rather than Alzheimer's specifically, could have altered peoples' perspective or that Alzheimer's (as the dominant dementia condition) may have a higher salience in the public domain which leads to greater fear cognitions. It must also be recognised that the French et al. (2012) study focused on older adults (65-91 years), which may indicate that as well as proximity to people with dementia, proximity to likelihood of diagnosis is influential on psychological factors such as fear. Regardless, it does indicate that the relationship between exposure to dementia, of all kinds, and individuals' perceptions of fear is an area warranting further investigation. This is particularly relevant as if this study's current findings can be replicated, they would indicate that more regular exposure to people with dementia challenges negative cognitions with the exposure allowing people to feel more comfortable and less fearful.

Although increased familiarity was shown to be associated with reduced fear, surprisingly it was not found to be a significant predictor of attitudes towards people with dementia which contradicts previous research (von Dem Knesebeck et al., 2014). Research has previously found that people feel uncomfortable being in the presence of family and friends with dementia, or even ashamed of family members with Alzheimer's disease (Corner & Bond, 2004; Jang et al., 2010). Our findings are more in line with the Contact Hypothesis (Pettigrew,

1998), which states that increasing contact will reduce prejudice and negative perceptions. However, the Contact Hypothesis fails to take into account the content and types of contact and clearly the previous research (Corner & Bond, 2004; Jang et al., 2010) would indicate that contact alone doesn't reduce prejudice, but prejudice reduces contact (Binder et al., 2009). Taken holistically this may mean that people with existing prejudices towards people with dementia before a family member develops the condition may then show a reduction in subsequent diagnosis post contact compared to those with lower preceding prejudices.

Results indicated that age was not significantly associated with attitudes towards people with dementia. This finding contradicts previous research indicating that older people are more likely to show more positive reactions to people with dementia than younger people (von Dem Knesebeck et al., 2014). Further, this is an unexpected outcome as age has previously been found to be a factor effecting attitudes towards those with Alzheimer's disease (Kalaitzaki et al., 2012).

**Limitations**

It should be noted however that although the overall participant age range in the study is good, analysis does still indicate a positive skew of with participants mean age being only 24 years. As a result, there may have been insufficient variation in age across the participant population to explore this influence sufficiently. Further, as previously mentioned scale reliability analysis for the ADKS was poor and therefore the lack of significant association between knowledge of dementia and attitude towards people with dementia is perhaps not surprising. The dichotomous nature of the participant responses for this measure may drive inconsistency by encouraging participants to guess. Alternative measures may allow a more accurate exploration of how education and knowledge of dementia may influence people's attitudes.

**Future directions**

In the future it would be beneficial to adopt a qualitative approach to obtain more contextual information about participants' experiences with people with dementia, to help provide insight into what makes more positive or negative experiences. Further, this may produce a more accurate representation of people's familiarity with dementia rather than measuring the amount of contact. Previous research has shown how socio-economic factors such as education level and household income may be associated with attitudes towards dementia (Chou et al., 1996) and future research should combine this with the other existing factors to try and establish more clearly what may be driving stigmatised perceptions.

To conclude, although this study has only been able to find confirmation of the negative influence of fear of dementia on people's attitudes towards individuals with dementia, it is still too early to discount the contribution of factors such as familiarity, knowledge and age. Reducing fear of dementia in the public would be clearly beneficial, albeit only likely to make a relatively small change in behaviour and attitudes. In general there is a lack of research into what does effect attitudes towards people with dementia, and therefore it is challenging to try and design interventions to increase help-seeking and reduce stigma. Research is needed to both help promote positive perceptions of people with dementia and help reduce, or remove, stigma. This is important as the stigma that surrounds dementia is a known barrier to help-seeking (Clement et al., 2015). Interventions need to be developed that can target the causes of fear in the public alongside further research to try and provide insight into what is clearly a complex model of influences on dementia attitudes.

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