

**A cross-sectional investigation of public attitudes towards dementia in Bristol and South Gloucestershire using the Approaches to Dementia Questionnaire**

**Running title:** Attitudes toward dementia

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## **Abstract**

**Background:** Globally, estimates suggest 36 million people were living with dementia in 2010, with around 800,000 of these living in the United Kingdom. These figures are expected to rise. To date, attitudes toward dementia have largely been explored with health care professionals supporting people affected by dementia. This study sampled person-centred attitudes to dementia across the Bristol and South Gloucestershire area general population. This is important as positive attitudes are consistently associated with more favourable behaviours.

**Methods:** A survey was carried out using a modified version of the Approaches to Dementia Questionnaire (ADQ) Data from people living outside the area, and people who were working with people affected by dementia were omitted from the analysis. Responses from the remaining 794 ADQ questionnaires were weighted to correct for under-represented age, gender and ethnic groups.

**Results:** Younger people held more positive attitudes toward dementia than older people. Individuals who identified themselves as White held more positive attitudes than non-White individuals. Individuals with personal experience of dementia held more positive attitudes than those with no experience of dementia. When considering age differences gender played a role, with younger men having more positive scores than other groups.

**Conclusions:** This is one of the first surveys of public attitudes to dementia to use a validated questionnaire such as the ADQ. The study provides a baseline of attitudes towards dementia for the Bristol and South Gloucestershire areas, against which we will be able to compare changes over time.

**Keywords:** dementia, Alzheimer's disease, attitudes, Approaches to Dementia Questionnaire General (ADQ), stigma

## **Attitudes toward dementia in Bristol and South Gloucestershire: A cross-sectional investigation using the Approaches to Dementia Questionnaire**

### **Introduction**

Global estimates suggest there were 36 million people living with dementia in 2010, and this figure is set to increase to 66 million by 2030 and to 115 million by 2050 (Alzheimer's Disease International, 2013). In the United Kingdom (UK), there are likely to be between 670,000 and 800,000 people living with dementia (Matthews *et al.*, 2013), and again this figure is expected to rise towards 1.7 million by 2051 (Knapp and Prince, 2007). In anticipation of these major global demographic changes, many countries, and in particular those countries with major economies that are part of the G20, have begun to develop and enact plans to address Alzheimer's disease as a national priority (Rosow *et al.*, 2011). Across the UK, policy priorities have focussed on achieving an early diagnosis, and preventing or delaying admission into institutional care (Department of Health (DoH), 2013). This increased emphasis on people affected by dementia living well within the community means that public attitudes towards people affected by dementia have become of increasing importance in the UK as evidence by, for instance awareness campaigns launched to build 'dementia friendly' communities in order to reduce stigma and improve public attitudes to dementia.

In order to meet the health needs of people living in Bristol and South Gloucestershire, the Clinical Commissioning groups, local authorities, Universities, NHS trusts and third sector organisations collaborated in 2012 to establish Bristol Health Partners (BHP). The aim of BHP is to address the major public health needs across the city, and in order to achieve this aim, BHP established 18 Health Integration Teams (HITs), one of which

focussed on developing services for roughly 7,500 people affected by dementia in Bristol and South Gloucestershire<sup>1</sup>. The dementia HIT continues the interdisciplinary and cross-organisational ethos of BHP by bringing together academics, clinicians and commissioners with expertise in dementia care in order to achieve the best quality of life for people and families affected by dementia. The aims of the dementia HIT include improving the training and education of staff working in Bristol with people affected by dementia, to promote public awareness of dementia and to improve attitudes across the city towards people who are affected by the illness.

### **Attitudes and behavior**

There is a large body of evidence indicating a link between attitudes and behaviour with, typically, more favourable attitudes resulting in positive responses to the attitude object (Fishbein and Ajzen, 2010). In the case of dementia this had been widely explored in relation to professionals working with individuals living with dementia (e.g., Kokkonen *et al.*, 2014; Leung *et al.*, 2013; Lintern, 2001). Positive attitudes amongst nursing staff working within institutional care have been linked to training, with those staff who had received training having more positive attitudes about people living with dementia (Leung *et al.*, 2013). In turn, positive attitudes toward dementia are associated with the provision of higher quality by staff (DoH, 2013; Lintern, 2001; Travers *et al.*, 2013).

Research into attitudes toward dementia has tended to focus specific issues such as screening for dementia (Bond *et al.*, 2010) or euthanasia (Williams *et al.*, 2007). Public survey of attitudes toward dementia have been undertaken (e.g., McParland *et al.*, 2012), but

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<sup>1</sup> Although 4,609 people have a formally recorded diagnosis of dementia in Bristol, it is believed that there is a significant dementia gap of roughly 3,500 people who are undiagnosed (Dementia Prevalence Calculator, 2015).

these have been outside of England, UK. These surveys suggest that the general public has, at best, a fair to moderate knowledge about dementia, and that there are often both misconceptions (e.g., dementia is a normal part of ageing), and a lack of clarity about at which point normal age-related memory loss problems become severe enough to indicate dementia. Moreover, many surveys did not make use of validated scales (Cahill *et al.*, 2015), thus limiting the ability of researchers to make meaningful comparisons across settings, populations, or over time.

### **Surveying public attitudes towards dementia in Bristol and South Gloucestershire**

One widely used measure is the Approaches to Dementia Questionnaire (ADQ, Lintern, 2001). Originally developed for exploring attitudes in staff working with people affected by dementia, the 19-item scale had a score range from 19 to 95. The ADQ is made up of two sub-scales: ‘*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); and ‘*Hope*’ (8 items indicative of a sense of optimism or pessimism about the abilities and the future of the person affected by dementia). 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. The ADQ has been shown to be consistently reliable and easy to administer and score (Kokkonen *et al.*, 2014), and used to collect data from large samples (Travers *et al.*, 2013).

Over the last few years, online surveys have increasingly replaced the use of either interviews or pen and paper questionnaires as a means of collecting data. An online survey

has a number of advantages over more traditional forms of evaluation including being efficient and cost-effective to administer (Sommer and Sommer, 2001), and allowing participants to access and complete the survey at a time that is convenient to them (Eysenbach and Wyatt, 2002). The ADQ has been used as an online survey; a Chinese version of the ADQ reported results from 1,700 care-home staff (Leung *et al.*, 2013).

### **Aim of this study**

The aim of the current study was to carry out a survey of public attitudes towards people affected by dementia in Bristol and South Gloucestershire. As well as being of interest in its own right, this survey would also act as a baseline measure against which changes in attitudes towards people affected by dementia could be reassessed at timely intervals. This is anticipated to provide a gauge against which to measure whether there are changes in local attitudes toward dementia (Sommer and Sommer, 2001).

### **Methods**

#### **Ethics**

Ethical approval was granted by the University of the West of England (UWE). The online survey was hosted by the Avon and Wiltshire Mental Health Partnership NHS Trust<sup>2</sup>. Participants were informed that the study was being carried out by BHP (with the partner organisations listed).

#### **Alterations to the ADQ**

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<sup>2</sup> <https://www.oc-meridian.com/AWP/survey/ApproachesToDementia>

With the permission of the authors of the questionnaire, the wording of some questions of the online version was adapted in order to be consistent with contemporary language in dementia care. In all six of the items were changed (three relating to the Hope and three to the RoP scale)<sup>3</sup>.

### **Distribution of the survey**

People living and working locally were encouraged to complete the online ADQ during a seven-month period between September 2013 and March 2014. An opportunistic sampling method was used (Sommer and Sommer, 2001) with the online survey being publicised across the Bristol and South Gloucestershire area through the members of the dementia HIT, including via social media. This survey was open to everyone living in the BHP area including people affected by dementia, staff who worked in dementia care, as well as those who had more limited knowledge of the condition. During this period paper versions of the ADQ were also distributed: to people attending dementia awareness training, to health champions who were working directly in the community with no specialist knowledge of dementia, and to community groups who were about to start a reminiscence project.

### **Demographic information**

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<sup>3</sup> Items 1 and 6 referred to “*dementia sufferers*” and this was replaced by the phrase “*people with dementia*”. Item 5 (“*It is important for people with dementia to have stimulating and enjoyable activities to occupy their time*”) and 12 (“*Good dementia care involves caring for a person's psychological needs as well as their physical needs*”) were thought to be oriented towards a care environment. Both were slightly modified in order to be more inclusive. They now read “*It is important for people with dementia to continue to be active and involved in the things that interest them*” and “*Achieving a good quality of life for people with dementia involves taking account of their psychological and social needs as well as their physical needs*”. Item 13 (“It is important not to become too attached to residents”) was altered to “*It is important not to get too attached to someone with dementia*”, while in item 19 the word “special” was replaced by “*particular*” as “*special*” is a word associated with services and disability.

Participants were also asked to provide general background information on their age, gender, ethnicity, whether they were living in the Bristol or South Gloucestershire area, whether they have been affected by dementia, and whether they worked with people with dementia.

## **Participants**

Responses from 2,201 individuals were obtained (online, 1918; paper, 283). In order to examine public attitudes towards dementia of people living within Bristol and South Gloucestershire, only data from individuals who identified themselves as living in this area were analysed, thereby excluding respondents who identified themselves as having worked with people affected by dementia in order to maximise the representativeness of this sample. In all, data from 794 individuals were included (online, 761; paper; 33) as shown in Table 1. Data from this subset was then weighted according to population statistics from the Office of National Statistics in order to adjust for the over-representation of some groups (e.g., White females) and an under-representation of other communities (e.g., males of mixed ethnicity) (Gorman *et al.*, 2014)<sup>4</sup>.

## **Statistical analysis**

A series of exploratory and main analyses were conducted on the ADQ data. Chi-square was used to undertake exploratory analysis with regards to the representativeness of the sample. Prior to this analysis, demographic data were re-grouped into dichotomous variables as some demographic samples had only one individual assigned to the group. For the main analyses, two-sided *t*-test analyses were performed on the weighted data to explore differences in scale scores between demographic groups in respect to the ADQ responses. Cohen's *d* was used to

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<sup>4</sup> <http://www.ons.gov.uk/census>, downloaded on 26<sup>th</sup> August 2015.



quantify effect size. In general, Ellis (2010) cautiously gives broad rules of thumb for the interpretation of  $d$ , to the effect that  $d < 0.1$  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 in between participants who either were or were not affected by dementia. No differences were detected in terms of gender ( $\chi^2(1) = 0.001, p = .98$ ), age group (those aged under 65 and those aged 65 and over) ( $\chi^2(1) = 0.81, p = .37$ ), or having worked with someone affected by dementia ( $\chi^2(1) = 1.59, p = .21$ ). However, there was a difference between White and non-White participants, with a larger proportion of White individuals (44.8%) reporting being personally affected by dementia than non-White respondents (2.2%),  $\chi^2(1) = 45.53, p < .001$ . In addition, a larger proportion of women reported working with people affected by dementia compared to men (41.2% versus 8.6% respectively),  $\chi^2(1) = 17.77, p < .001$ .

### **Exploring demographic differences in responses on the ADQ**

Table 2 shows the weighted descriptive statistics of the ADQ arranged by the demographic background of participants. Whilst overall data indicates a largely positive attitude toward people affected by dementia in the sub-sample (Hope and RoP mean item scores 3.41 and 4.32 respectively, out of a maximum of 5), there may be some differences in attitude based on demographic characteristics (e.g., mean item score of women on the Hope and RoP scale are 3.39, and 4.45 respectively. Men achieved an identical mean score on the Hope scale to women, and a slightly lower average item score of 4.35 on the RoP scale.). In order to explore this, a series of analyses were conducted examining gender, age, ethnicity and experience with dementia.

### **Gender differences**

No differences in scores were found between the genders on the Hope ( $t(790) = -1.06, p = .29, d = .08$ ), RoP ( $t(790) = -1.55, p = .12, d = .11$ ), or total scores ( $t(790) = -1.52, p = .13, d = .11$ ).

### **Age differences**

Younger respondents (those aged under 65) scored at a higher level on both the Hope ( $t(790) = 5.83, p < .001, d = .50$ ), and the RoP scales ( $t(790) = 3.03, p = .002, d = .28$ ) than those aged 65 and over. Similarly, the total ADQ score was significantly higher for the younger age group compared to the older age group ( $t(790) = 5.13, p < .001, d = .47$ ).

### **Ethnicity differences**

Individuals who identified themselves as White scored at a higher level on the Hope ( $t(789) = 5.46, p < .001, d = .72$ ) and the RoP scales ( $t(789) = 3.90, p = <.001, d = .66$ ) as well as on the total scores ( $t(789) = 5.44, p < .001, d = .83$ ) than individuals of non-White ethnic groups.

### **Differences based on individual's personal experience of dementia**

There was a significant difference between individuals who reported having been affected by dementia and those who had not been. People who had been affected by dementia scored higher on the RoP scale ( $t(792) = 4.57, p < .001, d = .32$ ) and overall ( $t(792) = 3.07, p = .002, d = .22$ ), although there was no difference between these two groups on the Hope scale.

### **Gender and age differences**

Previous research indicates that gender, age and experience of dementia are all likely to influence attitudes (Fishbein and Ajzen, 2010), therefore, a further chi-square and ANOVA analysis was run to explore potential interactions. Splitting the sample into four demographic subgroups (males aged  $\leq 64$ , males aged  $\geq 65$ , females aged  $\leq 64$ , females aged  $\geq 65$ ), chi-square results indicated no differences between demographic groups and personal experience of dementia ( $\chi^2(3) = 1.33, p = .72$ ). However, ANOVA results indicated an interaction between gender and age group ( $F(2,790) = 3.40, p = .03$ ). Univariate follow-up tests showed interactions present on the RoP ( $F(1,789) = 6.69, p = .01$ ) and total scores ( $F(1, 789) = 6.28, p = .01$ ), but not the Hope scale ( $F(1, 789) = 2.97, p = .09$ ). Examination of mean scores showed younger men scored slightly higher than the other groups on these scales (weighted means are shown in Table 3).

## Discussion

This is one of the first surveys of public attitudes towards dementia to use a validated questionnaire such as the ADQ. Typically where large-scale surveys have focussed on the general public unvalidated questionnaires were used (e.g., McParland *et al.*, 2012). In instances where validated scales were used, the focus was on attitudes of staff working in dementia care rather than the general public (e.g., Lintern, 2001; Moyle *et al.*, 2012). By contrast, this study provides a baseline of attitudes held by the layperson towards dementia for the Bristol and South Gloucestershire areas, against which we will be able to compare changes over time.

In addition to its role as a baseline measure, a number of elements stand out from this current sampling. Importantly, although we have identified age, ethnicity and experience of dementia variation in attitudes within the general population in Bristol and South Gloucestershire, nevertheless scores on the ADQ were generally positive, and certainly seem to be comparable with those found amongst dementia care workers. The average item score in this study of 3.41 on the Hope scale and 4.32 on the RoP scale are similar to the reported average item scores of care staff for the Hope scale of 3.66 (Moyle *et al.*, 2012) and 3.71 (Travers *et al.*, 2013), and 4.35 and 4.49 for the RoP scales.

A consistent finding within the research literature is that age plays an important role in mediating a range of attitudes and beliefs about dementia, both for staff working in dementia care, and of the general public. Thus Leung *et al.*, (2013) reported staff working in residential homes in Hong Kong who were in their twenties scored at a higher level on the

ADQ than did their older colleagues, while Kada *et al.*, (2009) found staff within Norwegian nursing homes aged over 50 years of age reported significantly lower hope attitudes than did those aged under 40. Similarly, in a survey of public opinion about dementia in Northern Ireland, McParland *et al.*, (2012) reported older people were more likely to hold stigmatising views such as being more likely to believe newly diagnosed people with dementia were not able to be able to lead independent lives. This difference in attitudes also seems to be apparent in emotional responses to dementia. A 2014 YouGov poll commissioned by channel five news in the UK found the fear of dementia was particularly strong amongst older people, where dementias was feared even more strongly than cancer<sup>5</sup>. Other previous research indicates that gender also plays a significant role in attitudes towards people affected by dementia, with women having more positive views than men. McParland *et al.*, (2012) found that across some of their items women had slightly different attitudes to men – for instance they were a little less likely to agree that “*there comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe*” and slightly more likely to feel that “*people with dementia are not treated like thinking human beings*”. Women were also distinctly more reluctant to see residential care as the best option.

In this study, although we found that gender was not significant on its own, there was an interaction between age and gender, with younger men having significantly more positive attitudes than either older men or women of all ages. Although there was no significant difference between the groups on their personal experiences of dementia, we do not know the nature or the quality of these personal experiences. Thus, it may be that even young men with some personal experience of dementia have less experience of providing personal care than women or older people.

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<sup>5</sup> <http://www.channel5.com/shows/5-news/features-archived/channel-5-news-poll-people-fear-dementia-warning-more-than-cancer-research> (accessed 7th October, 2015)

Research elsewhere suggests that the impact of personal experience of dementia on attitudes is complex. Thus, McParland *et al.* (2012) found that knowing someone affected by dementia was not associated with a more positive attitude toward dementia, although in our study we did find that personal experience of dementia was significantly associated with a higher RoP score. However, while personal experience may enable people to be more aware of the enduring human nature of people affected by dementia, it does not necessarily mean that people will also be more hopeful about living well with dementia. Thus, having a parent who develops dementia has been associated with greater personal concerns about developing the disease oneself but does not translate into greater levels of anticipatory anxiety about dementia (Cutler and Hodgson, 1996). This is consistent with our finding of no difference between participants with and without personal experience of dementia on the hope scale.

It is likely that there are differences between people from different communities in their knowledge and attitudes towards dementia. Compared to similar Caucasian communities, Chinese people are more likely to believe that Alzheimer's disease is a normal part of ageing (Gray *et al.*, 2009; Low *et al.*, 2010), less likely to correctly recognize symptoms of dementia (Low *et al.*, 2010), and have less knowledge about Alzheimer's disease (Ayalon and Arean, 2004). In this study, while we were able to identify that White participants had more positive attitudes towards dementia than non-White participants, disappointingly, due to lack of data we were not able either to examine interactions between variables, nor to look at a more detailed breakdown by ethnicity.

### **Study limitations**

Although the data collected was weighted in order to make the sample more representative of the Bristol and South Gloucestershire population, there are a number of reasons why the results are not completely representative of the population currently living in the dementia HIT area. For instance, data on educational level was not collected. There was an underrepresentation of views from people of non-White ethnicity. Furthermore, even though we were able to exclude people who worked in dementia care from our analysis, nevertheless our method of sampling is likely to have meant that people with an interest in dementia from the general population would still have been over-represented.

## **Conclusion**

As increasing emphasis in the UK and elsewhere is being placed on promoting public awareness of dementia and overcoming the stigma that has surrounded the condition, it is important to understand and to track changes in public understanding of dementia. The distribution of a slightly modified version of the Attitudes to Dementia Questionnaire across the Bristol and South Gloucestershire area has enabled us to sample person-centred attitudes across the area. Having weighted the data to reflect the diverse nature of the population, our analysis is consistent with research elsewhere such as the finding that younger people tend to have more positive attitudes. The study also highlights new areas for future study, such as exploring further the finding that when considering the impact of age, it was clear gender played a role in attitudes. In addition, having now created a baseline, it will be possible to chart changes in attitudes across time as the work of the dementia HIT continues to grow.

## **Conflict of Interest**

None

### **Description of authors' roles**

R. Cheston designed the study, and co-wrote the paper. J. Hancock facilitated the set-up of the online questionnaire to collect the data, carried out the statistical analysis, and co-wrote the paper. P. White was responsible for checking the statistical analysis, and commenting on drafts of the paper. Other members of the Bristol and South Gloucestershire Dementia HIT have contributed to the development and implementation of the study at different stages, and have opportunities to comment on the paper.

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**Table 1.** Demographic data for the sample ( $n = 794$ )

	<b>Male</b>	<b>Female</b>	<b>Total</b>	<b>Bristol/ South Glos. population</b>
<b>Age</b>				
16 to 24	64 (8.1%)	63 (7.9%)	127 (16.0%)	98,916
25 to 49	177 (22.2%)	179 (22.5%)	356 (44.7%)	258,706
50 to 64	80 (10.1%)	84 (20.6%)	164 (20.7%)	115,005
65 and over	64 (8.1%)	81 (10.2%)	145 (18.3%)	108,267
Missing			2 (0.3%)	
<b>Ethnicity</b>				
White	368 (46.4%)	379 (47.7%)	747 (94.1%)	609,166
Asian/Asian British	0 (0.0%)	8 (1.0%)	8 (1.0%)	23,548
Black/Black British	14 (1.8%)	8 (1.0%)	22 (2.8%)	27,772
Mixed Ethnicity	1 (0.1%)	8 (1.0%)	9 (1.1%)	19,105
Other Ethnic Group	2 (0.3%)	1 (0.1%)	3 (0.4%)	3,815
Missing			5 (0.6%)	
<b>Affected by dementia</b>				
Yes	201 (25.3%)	194 (24.4%)	395 (49.7%)	
No	185 (23.3%)	212 (26.7%)	397 (50.0%)	
Missing			2 (0.3%)	

**Table 2.** Descriptive statistics of ADQ data for people living in the Bristol Health Partners area weighted to account for ethnicity, gender and age ( $n = 794$ ).

		<b>Hope scale</b>	<b>RoP scale</b>	<b>Total</b>
<b>Demographic</b>		<b>Mean <math>\pm</math> SD</b>	<b>Mean <math>\pm</math> SD</b>	<b>Mean <math>\pm</math> SD</b>
Gender	Female	27.08 $\pm$ 5.04	48.95 $\pm$ 4.61	77.70 $\pm$ 8.48
	Male	27.08 $\pm$ 5.16	47.84 $\pm$ 5.09	75.58 $\pm$ 9.03
Age group	$\leq 64$	27.70 $\pm$ 4.29	47.82 $\pm$ 4.70	75.52 $\pm$ 7.84
	$\geq 65$	25.30 $\pm$ 5.31	46.53 $\pm$ 4.35	71.80 $\pm$ 7.90
Ethnicity	White	27.46 $\pm$ 4.40	47.72 $\pm$ 4.67	75.17 $\pm$ 7.82
	Non-White	23.61 $\pm$ 6.15	44.91 $\pm$ 3.75	68.52 $\pm$ 8.23
Affected by dementia	Yes	27.37 $\pm$ 4.69	48.32 $\pm$ 4.47	75.69 $\pm$ 7.87
	No	27.14 $\pm$ 4.49	46.83 $\pm$ 4.74	73.97 $\pm$ 8.00

Note: RoP scale = Recognition of personhood scale

**Table 3.** Weighted descriptive statistics of ADQ data by gender and age group.

	<b>Hope scale</b>	<b>RoP scale</b>	<b>Total</b>
<b>Demographic group</b>	<b>Mean <math>\pm</math> SD</b>	<b>Mean <math>\pm</math> SD</b>	<b>Mean <math>\pm</math> SD</b>
Male aged $\leq 64$ ( $n = 321$ )	27.70 $\pm$ 7.71	48.96 $\pm$ 12.24	76.75 $\pm$ 18.30
Male aged $\geq 65$ ( $n = 64$ )	24.71 $\pm$ 8.06	45.69 $\pm$ 6.16	70.41 $\pm$ 11.62
Female aged $\leq 64$ ( $n = 326$ )	27.47 $\pm$ 3.74	47.65 $\pm$ 4.00	75.11 $\pm$ 6.64
Female aged $\geq 65$ ( $n = 81$ )	25.80 $\pm$ 6.89	47.18 $\pm$ 5.87	72.97 $\pm$ 10.16

Note: RoP scale = Recognition of personhood scale