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Micah Huckabee

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The Effects of a Dementia Simulation Experience on Attitudes Towards People with Dementia

Micah L. Huckabee

University of Arkansas

Primary Investigator: Michelle Gray, Ph.D.

Committee Members: Alisha J. Ferguson, Ph.D. and Amanda L. Sullivan, Ph.D.

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Abstract

Introduction: The neurodegenerative effects of dementia resulting in cognitive and behavioral impairments is plausibly one of the reasons for a societal stigma towards individuals with dementia. Societal stigmas are associated with decreased life satisfaction, depressive symptoms, and decreased psychological well-being for stigmatized individuals. In an effort to improve attitudes towards individuals with dementia, this study utilized a dementia simulation to measure attitudinal changes after a dementia simulation. **Methods:** There were 33 participants in this study (13 male and 20 female) between the ages of 18 and 25. Participants completed a Dementia Attitudes Scale (DAS) survey, and then they dressed in a set of props that mimicked the effects of aging and dementia. Participants were then instructed to complete a series of tasks common to the routine of an older adult with dementia. Upon completion, participants were instructed to remove the props and complete the DAS survey again. **Results:** Attitudes improved significantly from pre- to post- simulation (102.5 to 108.1) by 5.54% through improvements in social comfort and dementia knowledge. **Discussion:** Because dementia simulations have the ability to improve attitudes towards dementia, thus destigmatizing individuals with dementia, dementia simulations should be made readily available for the general public in an effort to improve the life satisfaction and psychological well-being of individuals with dementia.

Introduction

Dementia is a neurodegenerative disease that is portrayed by loss of memory, and impairments in cognitive functioning and behavioral tendencies. The most common form of dementia is Alzheimer's Disease as it currently affects 47 million people worldwide and is expected to increase to 131 million people by the year 2050 (Anda, Chapman, Moore, Strine, & Williams, 2006; Comas-Herrera, Guerchet, Karagiannidou, Knapp, & Prince, 2016). The impairments in cognitive functioning in dementia result in difficulty with processing thoughts, leading to obstructions in understanding and producing speech. These impairments also lead to issues with the ability to recognize objects and carry out motor movements, despite the physical potential for the movements to occur (Grebb, Kaplan, & Sadock, 1995). These behavioral deviations from social norms by individuals suffering with dementia is plausibly one of the reasons for a societal stigma surrounding the disease. The behavioral reaction for those with a stigma towards individuals with dementia includes a desire for social distance from the individual with the disease (Werner, 2005). This stigma towards people with cognitive impairments resulting in social distance/isolation greatly affects individuals with the disease in a negative manner, causing low self-esteem and decreased psychological well-being (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). In a study on the effects that stigmas have on the well-being and life satisfaction of those with mental disabilities, it was found that stigmas correlated to decreased life satisfaction and depressive symptoms (Markowitz, 1998).

In order to improve the overall health and life satisfaction of individuals suffering with dementia, efforts must be made to destigmatize these individuals by positively changing the negative attitudes and perceptions that people have towards individuals with dementia (Markowitz, 1998; Anda, Chapman, Moore, Strine, & Williams, 2006). One way to improve

attitudes of adults towards people with dementia is to allow non-demented adults to experience what it is like to live with dementia, which has not been done in a controlled research setting (Buelow, McFadden, Miron, & Nazario, 2017). Research suggests that experiential learning is an effective way to better understand another person's perspective, but not much has been done to see how personally experiencing dementia can possibly change the attitudes of people towards individuals with dementia (McFadden & O'Connor, 2010; Wood, 2002). Previous research has concluded that empathy and attitudes of healthcare providers directly impacts patient care, and the quality of care for older adults may be enhanced through curriculum and simulation activities for healthcare providers (Chen, Kiersma, Yehle, & Plake 2015). Other studies have indicated that aging simulation increases empathy of young adults towards older adults, but not much has been done to demonstrate how a dementia simulation will affect attitudes of adults towards individuals with dementia (Varkey, Chutka, & Lesnik, 2006). For this project, participants will experientially learn what it means to briefly live with dementia as an older adult by undergoing a dementia simulation experience.

The purpose of this research project is to measure the attitudes of adults before and after a dementia simulation experience through a survey to determine if briefly experiencing dementia can destigmatize the negative attitudes in our society towards individuals suffering with the disease. The survey will ask questions that will determine "dementia knowledge" and "social comfort" before and after the simulation (McFadden & O'Connor, 2010). We hypothesize that the attitudes of participants will change positively through increased dementia knowledge and increased social comfort towards those with dementia after the simulation experience. If our hypothesis is supported, then simulation experiences should be made readily available in order to destigmatize dementia. This change in negative attitudes towards individuals with dementia

could improve the overall health of individuals with dementia and positively affect the perceptions of people who are commonly around people with dementia, including caregivers, physicians, and family members (Markowitz, 1998; Anda, Chapman, Moore, Strine, & Williams, 2006).

Literature Review

Alzheimer's Disease, the most common form of dementia, is a neurodegenerative disorder marked by cognitive decline (NIH, 2016). Some of the main components of Alzheimer's Disease include the loss of connections of nerve cells in the brain and the build-up of amyloid plaques and neurofibrillary tangles. These changes to the brain cause a significant decrease in cognitive and functional ability in adults with Alzheimer's Disease and eventually lead to complete dependence on caregiver (NIH, 2016).

These negative effects of the most common form of dementia could be the reason for the societal stigma towards individuals with dementia (Mukadam & Livingston, 2012). This stigma can lead to low self-confidence, isolation, decreased life satisfaction, and depressive symptoms among individuals with dementia (Mackenzie, 2006; Link, 1987; Markowitz 1998). In order to improve the quality of life for individuals with dementia, efforts must be made to decrease the stigma, increasing positive attitudes towards individuals with the disease. The purpose of this study is to determine an effective mechanism for increasing positive attitudes towards individuals with dementia, thus decreasing the stigma and improving life satisfaction for individuals with dementia.

Societal Stigma

Stigma is defined as living in social disgrace due to a quality that discounts a person as inferior (Mukadam & Livingston, 2012). The cognitive impairments caused by dementia that can

result in socially inappropriate behaviors is plausibly the reason for the societal stigma towards those with the disease (Mukadam & Livingston, 2012). One study showed that general practitioners perceived people with dementia as unable to exhibit reciprocity, and these perceptions were associated with a stigma towards individuals with dementia (Gove, Small, Downs, & Vernooij-Dassen, 2017). It was also found that caregivers saw patients with dementia more negatively than they saw them positively (Askham, 1995), and nursing home workers described people with Alzheimer's Disease more negatively than they described healthy older adults (Kahana & Ercher, 1996).

Attitudes can be described as the combination of emotional, cognitive, and behavioral factors that contribute to a reaction to a person (Breckler, 1984). A positive correlation was found between knowledge about caring and treating older adults and positive attitudes and perceptions towards aging (Bleijenberg, 2012), and studies have shown that nursing and pre-medical undergraduates have accounted for lower amounts of knowledge towards caring for older adults (Eltantawy, 2013; Liu, Pu, Wang, & Hu, 2014). This lack of knowledge can be correlated to more negative than positive attitudes towards aging adults.

Effects of the Stigma

There are many negative effects experienced by stigmatized individuals. Because of the stigma associated with dementia, those with the disease may begin to also view themselves in a negative manner, leading to low self-confidence, isolation, and internalized shame (Link, 1987; Mackenzie, 2006; Burgener & Berger, 2008). Because of these symptoms of stigma, those with dementia may not take the steps to enhance their situations that they might otherwise take if there was no stigma at all (Link, 1987).

Another effect of stigma is that individuals may not seek early diagnosis for dementia because it is a very negatively viewed disease (Mukadam, Cooper, & Livingston, 2011). This can be highly problematic because a lack of early diagnosis is associated with poor health outcomes, increased burden on the caregiver, and a lack of adequate planning for care for the individual (National Audit Office, 2007; Mukadam & Livingston, 2012). General practitioners with negative attitudes towards individuals with cognitive impairments have reported that they lack confidence in themselves to improve the condition of their patients with dementia, and the reverse is true for individuals with positive attitudes towards dementia (Turner, Iliffe, Downs, Wilcock, Bryans, & Levin, 2004). This shows that the general practitioners with negative attitudes may not be able to properly diagnose and care for individuals with dementia since they lack the confidence in themselves to improve the quality of life of their patients with dementia (Turner, Iliffe, Downs, Wilcock, Bryans & Levin, 2004).

An increase in stigma towards individuals with dementia is also associated with an increase in the burden of caregivers (Werner, Mittelman, Goldstein, & Heinik, 2012). Caregivers reported a reduction in the social and support system for themselves and individuals they cared for as the number of visits and social interactions with their person with dementia decreased as time progressed (Liu, Hinton, Tran, Hinton, & Barker, 2008; Werner, Goldstein, & Buchbinder, 2010). If caregivers lack the support they need to lighten the burden, they are more susceptible to experience depression and physical illness, leading to less effective care for their person with dementia and also leading to an increased cost of healthcare (Werner, Mittelman, Goldstein, & Heinik, 2012).

Interventions and Experiential Learning as a Mechanism to Change Attitudes

Because of these detrimental social and physical outcomes that negative attitudes have on stigmatized individuals, there must be a way to decrease the stigma that surrounds dementia patients. Increasing public knowledge about dementia has the potential to decrease the stigma, since knowledge and attitudes are positively correlated (Mukadam & Livingston, 2012; Bleijenberg, 2012).

Studies have shown that attitudes and knowledge are improved after interventions (George, 2014; Garrie, Goel, & Forsberg, 2016; Maharaj, 2017). In one study, students expressed more positive attitudes towards what they were learning about when they experientially learned versus simply attending a traditional lecture (Pugsley & Clayton, 2003). Another study found that nursing students who experientially learned through clinical placements had more positive attitudes and improved knowledge than other students who learned with an online module or had no interactions with patients with dementia (Kimzey, Mastel-Smith, & Alfred, 2016).

Nursing education has adapted to implement simulation as an effective part of instruction (Maharaj, 2017). Nursing students who experienced a simulated interaction with actors portraying someone with Alzheimer's Disease had a significant increase in knowledge about Alzheimer's Disease from before to after the simulation (Maharaj, 2017). In addition to this, experiential learning through the form of creative storytelling with patients with dementia resulted in more positive attitudes and a more humanistic and individual-centered perspective for students towards dementia patients (George, 2014).

Positive Outcomes to Improved Attitudes and Knowledge Towards Dementia

Improved attitudes and knowledge surrounding dementia can have the potential to greatly improve the care, and in effect, the quality of life of dementia patients (Kimzey, Mastel-Smith, & Alfred, 2016). Students who have more positive attitudes and a steady knowledge of dementia

have a better understanding and an eagerness to work with dementia patients (Baillie, 2012; Andrew, Robb, Ferguson, & Brown, 2011; Brown, Nolan, Nolan, Davies, & Keady, 2008). This can have huge implications on the quality of care that dementia patients can receive (Kimzey, Mastel-Smith, & Alfred, 2016). As previously mentioned, general practitioners with more positive attitudes towards dementia have reported they have more confidence in their ability to improve the conditions for those with dementia than those with negative attitudes (Turner, Iliffe, Downs, Wilcock, Bryans, & Levin, 2004). Also, reductions in the stigma towards dementia can lighten the burden on caregivers, improving their condition so that they can provide more quality care for their person with dementia (Werner, Mittelman, Goldstein, & Heinik, 2012).

Interventions that have the potential to improve attitudes and knowledge towards those with dementia will have the greatest impact if it can target the general public as well as medical professionals (Mukadam & Livingston, 2012). It would also be beneficial for the intervention to have a brief time-commitment so that it can involve future medical professionals (medical students) with very busy schedules (Garrie, Goel, & Forsberg, 2016).

Methods

Participants

There were 33 participants in this study between the ages of 18 and 25 (mean age = 20.64 + 1.636). There were 13 males and 20 females. All participants completed an Informed Consent that was approved by the Institutional Review Board at the University of Arkansas prior to the trial.

Procedure

Upon arrival to the Exercise Science Research Center, the participant completed the informed consent, and then age, sex, height, and weight of the participant were recorded. After

this, the participant completed a Dementia Attitudes Scale (DAS) questionnaire as a baseline measure of attitudes towards individuals with dementia. The DAS questionnaire is a 20-question survey that has a two-factor structure, measuring “dementia knowledge” and “social comfort,” and it was utilized in this study to measure the change in attitudes of adults towards people with dementia before and after a simulation experience (McFadden & O’Connor, 2010). An example of a dementia knowledge question is “Difficult behaviors may be a form of communication for people with Alzheimer’s Disease and Related Dementias (ADRD),” and an example question for social comfort is, “I feel confident around people with ADRD.” Participants could choose from 7 options, ranging from “strongly agree” to “strongly disagree.” Several questions were reversed scored, but the more positive the total score on the DAS questionnaire, the more positive attitudes and vice versa for more negative scores. The most positive total score possible on the DAS scale is 140, as the survey contained 20 questions, each worth 7 points, and the lowest score possible is 20, indicating the most negative attitudes. See the Appendix for the complete DAS questionnaire ((McFadden & O’Connor, 2010). The DAS greatly correlates with other scales that measure ageism and attitudes towards disabilities, so it is a valid method of measuring attitudes of adults towards people with Alzheimer’s Disease (McFadden & O’Connor, 2010).

Upon completion of the survey, the participant was asked to put on a set of accessories that imitate the symptoms of dementia as well as normal aging. These props included glasses that impaired vision, simulating cataracts, and oversized nitrile gloves that mimicked a loss of sense of touch and tactile function. A music player with headphones was used to give off irritating background noises to induce confusion and make the participant feel disconnected from the world around them, a symptom of dementia.

Once dressed in these props, the participant was directed outside of a room that imitated a kitchen/living area. The participant was instructed to complete a series of tasks in the room, reproducing the normal routine of an older adult with dementia. The participant was given the instructions one time verbally. The tasks included: “Fill the blue pill bottle. Lay out an outfit to wear including the red sweater. Put toothpaste on the toothbrush. Pay the electric bill. Sort out \$2.89 in real coins.” These tasks were not as simple as they seemed. For instance, there were two different colored pill bottles in two different locations, but the participant was instructed to only fill the blue pill bottle. The red sweater was located in a pile of clothing, so it required some sorting to locate it. In addition, the participant needed to remember to lay out an entire outfit including socks, pants, and other garments. An electric bill was laid out in one location, but there was also a water bill laid out in another location, forcing the participant to remember which one was instructed. For the sorting of \$2.89, the participant was sorting coins from a mason jar full of coins. The details involved in the tasks required for the participant to recall the exact instruction in order for the task to be successfully accomplished.

Once the participant completed the tasks, the participant was instructed remove the props they were wearing, and the participant was informed of the tasks successfully and unsuccessfully completed as well as the consequences of not completing the specific task successfully. For instance, if the participant filled the wrong pill bottle, they were told that they took the wrong medications that day. If the participant failed to pay the electric bill, they were told that their gas might get shut off later that day. No participants actually completed all of the tasks successfully. Thirteen participants were able to complete at least three tasks successfully, and the other twenty completed two or less of the tasks successfully. After being informed of the tasks accomplished, the participant was escorted out of the room and debriefed about their thoughts and feelings

during the simulation. Following the debriefing, the participant completed the DAS questionnaire again.

Statistical Analysis

Total scores on the DAS pre- and post- simulation indicate the change in attitude, with higher numbers indicating a more positive attitude, and lower numbers indicating a more negative attitude. An analysis of variance (ANOVA) with repeated measures was used to determine the effects of the dementia simulation experience. Since men and women may experience change at different rates or in different ways, sex differences were accounted for statistically. In addition, individuals who have known someone with dementia may also experience change in attitudes at a different rate or in different ways than individuals who have not known someone with dementia. The DAS questions can be divided into “social comfort” and “dementia knowledge” categories. The independent variables were sex, whether or not the participant knew someone with dementia, and social comfort and knowledge pre- and post-simulation. The dependent variable was time (DAS before and after the dementia simulation experience). Statistical significance was set at $\alpha = .05$.

Results

The purpose of this experiment was to determine whether or not a dementia simulation would change attitudes towards individuals with dementia. We hypothesized that experientially learning through a dementia simulation would change attitudes in a more positive way, determined by pre- and post-simulation scores on the DAS questionnaire.

As seen in Figure 1, there was a significant difference in pre- and post- scores with the pre-simulation score of 102.5 and post-simulation score 108.2 ($p = .012$). This change equates to a 5.54% improvement in attitudes in the positive direction.

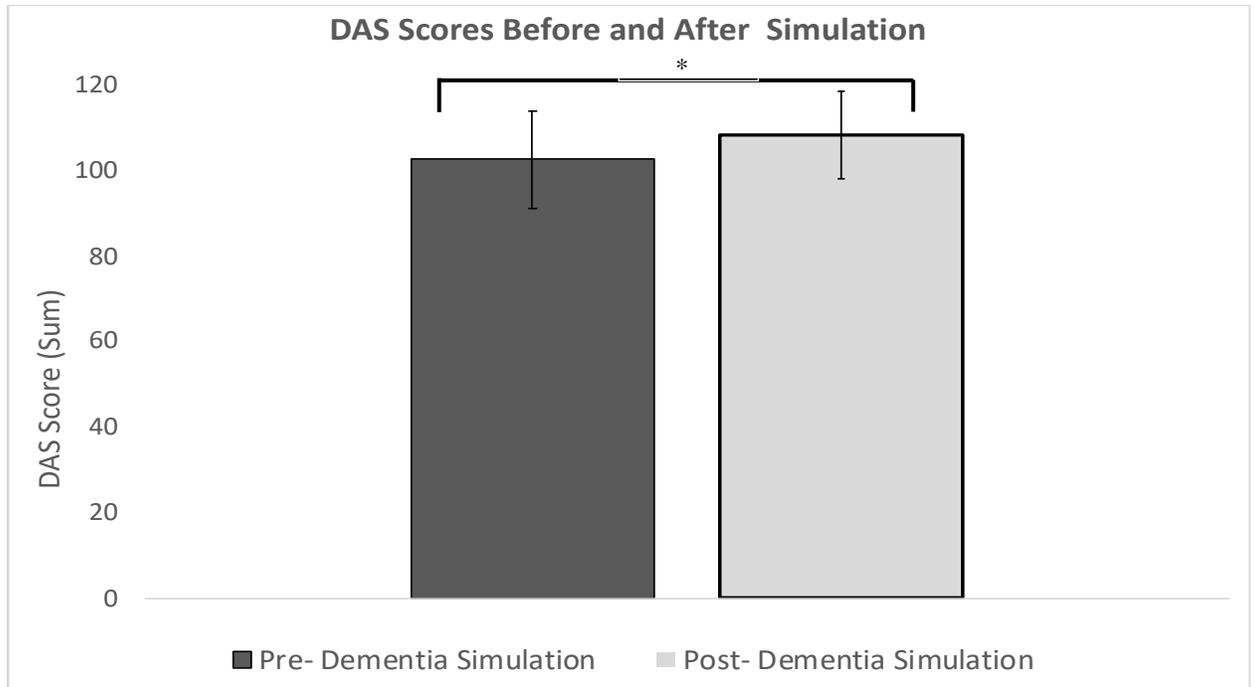


Figure 1. This graph shows the DAS scores pre and post simulation. * represents a significant difference over time.

Table 1. DAS Scores Pre- and Post- Simulation

	DAS Sum Mean	Standard Deviation	P-Value
Pre-Simulation	102.5	11.5	.012
Post-Simulation	108.2	10.3	

There was not a significant difference between individuals who had previously known someone with Alzheimer's Disease or dementia ($p = .55$), and there was not a significant difference between sexes ($p = .57$). However, there was a trend for significant change for an increase in social comfort after the simulation with pre-simulation mean of 43.00 (± 9.2) and post-simulation mean of 45.67 (± 7.2) ($p = .067$). There was a significant change for an increase in dementia knowledge scores after the simulation with the pre-simulation knowledge mean of 59.33 (± 4.4) and post-simulation knowledge mean of 62.53 (± 5.2) ($p < .001$).

Discussion

The purpose of this study was to determine whether or not a dementia simulation would change attitudes towards individuals with dementia. The results of this study support our hypothesis, that briefly experiencing dementia significantly improves attitudes towards those with dementia by 5.54% through the improvement of social comfort and dementia knowledge. Because of this increase in positive attitudes, which can result in improvements in quality of care, overall health, and life satisfaction for individuals with dementia, the results of this study can be categorized as clinically significant (Kimzey, Mastel-Smith, & Alfred, 2016; Markowitz, 1998). After the simulation, several participants mentioned that they felt “frustrated, stressed, and useless” while attempting to complete the tasks. One participant who knew someone with dementia, mentioned that she was “grateful for the eye-opening experience,” and wished that her family members could also participate in a dementia simulation. This increase in positive attitudes and awareness towards individuals with dementia makes dementia simulations a beneficial and useful mechanism for improving attitudes and destigmatizing dementia.

Limitations

There were several limitations to this study that could be improved upon in future research studies. The fact that all of the participants were between the ages of 18 and 25 with a mean age of 20.64 shows that the results of this study can only be relevant for younger adults and should not be generalized for all ages. All of the participants in this study were students at the University of Arkansas, so these attitudes and changes in attitudes are relevant to this population and cannot be used to conclude attitudinal baselines and changes for other age groups and populations. The demographics of the participants in this study could possibly be the reason that baseline attitudes were so high (102.5 out of 140). It would be interesting to see how

different ages and populations score pre- and post- simulation, and if these scores would differ significantly from the participants in this study. Another limitation is the unevenness in the genders of the participants in this study, with 13 males and 20 females. No significant difference was found between the two genders, but this might have been different if there were more equal numbers representing each gender. Another limitation to this study is the small sample size of 33 participants. Future research should include more participants and more diverse age groups.

Conclusion

A dementia simulation is a time efficient way to improve attitudes towards individuals with dementia. Because of the positive attitudinal change and short time commitment, dementia simulations should be made readily available to caregivers, family members, and health care providers who are caring for and spending time with individuals with dementia. Readily available dementia simulations have the potential to decrease the stigma surrounding dementia, and in effect improve the overall health and quality of life for individuals with dementia (Mackenzie, 2006; Link, 1987; Markowitz 1998). Future studies involving dementia simulations and attitudinal changes should include more participants and different age groups. It would also be interesting for future studies to measure changes in attitudes before and after a dementia simulation for specific groups such as physicians, medical students, caregivers, and children of individuals with dementia. Based off of this study, dementia simulations have the capacity to improve dementia knowledge and social comfort, and it is because of this that they should be utilized in an effort to destigmatize dementia.

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Appendix

The Attitude Toward Alzheimer's Disease and Related Dementias Scale

Directions: Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym "ADRD" in each question stands for "Alzheimer's disease and related dementias."

1. It is rewarding to work with people who have ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

2. I am afraid of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

3. People with ADRD can be creative.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

4. I feel confident around people with ADRD

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

5. I am comfortable touching people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

6. I feel uncomfortable being around people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

7. Every person with ADRD has different needs.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

8. I am not very familiar with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

9. I would avoid an agitated person with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

10. People with ADRD like having familiar things nearby.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

11. It is important to know the past history of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

12. It is possible to enjoy interacting with people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

13. I feel relaxed around people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

14. People with ADRD can enjoy life.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

15. People with ADRD can feel when others are kind to them.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

16. I feel frustrated because I do not know how to help people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

17. I cannot imagine taking care of someone with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

18. I admire the coping skills of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

19. We can do a lot now to improve the lives of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

20. Difficult behaviors may be a form of communication for people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree