ATTITUDES ABOUT OLDER ADULTS WITH DEMENTIA

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Abstract

Dementia, a term that describes a variety of brain conditions marked by gradual, persistent, and progressive cognitive decline, affects 5 to 8% of older adults. Persons with dementia are sometimes perceived by others as having lower personhood than persons without dementia. Personhood is a “status that is bestowed upon one human being, by others, in the context of relationship and social being... implying recognition, respect, and trust” (Kitwood, 1997, p. 8). Older adults are sometimes perceived less favorably than younger adults. It is unknown, however, if beliefs concerning personhood in dementia and attitudes about older persons differ as a function of demographic group (e.g., how younger vs. older adults perceive persons with dementia). This study was aimed to investigate age differences in attitudes toward older adults and dementia, as well as in personhood perception about persons with dementia. A between-subjects research design was used. Four groups including young adults (18-35 years old), middle-aged adults (40-60 years old), older adults (65 years old and older), and informal caregivers of persons with dementia were compared. Baseline dementia knowledge was highest in caregivers and older adults and lowest in young and middle-aged adults. The majority of participants had neutral attitudes toward older persons. Negative attitudes were least common in older adults and positive attitudes were infrequently reported by young adults. Caregivers had positive attitudes toward persons with dementia whereas the other groups had neutral attitudes. Overall, most young adults and older adults ascribed lower personhood to persons with dementia in comparison to middle-aged adults and caregivers.
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1. INTRODUCTION

1.1 Overview

The Canadian population is aging rapidly. With a rapid increase of the older population, there is an increase in the prevalence of dementia. Currently, 564,000 Canadians are living with dementia. This number is projected to increase to 937,000 by 2031 (Duong, Patel, & Chang, 2017). In 2009, about 4.6 million people were diagnosed with dementia (Prince et al., 2013). Since then, the world prevalence of dementia has increased to 10 million per year (WHO, 2017) and is expected to reach 81.1 million per year by 2040 (Prince et al., 2013). Dementia not only affects persons who have the condition but also friends, family, and caregivers. Thus, it is imperative to promote knowledge and positive attitudes about dementia because of the prevalence of dementia in the population. This paper provides a comprehensive review of the literature on dementia, dementia knowledge, dementia attitudes, and attitudes toward older persons.

1.2 Dementia

Dementia is an overarching term used to describe a variety of brain conditions marked by gradual, persistent, and progressive cognitive decline (Duong, Patel, & Chang, 2017). Cognitive impairment typically presents as a combination of “memory loss, communication and language impairments, agnosia (inability to recognize objects), apraxia (inability to perform previously learned tasks) and impaired executive function (reasoning, judgement and planning)” (Duong, Patel, & Chang, 2017). Other clinical symptoms include changes in personality, eyesight, and mobility.

In an effort to reduce the stigma that is associated with the term dementia, the American Psychiatric Association redefined it in the Diagnostic and Statistical Manual of Mental
Disorders, Fifth Edition, (DSM-5; American Psychiatric Association [APA], 2013) as a “major neurocognitive disorder. However, the term dementia is still widely used, even by the Alzheimer’s associations in both Canada and the United States (Higgs & Gilleard, 2015). For the purposes of this thesis, the term dementia will be used.

1.2.1 Etiology

Dementia may occur due to several neurocognitive disorders: Alzheimer’s disease, frontotemporal lobar degeneration, Lewy body disease, prion disease, traumatic brain injury, or vascular disease (APA, 2013). Alzheimer’s disease is the most common cause of dementia and accounts for 60 to 90% of cases (Alzheimer’s Association, 2017). Alzheimer’s disease is a slowly progressive, fatal, neurodegenerative disease that produces a wide range of symptoms caused by many changes in the brain (Alzheimer’s Association, 2017).

Several factors may influence dementia onset, including alcohol use, age, diet, hereditary factors, infection, and stroke (Graham, Ballard, & Sham, 1997). Age is a major risk factor of dementia with diagnosis increasing exponentially over the age of 60 years. Typical dementia onset age is between 65 and 80 years (Glymour, 2017). Onset before 60 years is considered early-onset dementia and after 85 years, old-onset. Dementia can be categorized as occurring in three stages: mild (early stage), moderate (middle stage), and severe (late stage) (Reisberg, Ferris, de Leon, & Crook, 1982). These stages can be distinguished by the symptoms present in each. Symptoms get more severe as dementia progresses through the three stages. The progression of dementia varies by person and type of dementia. Protective factors, which reduce the risk of dementia, include aerobic exercise, an active social life, healthy diet, intellectual activity, and protecting your head (Alzheimer’s Society of Canada, 2010).

1.2.2 Epidemiology
Dementia is the sixth leading cause of death in the United States (Theis, Bleiler, & Alzheimer’s Association, 2013). Not only does dementia affect persons who have the condition but also caregivers, family, friends, and society at large. Dementia-related costs (long-term care, health care, hospice care) in the United States are projected to approach $1.2 trillion annually by 2050 (Rao, Dove, Cascino, & Petersen, 2009). In Europe and Asia, dementia incidence and prevalence are higher in women compared to men; however, data about sex differences are less consistent in North American studies (Fratiglioni & Qui, 2013). There has been a downward trend in epidemiology rates in the USA (Langa et al., 2008; Rocca et al., 2011). In Europe, there is a stable age-specific prevalence of dementia while in Asia, dementia prevalence continues to increase (Dodge et al., 2012). Age-specific prevalence is similar across countries with variations in the oldest old, i.e., over 90 years (Prince et al., 2013). In community settings, people over 65 years tend to live 3 to 9 years after dementia onset with some living up to 20 years (Xie, Brayne, Matthews, & the Medical Research Council Cognitive Function and Ageing Study collaborators, 2008). In clinical settings, people tend to live 10 to 12 years after dementia onset (Rabins, Lyketsos, & Steele, 2006). More than 50% of dementia cases reach the severe stage 3 years after onset. Women tend to survive longer in the severe stage of dementia than men which allows them to live longer than men post dementia onset (Rizzuto et al., 2012). Rates vary based on age at onset.

1.2.3 Comorbidity

Comorbidities are prevalent in persons with dementia and may exacerbate the progression of dementia (Savva & Stephan, 2010). Dementia is highly correlated with conditions common in older persons such as diabetes, stroke, and visual impairment (Bunn et al., 2014). Dementia tends to present as Alzheimer’s disease alone (most common) or in
combination with other lesions which may increase cognitive impairment associated with other types of dementia (Magaki, Yong, Khanlou, Tung, & Vinters, 2014). Mortality in dementia has been related to comorbidity with pneumonia, cardiovascular disease, and lung disease. Delirium is also seen in persons with dementia (Swanson & Carnahan, 2007). In fact, dementia may exacerbate delirium. Other common comorbidities include: anxiety, depression, psychotic disturbances (hallucinations, paranoia), and behavioural disturbances (agitation, aggression) (Swanson & Carnahan, 2007).

1.3 Personhood

Dementia care, especially pain undertreatment, is influenced by personhood perception (Malloy & Hadjistavropoulos, 2004). It was believed that dementia stripped people of their personhood status (Herskovits, 1995); however, Kitwood (1997), proposed that negative social interactions were responsible for a measure of the decline in personhood status. Kitwood (1997) conceptualised personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being... implying, recognition, respect, and trust” (p. 8). Three levels of personhood have been identified in Buron’s Personhood Model for Dementia Care (2008): 1) biologic personhood, 2) individual personhood, and 3) sociologic personhood (Buron, 2008). Biological personhood focuses on sentience, i.e., the capacity to think subjectively. Persons living with severe dementia may not be capable of sentience. Other’s perception of individual personhood is centred around the ability to communicate and model self-awareness, marked by psychological continuity (Jenkins & Price, 1996). This is critical because the capacity to communicate declines as dementia progresses. If an individual is unable to verbally communicate information about his or her past and present life because of cognitive impairment, it may become more difficult to ascribe individual personhood. Finally,
the sociologic level is concerned with how society perceives and treats the individual living with dementia (Cecchin, 2001). Membership in social groups provides a basis for ascribing sociologic personhood. Typically, this is the first level of personhood perception that is affected in an individual as dementia progresses. This is followed by a decline in the amount of personhood ascribed to individuals living with dementia as they become less able to communicate with social contacts.

To overcome the decline in verbal communication skills, caregivers may rely on interpreting nonverbal communication, such as facial expressions or gestures (Lautenbacher, Hofer, Kunz, 2015). The age-related neuropsychological decline hypothesis states that younger persons may be more proficient at decoding facial expressions than older adults. The own-age bias, however, proposes that people are better at interpreting expressions of individuals closer to them in age. Personhood perception is associated with effective communication, thus, there may be age related difference in personhood perception.

Caregivers may revert to ascribing the basic biologic level of personhood to individuals and subsequently approach care in a paternalistic manner (Buron, 2008). The personhood status ascribed to an individual is thought to originate at birth and is subject to change as the individual’s age and physical condition changes. This becomes complicated when changes are accompanied by negative states. This model serves as a framework for understanding, evaluating, and improving person-centred interventions. Persons with dementia tend to be ascribed lower personhood than older adults without dementia (Miron et al., 2017). High personhood perception in dementia positively influences health providers’ attitudes about dementia (Hunter et al., 2013; Kitwood, 1997); however, this has not been reported for the general population. High personhood perception in dementia may also positively influence
laypersons’ attitudes about dementia and aging as dementia is more commonly seen in the older population.

1.4 Person-centred Dementia Care

Person-centred care (PCC) is a value-driven, empowering approach designed to ensure persons with dementia feel valued, supported, and socially confident (Epp, 2003; Younger & Martin, 2000). PCC is deemed successful when caregivers ascribe personhood to persons with dementia despite declining cognitive abilities. Unlike PCC, the biomedical model neglects the whole person and focuses on the diseased brain, which is damaging to the person living with dementia. Kitwood challenged the biomedical view of dementia and focused on the social context and individual interactions (Sabat & Harre, 1992); dementia is only one aspect of life, not a defining factor. This approach to dementia care was further supported by Cheston and Bender (1999) who postulated that care should be centred on the individual with respect to family, marriage, culture, ethnicity, and gender.

Although limited in the literature, personhood has been identified as a central issue in understanding and improving person-centred dementia care (Epp, 2003). Central to personhood is the perspective that dementia is more than neuropathologic damage; other factors like personality and social psychology play a role. Focusing on negative affects may perpetuate negative perceptions and attitudes toward persons with dementia. Conversely, sustaining positive relationships through PCC has been shown to improve personhood status (Epp, 2003).

1.5 Dementia Knowledge

Dementia literacy is defined as beliefs and knowledge about dementia that promote recognition, management, or prevention (Low & Anstey, 2009). People tend to be good at recognizing dementia symptoms, however, there is a lack of knowledge about dementia risk
factors (Low & Anstey, 2009). Increased contact with dementia is linked to better dementia knowledge (McParland, Devine, Innes, & Gayle, 2012); however, caregivers tend to lack basic dementia knowledge, especially about causes, prevalence, and symptoms of the disease (Werner, 2001). This complements research done by Fortinsky and Hathaway (1990) who found that caregivers desired to receive more dementia knowledge, specifically about the stages of the disease, medical treatments, and the biomedical and genetic aspects of the disease.

Dementia knowledge does not differ significantly between men and women; however, women tend to be more aware of dementia symptoms than men (Sahin et al., 2016). Dementia knowledge significantly decreases as age increases and in less educated populations (Li et al., 2011). This trend is also seen in populations with low exposure to dementia knowledge. Many older adults believe that dementia is a normal occurrence in old age and are unaware of the typical symptoms of dementia (Sahin et al., 2006). Thus, university students, caregivers, laypersons, and older adults should be targeted for improving dementia knowledge (Gwon, 2008) as persons with more dementia knowledge tend to have more positive dementia attitudes (Lee, 2012; Song, 2002).

1.6 Attitudes Toward Aging

Attitudes toward older adults are influenced by a myriad of factors including individuals’ contact with older adults and knowledge about aging (Allan & Johnson, 2008). As people age, they are more likely to believe that age is related to dementia or is a risk factor for dementia (Heese, 2015). Negative stereotypes of older adults are formed when young via media which portrays older adults as disadvantaged, disengaged, and unfortunate (Sorgman & Sorenson, 2001). The results of a meta-analytic review of 232 effect sizes reflect that negative attitudes toward older adults are prevalent in young and middle-aged adults but absent in older adults.
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(Kite, Stockdale, Whitley, & Johnson, 2005). This is contrary to other findings which reflect negative attitudes toward aging in children, persons who work with aging populations, and aging populations themselves (Anderson, 1999). College-aged students tend to hold strong, negative stereotypes toward older adults (Robinson & Umphrey, 2006). Contrarily, Chasteen, Schwarz, and Park (2002) found that younger and older adults share similar stereotypes of younger and older persons. Stereotypes of older persons tend to be stronger than those of younger persons, however, stereotypes of older adults are positive or mixed. Older adults are thus perceived as less competent, evaluated less favorably, and treated more negatively than younger adults. This is consistent with the Social Identity Theory which proposes that individuals try to maintain positive views of their ingroups (Tajfel & Turner, 1979).

Older adults were once young; hence, they can identify with that group and strive to maintain a positive image. In contrast, young adults do not identify as a member of the old group. Instead, they seek to maintain a positive image of their ingroup by highlighting differences between the young and old groups. Young adults may also have anxiety about aging which may influence them to have negative attitudes toward aging (Allan & Johnson, 2008). Middle-aged adults also displayed negative attitudes towards older adults. It was proposed that middle aged adults have a stronger desire than young adults to maintain their positive self-image. This is achieved by devaluing older adults (Montepare & Lachman, 1989). Furthermore, negative attitudes towards older adults increase as age increase. Attitudes toward aging for individuals 75 years and older are more negative than attitudes towards aging for those 55-64 years old (Neugarten, 1975).

Older adults are also thought to be less capable of frequent or intense emotional expressions (Kunz, Mylius, Schepelmann, & Lautenbacher, 2008); however, empirical evidence
based on behavioural measures of facial expressions do not reflect an age-related decline in emotional expressiveness (Gibson & Farrell, 2004). In comparison to younger persons, pain expressions in older adults with dementia are evaluated as more painful even though the expressions do not vary according to the Facial Action Coding System (FACS) (Hadjistavropoulos, LaChapelle, Hale, & MacLeod, 2000; Lautenbacher, Hofer, Kunz, 2016). FACS (Ekman & Friesen, 1961) analyzes facial muscle movements to show distinguishable difference between facial expressions. This age-related bias in emotion perception may be because older persons are stereotyped as frailer and more prone to painful experiences than younger persons (Hadjistavropoulos et al., 2000).

Attitudes toward older adults can be improved by increasing contact with older adults or experientially learning about the aging process to understand some of the characteristics of aging (Paris, Gold, & Taylor; 1997; Schulberg, 2005). Results concerning the relationship between ageism and knowledge, however, is mixed (Allan & Johnson, 2008). Regarding contact, persons who reside with one or more older adults tend to have higher anxiety about aging, whereas persons who had regular contact with older persons at work had lower anxiety about aging. Attitudes toward aging tend to influence attitudes about dementia because people believe that dementia is a normal part of aging. Thus, people with negative attitudes about aging may also have poor dementia attitudes or vice versa.

1.7 Attitudes toward dementia

Dementia generally carries a negative stigma (Jolley & Benbow, 2000; Sahin et al., 2006). Older persons with Alzheimer’s disease, a type of dementia, are evaluated more negatively than older adults with other illnesses (Kahana et al., 1996). Nursing and medical students generally possess more positive attitudes toward dementia than non-health-related
students (Yong, Yoo, & Yang, 2015); however, their dementia knowledge can be improved (Scerri & Scerri, 2013; Tullo & Young, 2014). On the other hand, caregivers and nursing-home staff tend to view persons with dementia more negatively than positively (Askham, 1995; Brodaty, Draper, & Low, 2003). This supports other findings that health providers’ attitudes towards dementia become increasingly negative as dementia progressed (Staples & Killian, 2012). Laypersons understand that persons with dementia are not necessarily incompetent, however, they have mixed attitudes about dementia (Werner, 2006).

Based on the literature, attitudes toward aging and dementia attitudes vary across age groups and are influenced by age and education (Heese, 2015). Adolescents have reported mixed attitudes toward dementia. Adolescents tend to believe that persons with dementia have valuable lives which eventually fade as the disease progresses. As a result, adolescents believe that older adults should be placed in nursing homes where they belong (Isaac et al., 2017). Middle-aged adults are more likely to be ashamed by family members with dementia in comparison to young and older adults (Zhang et al., 2017). Fifty percent of individuals with lower levels of education believe that “ageing was a major risk factor for dementia” (Heese, 2015).

Attitudes about dementia influence behavioural discrimination toward persons with dementia (Werner, 2006). Individuals with more dementia knowledge, however, tend to have more positive attitudes toward dementia (Lee, 2012; Song, 2002). Thus, increasing dementia knowledge has been proposed as a method to improve the attitudes of persons working with people with dementia (Staples & Killian, 2008). Increasing dementia knowledge may positively influence dementia attitudes and subsequently reduce the negative stigma associated with dementia.
1.8 Purpose

The current study expands the literature by providing a more comprehensive understanding of personhood perception in persons with dementia. The aim of this study was to assess age differences in personhood perception about persons with dementia (i.e., whether a person with dementia is likely to be perceived as being "less of a person" given their loss of mental faculties) and attitudes toward dementia.

1.9 Hypotheses

It is expected that age (i.e., young adults, middle-aged adults, older adults) and knowledge about dementia will impact attitudes toward dementia, attitudes about aging, and personhood perception. Based on previous results (Heese, 2015), age was expected to correlate negatively with attitudes toward persons with dementia and positively with personhood perception in persons with dementia. Specifically, experimental hypotheses are as follows:

a) Caregivers were expected to ascribe more personhood to persons with dementia than the other groups in the study because of their close association with a person with dementia.

b) Older adults were expected to have more negative attitudes toward persons with dementia when compared to young and middle-aged adults (Heese, 2015).

c) Young adults were expected to have more negative attitudes towards aging than middle-aged and older adults (Kite et al., 2005).

d) Older adults were expected to ascribe more personhood to persons with dementia than young and middle-aged adults.

2. METHODOLOGY

2.1 Participants
Participants from the community were recruited through Qualtrics Panels (Qualtrics, Provo, UT). Compensation was provided via Qualtrics. This method of recruitment is used widely and increasingly by many North American research universities (Tomfohrde & Reinke, 2016; Torres, Yadav, & Khan, 2017). Using this system, the study was completed online. Qualtrics panels maximize sample representativeness by including a variety of persons that match the target demographic (Qualtrics, 2017). Participants are profiled on demographic variables like gender, age, and level of occupation. Potential participants are approved once they complete detailed questionnaires about their background. Additionally, incentive programs are included to reward participants and promote engagement and completion.

Eligible participants were young adults (18-35 years old), middle-aged adults (40-60 years old), older adults (65 years old and over), and informal caregivers of older adults with dementia. Based on G*Power analysis using a moderate to large sample size = .20, alpha = .05, and power = .85, a sample size of \( n = 230 \) participants was expected to be sufficient to evaluate the hypothesized relationships. Participants provided informed consent before participating. All information obtained from the participants was kept confidential.

2.2 Procedure

Participants completed a demographic information questionnaire which included questions about age, gender, and level of education. First, participants completed the Dementia Knowledge Questionnaire (DKQ) to capture their existing dementia knowledge. Second, information about dementia was presented to participants in audio and written form. Third, Participants completed the DKQ for a second time to examine if their dementia knowledge increased as a result of the video. Fourth, participants completed the Dementia Attitudes Scale
(DAS), Ambivalent Attitudes Scale (AAS), and Personhood in Dementia Questionnaire (PDQ) which were used in the data analyses along with the demographic characteristics.

2.3 Measures

2.3.1 Demographics Information Sheet

Participants completed a demographic information sheet (see Appendix C) along with the measures outlined below. The questionnaire included questions about age, gender, and level of education.

2.3.2 Dementia Knowledge Questionnaire (DKQ)

The Dementia Knowledge Questionnaire (DKQ; Graham, Ballard, & Sham, 1997) is a tool used to assess knowledge about dementia. The DKQ consists of 7 multiple choice questions. The maximum score that can be obtained on the DKQ is nineteen. The first five questions have one correct answer and the last two questions have all but one correct answers. If the participant selects the incorrect option, no point is awarded for this question. Each question has an option “do not know” to discourage random guessing.

The DKQ assesses dementia knowledge in four domains: basic knowledge, epidemiology, symptomatology, and aetiology (see Appendix D). The first domain, basic knowledge, assesses the fundamental facts about dementia. Succeeding on this section requires knowing that dementia is a predominantly incurable disease of the brain to which older adults are the most susceptible. The second domain, epidemiological knowledge, assesses how much is known about the target population of people affected by dementia. To score well on this section participants must know that there are more than three types of dementia which affect approximately 5-20% of people over the age of 65.
The third domain, symptomatology, assesses clinical symptoms present in persons with dementia. Several bodily functions may be affected by the disease including: speech, memory loss, eyesight, bladder/bowel control, eyesight, mobility, life expectancy, and personality. A high score on this section is dependent on knowing which functions are affected by dementia. The fourth domain, aetiology, assesses the causes of the dementia which includes diet, alcohol, hereditary factors, strokes, and infection. Identifying any of the causes except old age increases the participants’ score by one point. Items on the DKQ include: “which part of the body is affected by dementia?”, “is there a cure for dementia?”, and “what percentage of people over 65 years of age have dementia?”.

The questionnaire was originally validated in carers of people with dementia. Carers in contact with an Alzheimer’s support group were the most knowledgeable and carers with no contact with mental health services for older adults were the least knowledgeable. This allowed the researchers to identify misconceptions and gaps in carers’ knowledge of dementia.

2.3.3 Dementia Attitudes Scale (DAS)

The Dementia Attitudes Scale (DAS; O’Connor & McFadden, 2010) is a psychometrically sound instrument for measuring attitudes toward dementia (see Appendix F). It consists of 20 items rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The DAS has a two-factor structure. Items in Factor 1, comfort, address the cognitive domain while items in Factor 2, knowledge, address the affective and behavioural domains. Six items are reverse coded. The DAS was developed around a model of attitude (Breckler, 1985) which ensures that relevant construct areas are represented. The multistep construction of the DAS, i.e., using both qualitative and quantitative methods, is a great strength. Items include statements like “I am afraid of people with Alzheimer’s Diseases and Related
Dementias (ADRD)” and “[It] is possible to enjoy interacting with people with ADRD” (O’Connor & McFadden, 2010).

The DAS was validated with college students and direct care workers. The DAS has acceptable reliability which is consistently above 0.8. Cronbach’s alpha of the DAS is 0.83. There is significant correlation between the DAS and other scales, for example Kogan’s Attitudes toward Old People Scale (Kogan, 1961) and Fraboni’s Scale of Ageism (Fraboni, Saltstone, & Hughes, 1990), which supports good construct validity and convergent validity. Moreover, more frequent contact with persons with dementia was positively correlated with more positive attitudes (Jackson et al., 2008). One limitation of the DAS is inflated positivity which may be due to social desirability, a lack of reverse scored items, and item transparency.

2.3.4 Ambivalent Ageism Scale (AAS)

The Ambivalent Ageism Scale (AAS; Cary, Chasteen, & Remedios, 2017) is a 13-item, two-factor measure of attitudes toward older adults (see Appendix G). A 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree) is used to rate all items excluding Item 1 and Item 2 which are rated on a 6-point scale ranging from 1 to 6. Two subscales are addressed in the AAS, benevolent and hostile attitudes. There are 9 benevolent items and 4 hostile items. Benevolent items address patronizing behaviours and paternalistic attitudes toward older adults. One such item is “it is helpful to repeat things to old people because they rarely understand the first time.” Hostile items address aggressive behaviours and attitudes toward older adults; for example, “old people are too easily offended.” These items were based on the Ambivalent Sexism Inventory. The AAS includes more benevolent items because of the abundance of scales to measure hostile ageist beliefs and the lack of scales to measure benevolence.
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The AAS has good test-retest reliability ($\alpha = .80$) even when taken at different settings at Time 1 and Time 2. The AAS scale has excellent internal consistency ($\alpha = .91$). The AAS has good discriminant validity in comparison to the Fraboni Scale of Ageism (FSA; Fraboni et al., 1990). The AAS and the FSA are highly correlated, $r (159) = .65$, $p < .001$. The hostile subscale is significantly and more strongly correlated with the FSA than the benevolent subscale. This is expected because the FSA contains items mostly assessing hostile ageism. Benevolent and hostile items have robust reliability, $\alpha = .89$ and $\alpha = .84$ respectively. There is positive correlation between benevolent and hostile ageism, $r (159) = .62$, $p < .001$. This suggests that the subscales can predict unique variances in attitudes and behaviour even though they are interrelated. The AAS is also useful in predicting warmth and competence stereotypes toward older adults consistent with the stereotype content model. High hostile ageist beliefs are linked to a perception of older adults as cold and incompetent. This is so regardless of benevolent ageist beliefs. Low hostile ageist beliefs and high benevolent ageist beliefs are accompanied by a perception of older adults as “warm and incompetent” (Cary, Chasteen, & Remedios, 2017). This supports the use of the AAS to identify distinct types of prejudice towards older adults.

2.3.5 Personhood in Dementia Questionnaire (PDQ)

The Personhood in Dementia Questionnaire (PDQ; Hunter et al., 2013) is a self-report instrument that is used to measure health-care respondents’ person-centred attitudes towards persons with dementia (see Appendix H). The PDQ consists of 20 items which are brief statements paired with a 7-point Likert scale ranging from 0 (disagree strongly) to 7 (agree strongly). Some items are reversed-scored. Sample items include “dementia takes away the beauty of those who are affected by it”, “residents with dementia have a sense of purpose”, and “residents with dementia who whine a lot should be isolated.” The PDQ is comprised of ten
themes about personhood which were generated using thematic analysis. This means that the statements were obtained from health care providers during interviews and focus groups. These themes capture biological, psychological, social, and moral aspects of personhood. For the purposes of this study, the word ‘residents’ will be replaced with ‘individuals’.

The PDQ has been found to have a Cronbach alpha of .81 (Hunter et al., 2013) and an average inter-item correlation of .21. The Pearson product-moment correlation between the PDQ and a modified version of the personhood subscale of the Person-Directed Care measure showed moderate convergent validity. The PDQ has been found to predict approaches to treatment of people with dementia, clinical care intentions (Hunter et al., 2013), long-term care staff resilience (Williams et al., 2015), and long-term care staff burnout (Hunter et al., 2016). The PDQ susceptibility to the social desirability bias is minimized as vulnerable items were excluded based on correlations with a measure of social desirability.

2.4 Analyses

All dependent variables were examined for accuracy of data entry, missing values, univariate outliers, normality of the distributions, and multivariate outliers. The various groups were compared using chi-square, one-way analysis of variance (ANOVA) or t-tests tests to determine if they differ based on demographic characteristics. A one-way multivariate analysis of variance (MANOVA) was planned to assess if personhood perception differs among the four groups (i.e., young adults, middle-aged adults, older adults, and caregivers) involved in the study. Possible covariates were considered and included as appropriate. Dependent variables were dementia knowledge, attitudes toward persons with dementia and aging, and personhood scores. ANOVAs were planned to follow MANOVA is significance. Significant ANOVAs were followed up using planned pairwise comparisons. Correlational (regression) analyses were
also used to explore predictors (e.g., demographics, dementia knowledge, attitudes toward aging) in relation to personhood perception.

2.5 Anticipated Relevance

Perceptions of dementia personhood have been studied in health professionals but not among laypersons. In health professional contexts, research suggests that staff personhood perceptions about persons with dementia affect clinical care (Norbergh, Helin, Dahl, & Hellze, 2006). Documenting attitudes and perceptions about persons with dementia in the general population could potentially lead to interventions for improving such attitudes and making our society more inclusive.

3. RESULTS

3.1 Data Checking

3.1.1 Accuracy of data entry

All dependent variables were screened for accuracy of data entry through the examination of descriptive statistics. Values for each variable were within range. Means and standard deviations for each variable were plausible.

3.1.2 Missing data

All dependent variables were screened for missing values through the examination of descriptive statistics. No missing values were identified.

3.1.3 Univariate outliers

All dependent variables were examined for outliers. As recommended by Tabachnick and Fidell (2013), cases in which standardized z-scores exceeded 3.29 were considered as potential outliers. No outliers were identified.

3.1.4 Normality of the distributions
Through examination of histograms, skewness and kurtosis statistics, normal probability plots, and detrended normal probability plots, all dependent variables (i.e., dementia knowledge, dementia attitudes, ageism, personhood perception) were identified as not meeting the assumption of normality. Transformations, however, were not performed to address the issues of skewness and kurtosis. Routinely transforming scores can obscure differences in the data (Lo & Andrews, 2015). For example, dementia knowledge was expected to increase at Time 2; thus, the scores would be skewed.

3.2 Demographic Characteristics

Recruitment took place in March 2018. Two hundred and twenty-four participants were recruited. Seventeen participants were excluded from all analyses because their reported age was outside of the target age groups. Thus, the final sample included 207 participants distributed as follows: 52 YA, 40 MA, 50 OA, and 65 CG. Results concerning the demographic characteristics of the sample are summarized in Table 1.

3.2.1 Age

To determine if the caregiver group differed from the participants in the age groups, an independent samples t-test was conducted. The mean for the NCG was 48.58 (SD = 17.36) and the mean for the CG was 49.00 (SD = 19.29). No significant difference in the age distribution across groups was found, \( t(206) = .148, p = .882 \).

3.2.2 Education

To determine if the level of education attainment differed across the groups, a one-way ANOVA was conducted. The mean for YA was 5.79 (SD = 1.59), the mean for the MA was 4.80 (SD = 1.14), the mean for OA was 5.78 (SD = 1.52), and the mean for CG was 5.77 (SD = 1.51). A statistically significant difference in educational attainment across the groups was
found, $F(3, 203) = 4.81, p < .003$. Using Bonferroni post hoc tests, significant differences were found between YA and MA, $p = .009$, MA and OA, $p = .011$, and MA and CG, $p = .007$. Examination of the means and standard deviations showed that YAs had higher scores than MAs, MAs had lower scores than OAs, and MAs had lower scores than CGs.

### 3.3 Effectiveness of Dementia Educational Information

DKQ scores were expected to be significantly higher after the dementia educational information was presented (DKQ2) compared to before this information was presented (DKQ1). To test the effectiveness of the dementia educational information in improving dementia knowledge, a paired samples $t$-test was conducted. The mean for the DKQ1 was 9.20 ($SD = 3.75$) and the mean for the DKQ2 was 14.49 ($SD = 3.29$). The difference between the means was statistically significant, $t(206) = 22.61, p < .001$. These findings support the effectiveness of the dementia educational information at increasing dementia knowledge.

### 3.4 Dementia Knowledge Questionnaire

To determine if the distribution of DKQ1 scores varied across the groups (YA, MA, OA, CG), a one-way ANOVA was conducted. According to the hypothesis, dementia knowledge was expected to be highest in OA and CG. Relevant means and standard deviations are presented in Table 2. An examination of Table 2 suggests that the means and standard deviations for OA and CG are consistent with the hypothesis. A statistically significant difference in the DKQ1 scores across the groups was found, $F(3, 203) = 9.51, p < .001$. Using Bonferroni post hoc tests, significant differences were found between YA and OA, $p = .002$, YA and CG, $p < .001$, MA and OA, $p = .003$, and MA and CG, $p = .002$. Examination of the means and standard deviations showed that YAs had lower scores than OAs, YAs had lower scores than CGs, MAs had lower scores than OAs, and MAs had lower scores than CGs.
3.5 Global Effects Analyses

Prior to conducting the analyses, Pearson correlations between the dependent variables were calculated. DKQ1 scores were significantly correlated with all dependent variables: DAS, $\chi^2(207) = .222, p < .001$, AAS, $\chi^2(207) = -.336, p < .001$, and PDQ, $\chi^2(207) = .334, p < .001$. Thus, DKQ1 scores were added as a covariate to subsequent analyses.

In order to test the significance of global effects of groups on DAS, AAS, and PDQ, a one-way multivariate analysis of covariance (MANCOVA) was conducted. Using Wilks’ lambda, a significant main effect of group was found, $\lambda = .870, F(3, 9) = 9.95, p < .001$, partial $\eta^2 = .130$. Follow up univariate analyses of covariance (ANCOVAs) were conducted.

3.5.1 Dementia attitudes and group

A univariate analysis of covariance (ANCOVA) comparing DAS scores across groups was conducted with DKQ1 as a covariate. Results of the ANCOVA reflect that there were significant differences in DAS scores across the groups, $F(3, 202) = 8.72, p < .001$, $\eta^2 = .115$. The means and standard deviations are presented in Table 2. Using Bonferroni pairwise comparisons, significant differences were found between scores of YA and CG, $p < .001$, MA and CG, $p = .006$, and OA and CG, $p < .001$. Examination of the means and standard deviations showed that YAs had lower scores on the DAS than CGs, MAs had lower scores on the DAS than CGs, and OAs had lower scores on the DAS than CGs.
### Table 1

*Demographic Characteristics for Young Adults, Middle-aged Adults, Older Adults, and Caregivers*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Young Adults</th>
<th>Middle-aged Adults</th>
<th>Older Adults</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (34.6%)</td>
<td>17 (42.5%)</td>
<td>21 (42.0%)</td>
<td>36 (55.4%)</td>
</tr>
<tr>
<td>Female</td>
<td>34 (65.4%)</td>
<td>23 (57.5%)</td>
<td>29 (58.0%)</td>
<td>29 (44.6%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some elementary school</td>
<td>1 (1.9%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Completed elementary school</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Some high school</td>
<td>0 (0%)</td>
<td>2 (5.0%)</td>
<td>0 (0%)</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>Completed high school</td>
<td>11 (21.2%)</td>
<td>17 (42.5%)</td>
<td>15 (30.0%)</td>
<td>14 (21.5%)</td>
</tr>
<tr>
<td>Some undergraduate education</td>
<td>12 (23.1%)</td>
<td>12 (30.0%)</td>
<td>7 (14.0%)</td>
<td>14 (21.5%)</td>
</tr>
<tr>
<td>Completed undergraduate education</td>
<td>11 (21.2%)</td>
<td>7 (17.5%)</td>
<td>13 (26.0%)</td>
<td>16 (24.6%)</td>
</tr>
<tr>
<td>Some graduate education</td>
<td>6 (11.5%)</td>
<td>0 (0.0%)</td>
<td>4 (8.0%)</td>
<td>5 (7.7%)</td>
</tr>
<tr>
<td>Completed graduate education</td>
<td>11 (21.2%)</td>
<td>2 (5.0%)</td>
<td>11 (22.0%)</td>
<td>14 (21.5%)</td>
</tr>
</tbody>
</table>
### Paid Carer

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>4 (7.7%)</td>
<td>48 (92.3%)</td>
</tr>
<tr>
<td>%</td>
<td>4 (10.0%)</td>
<td>36 (90.0%)</td>
</tr>
<tr>
<td></td>
<td>0 (0%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (32.3%)</td>
<td>44 (67.7%)</td>
</tr>
</tbody>
</table>

*Note. n = 207.*
3.5.2 Attitudes toward aging and group

An ANCOVA comparing AAS scores across groups was conducted with DKQ1 as a covariate. Results of the ANCOVA reflect that there were significant differences in AAS scores across the different groups, $F(3, 202) = 5.58, p = .001, \eta^2 = .077$. The means and standard deviations are presented in Table 2. Using Bonferroni pairwise comparisons, significant differences were found between scores of YA and OA, $p < .05$, MA and CG, $p < .05$, and OA and CG, $p < .01$. Examination of the means and standard deviations showed that YAs had higher scores on the AAS than CGs, MAs had lower scores on the AAS than CGs, and OAs had lower scores on the AAS than CGs.

3.5.3 Personhood perception and group

To determine if PDQ scores differ across the groups, an ANCOVA was conducted with DKQ1 as a covariate. Results of the ANCOVA reflect that there were significant differences in AAS scores across the different groups, $F(3, 202) = 8.29, p < .001, \eta^2 = .110$. The means and standard deviations are presented in Table 2. Using Bonferroni pairwise comparisons, significant differences were found between scores of YA and CG, $p = .001$, and OA and CG, $p < .001$. For the significant main effect of groups, examination of the means and standard deviations showed that YAs had lower scores on the PDQ than CGs and OAs had lower scores on the PDQ than CGs.
Table 2

*Descriptive Statistics for Dementia Knowledge, Dementia Attitudes, Attitudes Toward Aging and Personhood Perception*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Dementia Knowledge</th>
<th>Dementia Attitudes</th>
<th>Attitudes Toward Aging</th>
<th>Personhood Perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young adults</td>
<td>7.56 (4.03)</td>
<td>92.63 (13.95)</td>
<td>50.42 (15.72)</td>
<td>94.62 (15.86)</td>
</tr>
<tr>
<td>Middle-aged adults</td>
<td>8.00 (4.10)</td>
<td>94.38 (15.25)</td>
<td>42.15 (14.86)</td>
<td>98.33 (16.35)</td>
</tr>
<tr>
<td>Older adults</td>
<td>10.14 (2.95)</td>
<td>93.80 (14.80)</td>
<td>38.30 (12.29)</td>
<td>96.18 (15.13)</td>
</tr>
<tr>
<td>Caregivers</td>
<td>10.52 (3.12)</td>
<td>105.80 (13.77)</td>
<td>46.89 (18.27)</td>
<td>109.88 (16.69)</td>
</tr>
</tbody>
</table>

*Note. n = 207.*
ATTITUDES ABOUT OLDER ADULTS WITH DEMENTIA

4. DISCUSSION

This study involved an examination of age differences in knowledge and attitudes about aging, dementia, and personhood among laypeople. It was expected that the dependent variables (i.e., dementia knowledge, dementia attitude, attitudes toward aging, personhood perception) would be differentially affected as a function of age (i.e., young adults, middle-aged adults, older adults).

4.1 Impact of Age on Dementia Knowledge

It was hypothesized that older adults would demonstrate less dementia knowledge than young and middle-aged adults (Li et al., 2011). Findings from this study were not consistent with this hypothesis as older adults demonstrated significantly more dementia knowledge than young and middle-aged adults. In the study by Li and colleagues, participants were 1806 Shanghai residents distributed by age as follows: youth group (<36 years old), adult group (36-65 years old), and elderly group (>65 years old). Significant age differences in beliefs that “dementia is a normal part of aging” were reported. The older adult group, which corresponds to older adults in the present study, were more likely to agree with this statement, followed by the youth group (young adults in the present study), and then the adult group (middle-aged adults in the present study). The accuracy of identifying the symptoms of dementia was highest in the older adult group followed by the youth group and then the adult group. Most respondents with a primary education level were older adults; thus, dementia knowledge may have correlated with education. Education varied significantly across age groups in the present study; however, it was not correlated with dementia knowledge. Additionally, all older adults in the present study attained an education level of high school or above; thus, older adults in the present study may have more dementia knowledge than older adults in the study by Li and colleagues. The study by Li and
colleagues also had some limitations such as unequal distribution of participants to age groups, and the potential inclusion caregivers who were health care providers, as Li and colleagues did not screen for health care providers.

Findings from the present study, however, are in line with Zhang and colleagues’ (2017) finding that community-dwelling older adults have higher dementia knowledge about symptoms and lower dementia knowledge about prevalence. In Zhang and colleagues’ study, participants were 3,007 Chinese adults, aged 60 years and older, with 66.5% having more than 7 years of education. Results indicated that older adults with lower education had less dementia knowledge. The measure used in the present study to assess dementia knowledge (i.e., DKQ) awarded more points for questions about symptoms than questions about prevalence. Thus, the finding of higher dementia knowledge among older adults may be reflective of the way that scores were calculated for the DKQ.

4.2 Impact of Age on Dementia Attitudes

Older adults were expected to have more negative attitudes toward persons with dementia compared to young and middle-aged adults (Heese, 2015). This hypothesis is contrary to the findings of the present study as no significant differences between older and young adults as well as older and middle-aged adults were found. In Heese’s study (2015), 980 participants of different age, gender, ethnicity, religion, and education took part in the study. The diversity of the sample, as well the large sample size, may account for the presence of significant differences in dementia attitudes across the age groups. When asked about placing patients with dementia in care homes, most young adults (19–30 years) did not wish to place their relatives with dementia in these care homes. More respondents in the older age groups (41–55 years and 56–65 years versus 19–30 years and 31–40 years) desired to place their relatives with dementia in homes
instead of placing the burden on family members. The view that persons with dementia are a burden represents a negative attitude toward dementia more common to older and middle-aged adults than young adults.

Instead of age-related differences in dementia attitudes, results of the present study indicated that young, middle-aged, and older adults had more negative dementia attitudes compared to caregivers. Care staff attitudes and experiences of working with people with dementia tend to be positive (Moyle, Murfield, Griffiths, & Venturato, 2011). The highest level of job satisfaction was reported in care staff with dementia contact. Caregivers in the present study were persons with family members with dementia and dementia contact more than once per month, meaning that caregivers had more dementia contact than young, middle-aged, and older adults. As previously stated, dementia contact was related to positive dementia attitudes. Thus, the finding that caregivers have more positive dementia attitudes than young, middle-aged, and older adults, is in line with the results of previous studies (e.g., Moyle et al., 2011).

Additionally, Moyle and colleagues reported that care staff attitudes toward persons with dementia were significantly and positively correlated with job satisfaction. More positive dementia attitudes were found in care staff who used person-centred care, a method known to maintain personhood in persons with dementia. Young, middle-aged, and older adults in the present study had lower dementia knowledge than caregivers. Thus, they may lack knowledge about person-centred approaches which influences positive dementia attitudes.

4.3 Impact of Age on Attitudes Toward Aging

Young adults were expected to have more negative attitudes toward aging when compared to middle-aged and older adults (Kite et al., 2005). The findings of the present study were consistent with this hypothesis. This finding supports the Social Identity Theory (Tajfel &
Turner, 1979); that is, to preserve a positive self-image, young adults may project negative attitudes about aging onto older adults. Additionally, individuals may improve their understanding of aging and dementia as they age because of their increased risk of developing age-related diseases (Ayalon & Areán, 2004). Thus, young adults, compared to middle-aged and older adults, would be less likely to improve their understanding of aging. Negative stereotypes about older persons, formed during one’s youth (Sorgman & Sorenson, 2001), may generate negative attitudes which persist in young adults but are absent in middle-aged and older adults (Robinson & Umphrey, 2006).

Findings also suggest that, compared to caregivers, young adults had more negative attitudes toward older adults. In a study of family caregivers, attitude toward aging were mainly positive (Courts, Barba, & Tesh, 2001). Caregivers reported that older adults were still valuable and involved. Caregivers also had little anxiety about their own aging. This attitude may be present because most caregivers were 65 years of age or older and were able to live independently. Additionally, caregivers who provide more personal care and services to an aged family member possess more positive attitudes toward aging (Tauilili, Delva, & Browne, 2014). Young adults who are not caregivers may not have as much contact with older persons as caregivers; thus, caregivers would have more positive attitudes toward aging than young adults.

4.4 Impact of Age on Personhood Perception

Analyses revealed that personhood perception was significantly lower in young adults and older adults compared to caregivers. Thus, as hypothesized, caregivers ascribed more personhood to persons with dementia than young and older adults. This finding may be explained by the increased contact that caregivers have with persons with dementia compared to dementia contact of young and older adults. Caregivers in this study had family members with
dementia with whom they had contact more than once a month. This interaction creates opportunities for caregivers to provide person-centred care which has been shown to effectively preserve personhood in persons with dementia (Moyle et al., 2011). Family caregivers may have lived with a person with dementia which may have allowed them to value personal characteristics and achievements of such persons (Smebye & Kirkebold, 2013). Additionally, this relationship is a way to maintain relationships with persons with dementia and form close emotional bonds which help sustain personhood perceptions. Young and older adults who are not family caregivers may form reluctant helping relationships or task-centred relationships with person with dementia which is known to diminish personhood. Thus, the findings in the present study support the results of previous studies.

As expected, older adults ascribed more personhood to persons with dementia than young and middle-aged adults. This finding may be related to dementia knowledge which was significantly correlated with personhood perception. Older adults had similar levels of dementia knowledge when compared to caregivers. Caregivers ascribed more personhood to persons with dementia; thus, it possible that the same level of personhood perception in dementia can be expected of older adults. More researcher is needed, however, to support this claim.

4.5 Exploratory Analyses of Education

Differences in dementia attitudes and attitudes toward aging based on level of education have been previously demonstrated (Heese, 2015). Analyses showed differences in the level of educational attainment across the groups. More young adults, older adults, and caregivers attained a higher level of education (i.e., graduate school) than middle-aged adults. Level of education, however, was not correlated with any outcome variables. Thus, education was not further examined in this study.
4.6 Summary of Contributions

This study demonstrated that dementia knowledge was correlated with dementia attitudes, attitudes toward aging, and personhood perception in dementia. That is, a high level of dementia knowledge was indicative of more positive dementia attitudes, positive attitudes toward aging, and higher personhood perception. These findings were also demonstrated by informal caregivers in the study who had higher dementia knowledge and ascribed more personhood to those with dementia. Additionally, this study revealed significant age differences in dementia attitudes, attitudes toward aging, and personhood perception in dementia. Results from this study help clarify the relationship between dementia knowledge and dementia attitudes in laypersons. The inclusion of dementia knowledge analyses in addition to the measurements of dementia attitudes and attitudes toward aging produced a more complete picture of the relationship between age and personhood perception about persons with dementia. Until now, the relationship between dementia knowledge and dementia attitudes was studied in health care providers, students, or caregivers. Another strength of this study is that it provides information on age-related attitudes toward dementia, aging, and personhood perception. This information helps identify which populations are more susceptible to have lower dementia knowledge and, subsequently, negative dementia attitudes and lower personhood perception. Documenting attitudes and perceptions about persons with dementia within the general population could potentially lead to interventions for improving such attitudes and making our society more inclusive.

4.7 Directions for Future Research

Several limitations should also be considered when interpreting findings from this study. Online recruitment may have limited generalizability of the findings. For example, people
without internet access were excluded. In future studies, participants should be recruited in the local community via flyer, advertisements, and word of mouth to include participants without internet access. Another limitation is that the present study included only self-report measures. Participants may have responded in a way that was socially desirable to maintain a positive self-image. This would potentially bias the findings and provide an inaccurate representation of dementia attitudes in the general population. To overcome this, future studies can assess dementia attitudes and attitudes toward aging using vignettes or videos of persons with dementia and older persons. Participants facial expressions in response to the vignette/video could be recorded and rated as attitude toward dementia or aging.

Additionally, a longitudinal study could be done to assess the relationship between dementia knowledge and dementia attitudes over time. This may provide information about the nature of the relationship. For example, the study could include adolescents who are presented with dementia knowledge regularly for one year and young adults who are presented with information regularly for one year. This may allow researchers to understand if dementia knowledge is effective at promoting positive dementia attitudes when presented at a younger age. Furthermore, the quality of dementia knowledge can be assessed to highlight if there is a difference in dementia attitudes when presented with different levels of dementia knowledge.

4.8 Conclusion

This study investigated age differences in dementia knowledge, dementia attitudes, attitudes toward aging, and personhood perception in a sample of laypersons and informal caregivers. Findings suggest that dementia knowledge was correlated with dementia attitudes, attitudes toward aging, and personhood perception in laypersons and caregivers, and this effect varied with age. Ultimately, the present investigation provided support for the need to improve
dementia knowledge in laypersons (Gwon, 2008). The findings, however, were correlational; thus, claims about dementia knowledge directly influencing dementia attitudes and personhood perception cannot be made. With further experimental studies in this area, a clearer and more comprehensive understanding of the age differences in dementia attitudes and personhood perception, and the moderating effect of dementia knowledge could be attained. Future research in this area could thereafter lead to more positive dementia attitudes and reduce the marginalization of persons with dementia in society.
References


Appendix A: Research Ethics Board Certificate of Approval

University of Regina

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Christie Alexia Newton

DEPARTMENT
Psychology

REB#
2018-009

TITLE: Attitudes About Older Adults With and Without Dementia

APPROVED ON:
January 22, 2018

RENEWAL DATE:
January 22, 2019

APPROVAL OF:
Application for Behavioural Research Ethics Review, Consent Form (Qualtrics Panels, Community and Student Participants), Demographics Information Sheet, Dementia Information Sheet, Dementia Knowledge Questionnaire, Personhood in Dementia Questionnaire, Dementia Attitudes Scale and Ambivalent Ageism Scale, Script for Advertisement in Classrooms, Recruitment poster, Script for Centre of Ageing and health Participants, and Dementia Information Script

Full Board Meeting □ Delegated Review ☒

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html.

Raven Sinclair, BA, CISW, BSW, MSW, PhD
REB Chair

Please send all correspondence to:
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University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4777 Fax: (306) 585-4993
research.ethics@uregina.ca
Appendix B: Consent Form for Qualtrics Panels

Project Title: Attitudes About Older Adults With and Without Dementia

Principal Investigator: Christie Newton
Psychology Honours Student
University of Regina
(306) 585-4428
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Supervisor: Thomas Hadjistavropoulos, Ph.D., R.D.Psych.
Research Chair in Aging and Health Professor
University of Regina
(306) 585-4457
thomas.hadjistavropoulos@uregina.ca

Sponsor: Saskatchewan Health Research Foundation

1. BACKGROUND

Our population is aging and dementia (e.g., Alzheimer’s Disease) affects a significant portion of older adults. Dementia affects cognitive capacity (e.g., ability to think and speak) and the way others view the individual.

2. WHAT IS THE PURPOSE OF THE STUDY?

We are interested in examining the attitudes and beliefs of members of the public toward older adults with dementia.

3. WHAT DOES THE STUDY INVOLVE?

This study is taking place online on a compatible device of your choosing (computer, laptop, mobile phone, tablet) via Qualtrics. Community-dwelling laypersons and caregivers of people with dementia will complete a series of questionnaires concerning attitudes about older adults and dementia. This study will take approximately 20-30 minutes to complete.

4. WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

This research may improve attitudes about aging and dementia. This could help develop educational intervention to reduce marginalization of persons with dementia in society.
5. WHAT ARE THE POTENTIAL RISKS OF PARTICIPATING?

To our knowledge, there is no significant risk to participating in this study.

6. WILL MY PART IN THIS STUDY BE KEPT CONFIDENTIAL?

All data will be securely stored. The study’s researchers and research assistants will be the only persons with access to the data and these persons will employ the strictest rules of confidentiality. Participants will be assigned a participant number and all identifying information will be removed from the data. Electronic data will be kept in password-protected databases and on password-protected computers. Data from this study will be published and presented at conferences, but no identifying information will be released or published without your specific consent to the disclosure. Only group results will be presented in our reports. All data will be stored for no less than seven years following publication. When it is time to destroy the data, electronic data will be permanently deleted.

All data collected via Qualtrics will be anonymous. Data security is very important to Qualtrics. Many previous clients of Qualtrics have tested the system to be sure it meets the highest standards of data security. In each case, Qualtrics has surpassed expectations and received high praise from elite companies. Qualtrics’ most important concern is the protection and reliability of customer data. Their servers are protected by high-end firewall systems, and vulnerability scans are performed regularly. Complete penetration tests are performed yearly. All services have quick failover points and redundant hardware, and complete backups are performed nightly.

7. WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE IN THE STUDY?

We hope that you will assist us with this research project; however, your decision to participate is completely voluntary. You may terminate your participation at any time. However, withdrawal of complete responses is not possible because participants are completely anonymous.

8. WHAT WILL HAPPEN AFTER THE STUDY?

A summary of the results of this study will be added to our website when they become available. If you would like to receive a summary of these results, you may contact the Health Psychology Laboratory at (306) 585-4428 or the principal investigator, Christie Newton, at newton3c@uregina.ca. We hope that the result summaries will be available by September 2018.

9. WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS?

If you have any questions or would like more information about the study, please contact the Health Psychology Laboratory at (306) 585-4428 or the principal investigator, Christie Newton, at newton3c@uregina.ca. You may use this email address before, during, or after the study.
This project was approved by the Research Ethics Board, University of Regina on January 22, 2018. If you have any questions or concerns about your rights as a research participant, you may contact the Chair of the University Research Ethics Board at (306) 585-4775 or at research.ethics@uregina.ca.

Please select your choice below.

Clicking on the “Agree” button indicates that you have read the above information, you voluntarily agree to participate in this study, and you are at least 18 years of age.

Clicking on the “Disagree” button indicates that you decline to participate in this study.

- Agree
- Disagree
Appendix C: Demographics Information Sheet

1. Age:

2. Gender:
   - Male
   - Female
   - Other

3. What is the highest level of education that you completed?
   - Some elementary school
   - Completed elementary school
   - Some high school
   - Completed high school
   - Some undergraduate or post-secondary education
   - Completed undergraduate or post-secondary education
   - Some graduate education
   - Completed graduate education

4. How many years of formal education have you completed (including elementary, middle/high school and college/university)?

5. Do you have any family members with dementia?
   - If yes, please indicate the number of family members:

6. Please indicate how you are related to that family member:
   - Spouse
   - I am his or her son or daughter
   - I am his or her parent
ATTITUDES ABOUT OLDER ADULTS WITH DEMENTIA

❖ Other

7. Have you had any family members with dementia in the past?
   ❖ Yes
   ❖ No

8. Please indicate how you are related to that family member:
   ❖ Spouse
   ❖ I am his or her son or daughter
   ❖ I am his or her parent
   ❖ Other

9. Do you have any friends with dementia?
   ❖ Yes
   ❖ No

10. Have you had any friends with dementia in the past?
    ❖ Yes
    ❖ No

11. Do you have regular contact with individual with dementia?
    ❖ Yes
    ❖ No

12. Please indicate the frequency of contact:
    ❖ Daily
    ❖ A few times a week
    ❖ Once a week
    ❖ A few times a week but less than once a week
❖ Once a month
❖ Less than once a month

13. Have you ever cared for someone with dementia as a paid carer?
❖ Yes
❖ No
Appendix D: Dementia Knowledge Questionnaire

Please select the most correct answer. If you are not sure of the answer, please select 'Don't Know'.

1. Which part of the body is affected in dementia? (Please select all of the following that apply)
   a. Lungs
   b. Brains
   c. Heart
   d. Don’t Know

2. Dementia mostly affects people aged:
   a. 30-40 years
   b. 40-60 years
   c. Over 60 years
   d. Don’t Know

3. Is there a cure for dementia?
   a. Yes
   b. No
   c. Don’t Know

4. How many types of dementia are there? (Please select all that apply)
   a. One
   b. Two
   c. Three or more
d. Don’t Know

5. What percentage of people over 65 years of age have dementia?
   a. Less than 5%
   b. 5-20%
   c. 20-50%
   d. 50-70%
   e. 70-100%
   f. Don’t Know

6. Which factors can cause dementia? (Please select all of the following that apply)
   a. Diet
   b. Infection
   c. Hereditary factors
   d. Stroke
   e. Alcohol
   f. Old age
   g. Don’t Know

7. Dementia can affect the following: (Please select all of the following that apply)
   a. Vision
   b. Reasoning
   c. Memory
   d. Thinking
   e. Speech
   f. Continence
g. Life expectancy

h. Don’t Know

**Message to participants who fail the DKQ**

- You will need a minimum score of 9 in dementia knowledge to proceed. We will repeat the information about dementia one more time.
Appendix E: Dementia Information Script

❖ Dementia is a neurological condition that affects the brain.

❖ There are several types of dementia, but Alzheimer’s disease is the most common.

❖ Dementia is a group of conditions that involve a deterioration of the ability to speak, think, and reason.

❖ Dementias cause a gradual deterioration of cognitive abilities and in moderate to severe stages, people with dementia may require 24-hour care.

❖ Over 5% of people over the age of 65 have Alzheimer’s disease or another dementia.

❖ Dementia can affect ability to think, reasoning, memory, speech, continence, vision, and life expectancy.

❖ There is no known cure for the vast majority of dementias.

❖ Several factors can cause dementia, for example, diet, infection, hereditary factors, stroke, and alcohol. Contrary to popular belief, dementia is not caused by old age per se.
Appendix F: Dementia Attitudes Scale

Please complete the following:

1. It is rewarding to work with people who have dementia.
2. I am afraid of people with dementia.*
3. People with dementia can be creative.
4. I feel confident around people with dementia.
5. I am comfortable touch people with dementia.
6. I feel uncomfortable being around people with dementia.*
7. Every person with dementia has different needs.
8. I am not very familiar with dementia.*
9. I would avoid an agitated person with dementia.*
10. People with dementia like having familiar things nearby.
11. It is important to know the past history of people with dementia.
12. It is impossible to enjoy interacting with people with dementia.
13. I feel relaxed around people with dementia.
14. People with dementia enjoy life.
15. People with dementia can feel when others are kind to them.
16. I feel frustrated because I do not know how to help people with dementia.*
17. I cannot imagine caring for someone with dementia.*
18. I admire the coping skills of people with dementia.
19. We can do a lot now to improve the lives of people with dementia,
20. Difficult behaviours may be a form of communication for people with dementia.*

*Reverse-coded item.
Appendix G: Ambivalent Ageism Scale

1. It is good to tell old people that they are too old to do certain things; otherwise they might get their feelings hurt when they eventually fail.

2. Even if they want to, old people shouldn’t be allowed to work because they have already paid their debt to society.

3. Even if they want to, old people shouldn’t be allowed to work because they are fragile and may get sick.

4. It is good to speak slowly to old people because it may take them a while to understand things that are said to them.

5. People should shield older adults from sad news because they are easily moved to tears.

6. Older people need to be protected from the harsh realities of society.

7. It is helpful to repeat things to old people because they rarely understand the first time.

8. Even though they do not ask for help, older people should always be offered help.

9. Even if they do not ask for help, old people should be helped with their groceries.

10. Most old people interpret innocent remarks or acts as being ageist.

11. Old people are too easily offended.

12. Old people exaggerate the problems they have at work.

13. Old people are a drain on the health care system and the economy.
Appendix H: Personhood in Dementia Questionnaire

1. Residents with dementia have a sense of purpose.

2. Most residents with dementia are still capable of making some informed choices about their lives.

3. Residents with dementia have a basic right to make any choices they can about their care.

4. Residents with very advanced dementia are so low-functioning that they are no longer persons.*

5. Residents with end-stage dementia can no longer contribute to the world in any meaningful way.*

6. Residents with dementia contribute to a sense of community within our long-term care facility.

7. All residents with dementia should be treated with respect.

8. Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines.*

9. It is possible for residents with dementia to connect with each other in meaningful ways.

10. Residents with dementia want to socialize with the people around them.

11. Residents with dementia can continue to play an important role in their families.

12. Some residents with dementia have had an important role in my life.

13. Providing stimulation such as music is very helpful for a resident with end-stage dementia.

14. As dementia advances, residents with dementia no longer experience basic feelings such as pleasure.*
15. Residents with end-stage dementia have some awareness of what is happening around them.

16. Residents with dementia who whine a lot should be isolated.*

17. The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness.*

18. Residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically.*

19. Residents with dementia have feelings about their experiences.

20. Most residents with dementia feel the same range of emotions as I do.

*Reverse-coded item.