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<https://doi.org/10.18297/etd/4028>

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CHANGING PUBLIC PERCEPTION OF DEMENTIA: THE EFFECT AND
CREDIBILITY OF THREE INFORMATIONAL MODELS

By

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B.A., Georgetown University, 2017

M.S., University of Louisville, 2019

A Dissertation

Submitted to the Faculty of the

College of Arts and Sciences of the University of Louisville

in Partial Fulfillment of the Requirements

for the Degree of

Doctor of Philosophy

in Clinical Psychology

Department of Psychological and Brain Sciences

University of Louisville

Louisville, Kentucky

December, 2022

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DEDICATION

This dissertation is dedicated to my grandparents, Anthony and Eleanor Caruso, Phillip and Miriam DiGasbarro, and my great uncle, Peter Caruso. I strive to carry forth the strengths—humor, curiosity, dedication, creativity, compassion—they lovingly instilled in our family.

ACKNOWLEDGEMENTS

I would like to thank my graduate mentor, Dr. Benjamin Mast, for his guidance and compassion over the past five years. Thank you to my dissertation committee—Dr. Sara Bufferd, Dr. Susan Buchino, Dr. Suzanne Meeks, and Dr. Bernadette Walter—for the generous gift of your time and talents to help me through this process. I would also like to thank Dr. Steven Sabat from Georgetown University: his clinical neuropsychology seminar is where this all began.

For their unwavering love and support throughout my life, I am eternally grateful to my family. To my wonderful friends at UofL, Valery Bodziony, Jackie Ma, Kelly Shryock, and Allison Williams: I cannot express gratitude enough to each of you for the support and encouragement over the past few years. I would not be the clinician, researcher, or person I am today without you.

To my husband, Luke: the depths of your patience and compassion cannot be overstated. There is not space to list the countless ways you have supported me over the years. Your care and thoughtfulness in your work truly inspires me to be the best clinician and researcher I can be.

Finally, thank you to the participants in this study and the clients I have met and learned from over the years. This work would not exist without you, and I am deeply humbled and privileged to have collaborated with you over the last five years.

ABSTRACT

CHANGING PUBLIC PERCEPTION OF DEMENTIA: THE EFFECT AND CREDIBILITY OF THREE INFORMATIONAL MODELS

Diana T. DiGasbarro Hedrick

July 22, 2022

Background: Since the 1970s, Alzheimer’s disease and dementia have been portrayed in a medicalized, symptom-focused manner to help spread awareness, improve diagnosis, and push for treatment research. In recent decades, there has been movement towards a biopsychosocial, person-centered approach that considers social and psychological factors that interact with biological diseases processes. Common biopsychosocial approaches retain an emphasis on deficits and symptoms. New research has integrated positive psychology constructs and dementia. This integration of positive psychology principles and dementia care and research has the potential to more accurately capture the experience of having dementia.

Objectives: This dissertation tested how the portrayal of dementia affects perceptions of dementia in the general public. A second objective was to explore variables that predict attitudes about dementia. Finally, this dissertation aimed to assess the perceived credibility of the three informational models of dementia.

Methods: The final sample consisted of 255 English-speaking adults living in the United States, aged 19-80, recruited via Amazon MTurk. Participants were randomly assigned to one of three conditions: biomedical model of dementia, biopsychosocial model of

dementia, or positive psychology-informed model of dementia. Participants then read a vignette and answered a series of questionnaires. Statistical analyses were conducted using SPSS 28.

Results: A one-way MANOVA showed no significant difference in perception of dementia between the three dementia model conditions. Multiple linear regressions identified a series of variables that predicted attitudes and beliefs about people with dementia, with ageism emerging as a consistent predictor of both positive and negative perceptions. A one-way ANOVA showed that the positive psychology-informed model and the biopsychosocial model of dementia did not result in worse credibility ratings than the biomedical model.

Conclusions: Statistical limitations hinder the ability to draw strong conclusions about several of the analyses. Statistically sound conclusions include the emergence of ageism as a consistent predictor of beliefs about dementia, and the fact that the biomedical model did not have higher credibility ratings than the more holistic models of dementia. These findings encourage future research into the relationship between ageism and perception of dementia, and into the effects of disseminating a positive psychology-informed framing of dementia.

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CHAPTER I: INTRODUCTION

Dementia is a syndrome defined clinically by impairment in one or more cognitive domains that is severe enough to interfere with a person's ability to independently complete daily activities. Dementia can be caused by a number of diseases, with the most common cause being Alzheimer's disease¹, a progressive neurological disease. An estimated 5.8 million people have Alzheimer's disease in the United States as of 2019, a number that is expected to increase to 13.8 million by the year 2050 (Alzheimer's Association, 2019).

So far, this description of dementia is reminiscent of the introductory paragraphs to many academic articles, book chapters, and publicly available information from agencies like the Alzheimer's Association and the Centers for Disease Control (*What is Dementia?*, 2020; *What is Dementia?*, 2019). It provides a straightforward, easily comprehensible depiction of this common health condition. Yet it neglects the nuances of dementia; the psychological, social, and environmental factors related to dementia; the abilities that are retained throughout the course of dementia; the diversity of the lived experiences of people with dementia.

¹ Throughout this dissertation and in much of the study materials, the term "dementia" is primarily used, as this study is concerned with the way that the public perceives people experiencing the cluster of symptoms we call dementia. However, it is important to recognize that the majority of dementia research has taken place with participants who have Alzheimer's disease, and many of the public health studies cited used the language "Alzheimer's disease" in their materials rather than the more general condition "dementia."

It is only within the past fifty years that dementia has been defined in what is now considered the “traditional biomedical” manner (Ballenger, 2017). Throughout the world—past and present—dementia has been considered a normal part of aging, a mismatch in social needs and resources, a mental disorder, a punishment from God, and more (Gerritsen, Oyebode, & Gove, 2018). As humans, we aim to make sense of the world and the people around us, and our perception affects how we interact with each other (Gerritsen, Oyebode, & Gove, 2018). While this dissertation does not endorse a subjectivist approach to dementia, it explores if the use of different, evidence-based models of dementia can alter the way laypeople perceive and respond to people with dementia.

Review of Models of Dementia

Historical Context of Biomedical Model of Dementia

More than 75% of adults living in the United States are familiar with the term Alzheimer’s disease, an encouraging statistic given the high prevalence of Alzheimer’s disease in the population (Anderson et al., 2009). When delving deeper into what American adults know about Alzheimer’s disease, its causes, and preventative measures, the numbers drop drastically—74% of respondents to a nationwide survey reported knowing “little or nothing” about Alzheimer’s disease; 17% of respondents in another nationwide survey reported there is “nothing” a person can do to reduce the likelihood of developing Alzheimer’s disease (Anderson et al., 2009). Yet at least two separate nationwide surveys reported that over 60% of American adults were worried about

memory or mental capacity loss as they age (Anderson et al., 2009). These survey results depict a complex picture of how Alzheimer's disease and cognitive changes associated with dementia are understood in the United States.

While Alzheimer's disease appears to be an almost universally recognized term amongst American adults, that term and our current Western conceptualization of the disease and the dementia it causes have arisen only within the past five decades. Ballenger (2017) offers a succinct history of the disease in the Western world. While dementia has been experienced throughout human history, its definition as a clinical syndrome that is not a normal part of aging is as recent as the 20th century. Alzheimer's disease was coined in 1910 to describe the onset of dementia that occurred before age 65; that is, it was distinct from "senile dementia" that was viewed as common and inextricably linked with the aging process. Dementia came into the public health arena in the mid-20th century when state psychiatric institutions were increasingly inundated with older adults with dementia who were classified as insane and were committed to psychiatric institutions for long-term care (Ballenger, 2017).

Around this time, a theory of dementia as a mismatch between the needs of older adults and the resources available to them was proposed, with psychiatrist David Rothchild as a major proponent of this social "adjustment" conceptualization of dementia (Ballenger, 2017). Public policy followed with new supports and resources for older adults such as Medicare and the Older Americans Act of 1965. As Ballenger (2017) describes, the framing of dementia as a social issue followed by policy responses led to increasing optimism about aging and subsequent dismay when people continued to develop dementia.

Clearly, the purely psychosocial adjustment model of dementia was incomplete. In the 1970s, a major push began to conceptualize dementia as the result of a biological disease process rather than a normal correlate of aging or a product of purely psychosocial mismatch between the needs of older adults and their environment (Ballenger, 2017). The definition of Alzheimer's disease was expanded to include people with dementia younger and older than age 65, and it was painted in a dire light which was crucial in garnering public attention and funding support.

For decades, Alzheimer's disease and dementia more broadly have been approached from a medical model, where funding is largely allocated towards basic and pharmacological research with the aim of finding a medical cure. This medicalization of dementia not only shaped research aims by directing funds towards biomedical research and thus away from psychosocial studies, but it also changed the way dementia was thought of by clinicians and the public. Namely, the medicalization of dementia described a relatively simple link between neurological changes and the behaviors—for example, memory loss, agitation, behavior changes—observed in people with dementia (Lyman, 1989). This way of conceptualizing dementia has been related to “individualization” of the disease and its effects, in that the burden of disease and disability prevention falls upon each individual rather than at a societal level, and to “depersonalization,” in which the behaviors, attitudes, and feelings of the individual become automatically ascribed to the disease and external factors are not considered as being of particular relevance (Bond, 1992). This biomedical model of dementia outlined in the 1970s guides the prevailing diagnostic criteria of dementia used in the United States and globally (American Psychiatric Association, 2013; Faure-Delage et al., 2012; Tan et al., 2012).

To summarize, in the span of a century, explanatory models for what we currently call dementia shifted from a natural part of aging, to a consequence of mismatched psychosocial needs and resources, to a biomedical brain disease.

Additional Explanatory Models of Dementia

Yet, the conceptualization of dementia continues to evolve as time progresses and disciplines intersect. In the past two to three decades, a biopsychosocial model of dementia has emerged and gained traction in scientific and clinical domains. Broadly, a biopsychosocial model of dementia combines the socially derived model of a mismatch in needs and resources with the medical model while also integrating psychological correlates (Ballenger, 2017; Gaugler et al., 2019; Illife & Manthorpe, 2017; Spector & Orrell, 2010). This more nuanced conceptualization importantly distinguishes biological processes and resulting symptoms that cannot yet be altered from social and psychological aspects of dementia that may be amenable to intervention (Spector & Orrell, 2010).

In 2010, Spector and Orrell published a widely cited biopsychosocial model of dementia designed to help clinicians and researchers better understand the many factors that affect the progression of dementia. This model presents a significant departure from the traditional medical model. It details a nuanced process in which pre-existing and current health problems and biological factors, and pre-existing and current psychosocial characteristics interact with the disease process to influence functional and psychosocial outcomes in people with dementia. This model aims to allow for identification of “fixed” factors, such as education, that cannot be altered, and “tractable” factors, such as the environment, that can be a target of intervention that may change the disability and

experience of the person with dementia. Spector and Orrell's (2010) model describes biopsychosocial tractable factors in the context of preventing excess disability and allowing the person with dementia to remain as independent as possible for as long as possible given the biopsychosocial fixed factors at play for each individual.

While Spector and Orrell's (2010) biopsychosocial model seems to be one of the dominant models of dementia within dementia research, it is not the only biopsychosocial model of dementia that exists. As a response to the increasingly dominant medical model of dementia, the person-centered care movement emerged within the realm of dementia care and research in the 1990s. A prominent name in the field of person-centered care is Tom Kitwood. Kitwood's (1997) revolutionary contribution to dementia research emphasizes the interaction between the biological processes affecting cognition and functioning and the psychosocial environment of a person with dementia—a biopsychosocial conceptualization. He describes how the social context in which a person with dementia lives can greatly impact their functioning and well-being; in fact, a “malignant” social environment can make a person with dementia appear far more impaired than could be attributed to solely biological processes. Kitwood (1997) lists examples of “malignant social psychology,” which he defines as behaviors or attitudes exhibited by caregivers that, while not intentionally malicious, stem from a culture of dehumanizing people with dementia. In contrast to these malignant social factors, Kitwood (1997) lists elements of “positive person work” that provide examples of how the experiences of the person with dementia could be improved by creating a positive social environment. In order to create this positive social environment, though, it is

necessary to consider the person with dementia as a whole, unique *person* with inherent dignity that does not degrade in the face of cognitive or functional limitations.

Sabat (2008) describes a biopsychosocial model of dementia, which in many ways builds upon Kitwood's work, that includes the biological disease process, the way the individual reacts to the brain damage, the way that other people treat the individual with dementia, and how the individual with dementia reacts to how they are treated by others. Sabat's (2008) biopsychosocial model of dementia adopts a stance in which the person is viewed first, and *as if* they retain abilities and the capacity for meaningful action, while the disease process interacts with their social relationships, cognitive and functional abilities, and psychological characteristics. Sabat's (2008) biopsychosocial model of dementia differs from that of Spector and Orrell (2010) in that it more strongly emphasizes social and interpersonal factors and allows more space for the strengths and positive qualities of people with dementia. While Spector and Orrell's (2010) biopsychosocial model of dementia encourages intervention, improvement of quality of life, and capitalizing on pre-existing strengths—a marked difference from the medical model—it is within the context of alleviating symptoms and delaying decline. The work of Sabat and Kitwood, on the other hand, places a somewhat stronger emphasis on celebrating retained abilities and recognizing the strengths and personhood of the individual regardless of the severity of symptoms.

There are recent trends within the fields of dementia care and research that indicate movement towards a more positive psychology-based view of dementia, including explicit calls for better recognition of the positive qualities of people with dementia (Harris & Keady, 2008). Positive psychology, as formally defined in 2000 by

Seligman and Csikszentmihalyi, describes the practice of psychology that emphasizes positive traits and experiences as opposed to traditional clinical psychology which focuses on the reduction of symptoms and distress. In research and applied settings, the positive psychology movement aims to learn about and encourage positive qualities that make life worth living (Seligman & Csikszentmihalyi, 2000). In the context of dementia, there has not to date been a formal model of dementia that explicitly takes a positive psychology approach. While Kitwood and Sabat's (2008) biopsychosocial approaches are infused with positive psychology concepts, they do not explicitly emphasize equal acknowledgement of cognitive and behavioral changes and encouragement of strengths, traits, and abilities that make live worth living for people with dementia.

However, recent qualitative, psychometric, and applied research is laying a foundation from which a formal positive psychology-informed model of dementia might arise. Wolverson, Clarke, and Moniz-Cook (2016) published a systematic review and synthesis of qualitative research on "living positively with dementia." Twenty-seven studies were categorized into three main themes—engaging with the aging process, engaging with dementia, and "identity and growth"—with nine subthemes, including seeking pleasure and enjoyment, hope, humor, gratitude, and growing and transcending. Hickman, Clarke, and Wolverson (2018) conducted a qualitative study on the use of humor in dyads consisting of a person with dementia and their spouse. McGee et al. (2017) published a pilot study in which they tested five measures of positive psychology constructs in people with dementia: gratitude, life satisfaction, meaning in life, optimism, and resilience. DiGasbarro et al. (2020) found that a widely used measure of hope demonstrated adequate reliability and validity when used in recent nursing home

residents with cognitive impairment. Stoner et al. (2017) created a measure of positive psychology outcomes—hope and resilience—designed for use with older adults with dementia. Shannon, Bail, and Neville (2019) reviewed the research on “dementia friendly communities,” which are communities that have arisen in a few countries throughout the world. These communities are designed to accommodate the different needs of people with dementia while allowing them to remain an active member of a diverse (which here means people with and without cognitive impairment) community; thus, rather than taking an individualized approach to treating symptoms of dementia, these communities create a social and physical environment that supports people with dementia to continue to lead meaningful, socially-connected lives (Shannon, Bail, & Neville, 2019).

The recently published studies identifying positive characteristics in people with dementia and considering how to build an integrated social system that supports the differences experienced by people with dementia indicate that people with dementia do possess character strengths and traits and that “treatment” does not need to exist solely at an individual, deficits-focused level. A logical next step in this line of research is to determine how these strengths and traits can be used to enhance well-being and coping with challenges, and how the environment can positively shape the experiences of people with dementia. The recent interest in this line of research creates an encouraging potential foundation for a positive psychology-informed model of dementia that builds upon past biopsychosocial models and moves closer towards a balanced and accurate conceptualization of dementia.

Thus far, three existing models of dementia have been reviewed: the biomedical model, Spector and Orrell’s (2010) biopsychosocial model, and Sabat’s (2008)

biopsychosocial model. Evidence that creates a foundation for potential new model—a positive psychology-informed model—has also been presented. A full review of all explanatory or informational models of dementia is beyond the scope of this proposal, but it is important to note that the models reviewed here are largely Western-based conceptualizations of dementia. While dementia is almost universally recognized in some manner, the biomedical model of dementia, and even the biopsychosocial models described here are not necessarily widespread in lay communities around the world—including Western countries (Tan et al., 2012). For example, in Brazzaville, Republic of Congo, Faure-Delage et al. (2012) found that participants in the study attributed dementia to normal aging, mental or emotional stress, a lifetime of hardship, fate, or sorcery. In southwestern Uganda, Owokuhaisa et al. (2020) reported that participants attributed dementia to medical conditions—although not degenerative brain disease—normal aging, excessive worry, trauma, loneliness, poverty, substance use, and evil spirits. In Singapore, Tan et al. (2012) reported that most participants were split between attributing dementia to a medical illness—the biomedical model—and normal aging—the folk model, which the authors posit stems from religious beliefs about fate and destiny. In Brazzaville, the main “symptoms” of concern were related to the emotional suffering experienced by the person with dementia, financial strain on the family, and forgetfulness (Faure-Delage et al., 2012). Medical treatment was recognized as a viable response to dementia, but almost all participants indicated that consultation with religious leaders was also important (Faure-Delage et al., 2012). In southwestern Uganda, the main impacts of dementia that were identified were inability to perform self-care tasks, risk of injury or illness due to functional limitations, emotional symptoms, and vulnerability to neglect

and abuse (Owokuhausa et al., 2020). In Singapore, most participants reported they would not want to know if they had dementia and expressed negative, fatalistic views of it (Tan et al., 2012)

This brief and by no means comprehensive discussion of how dementia is viewed across the world serves to demonstrate the diversity of models of dementia. The biomedical model espoused in the United States, with its emphasis on cognitive deficits and medical treatment, is not the only or even the “best” way to conceptualize dementia. This is not to say the scientific evidence of the pathologies that are associated with dementia is subjective or inaccurate; but rather, a phenomenon as complex as dementia can be viewed through multiple lenses depending upon the values and beliefs of a community. This illustrates the notion that the emphasis placed on the deficits or strengths, limitations or abilities, of people with dementia is flexible and can be altered if a pre-existing cultural narrative causes undue harm to people with dementia.

Review of Public Perception of Dementia

Thus far, this dissertation has reviewed some of the literature and models that explain what dementia is. Next, the way people view dementia is discussed.

Attitudes about Dementia

The broadest way to classify how people feel about dementia is to discuss attitudes about dementia. This general notion of attitudes can encompass many constructs, such as fear, comfort, stigma, prejudice, emotions, understanding, and more. In-depth review of all these constructs is beyond the scope of this dissertation, but a

specific definition of attitudes, studies that assess predictors of attitudes and beliefs, and interventions that aim to change attitudes about dementia will be discussed.

Beginning with one definition of attitudes about dementia, O'Connor and McFadden (2010) developed a measure assessing attitudes, the Dementia Attitudes Scale (DAS). O'Connor and McFadden (2010) refer to the social psychology definition of attitudes, which encompasses cognitions, emotions, and behaviors as factors influencing how a person responds to a person, object, or event. While there are numerous measures of attitudes about people with disabilities, and numerous informal measures of attitudes about dementia, until the DAS, there was no measure with psychometric support that assessed attitudes about dementia (O'Connor & McFadden, 2010). Factor analysis of the DAS yielded a two-factor structure, with the measure assessing both knowledge about dementia and social comfort with people with dementia. These two factors assess beliefs about dementia, and behaviors and feelings of comfort being around people with dementia, respectively.

It is important to note that the DAS is designed to be used by caregivers and the general public. This measure stands out in this way, as it can be used to measure social components of attitudes rather than purely knowledge-based beliefs in the general population. Many studies of perceptions of dementia amongst the general public focus mostly on knowledge of dementia and risk factors (e.g., Anderson et al., 2009; Kim, Sargent-Cox, & Anstey, 2015; Tsolaki et al., 2009) rather than social or emotional feelings and beliefs about dementia. The information that is available relating to predictors of attitudes about dementia in the general public is somewhat mixed. For example, Ludecke, von dem Knesebeck, and Kofahl (2016) found that in Germany,

respondents to a large survey who were older, of higher SES, and more knowledgeable about dementia believed people with dementia to have lower quality of life compared to respondents without those demographic characteristics. Women and people who had experience caring for a person with dementia were less likely to believe that people with dementia are better taken care of in an institutional setting (Ludecke, von dem Knesebeck, & Kofahl, 2016). In Ireland, Rosato et al. (2019) found that being female, younger, and having more contact with and knowledge of dementia was related to higher levels of antipathy. Middle-aged adults, people with less education, and people with less knowledge of risk factors believed that higher levels of control are needed over people with dementia. In the United States, Stites et al. (2018) found that females were more likely to feel sympathy and pity and less likely to judge hygiene issues in people with dementia than males. O'Connor and McFadden (2010) remark upon the inconsistent findings in the literature as well, especially on the mixed findings on whether more exposure to people with dementia and more knowledge of dementia are related to more positive or negative attitudes about dementia. Some of these inconsistencies in the literature may be explained by the fact that there are many different ways that “attitudes” or “perceptions” are defined, and there is minimal utilization of standard measures of attitudes. Furthermore, classification of certain responses—such as pity—as “positive” or “negative” is complex, a topic which will be discussed in more detail in the next section when the literature on stigma is reviewed.

A primary reason for understanding the factors that affect attitudes about dementia is to create interventions or campaigns that aim to minimize harmful attitudes and maximize beneficial attitudes. Many of the interventions that have aimed to change

attitudes about dementia target caregivers or medical professionals who interact with people with dementia on a provider-patient basis. For example, George, Stuckey, and Whitehead (2013) conducted a small study on a creative narrative intervention, where medical students participated in a month-long elective spending time telling and listening to stories with people with dementia. After the intervention, the medical students' results on the DAS had improved significantly (George, Stuckey, & Whitehead, 2013). Although not explicitly intervening upon attitudes, recent initiatives to change the “culture of care” in institutions where people with dementia reside also addresses the question of how to change the way healthcare professionals and caregivers perceive and interact with people with dementia. This push stems from Kitwood's (1997) critique of malignant social psychology and proposal of positive person work, and aims to create cultural changes amongst healthcare workers and institutions to make dementia care more person-centered—respectful of dignity, individual differences, and quality of life (Dupuis et al., 2016; McGreevy, 2016; Surr et al., 2016). There are also many studies of family caregiver interventions aimed at improving the experiences of the caregiver and the person with dementia, which are beyond the scope of this dissertation.

There are fewer studies testing interventions aimed at changing attitudes about dementia in the general population. Sabat (2012) published a case study in which teaching undergraduate students about dementia using a biopsychosocial model resulted in students learning about what dementia is, the positive qualities and negative stereotypes experienced by people with dementia, and the needs of people with dementia. This case study did not include a measure of attitudes, but the pre-post design of this

small sample did show that an educational “intervention” increased positive attributes given to people with dementia by the students (Sabat, 2012).

Reynolds et al. (2017) published a qualitative study in which people with dementia joined an orchestra with students, family members, and professionals and performed for the public; people with dementia comprised 51.4% of the orchestra. Audience members ($N=109$) completed questionnaires, and Reynolds et al. (2017) reported that audience perceptions of dementia were more positive following the performance, and that their rating of the performance exceeded their expectations prior to the performance. Further research into how to change attitudes about dementia amongst the general public is needed, with larger samples and inclusion of more quantitative measures of attitudes and perceptions.

Dementia-related Stigma

Another major construct within the dementia literature is stigma. Although stigma is a complex construct with different subtypes and factors, it is defined in a broad sense as the application of a “socially discrediting stereotype by the wider society which provokes an individual to feel rejected in some way” (Rosato et al., 2019, p. 13). Stigma does not uniquely affect people with dementia, but stigmatizing beliefs about people with dementia are pervasive amongst healthcare workers, laypeople, and people with dementia themselves around the world, with studies of dementia-related stigma coming from Ireland, Israel, Brazil, Singapore, Brazzaville, and many other countries (Blay & Peluso, 2010; Faure-Delage et al., 2012; Herrmann et al., 2018; Rosato et al., 2019; Tan et al., 2012; Werner & Schiffman, 2018). Stigma related to dementia serves as a barrier to help-seeking and healthcare access, especially in early stages of dementia, and is associated

with isolation, psychological and emotional distress in the person with dementia, and social exclusion of the person with dementia and their family members (Herrmann et al., 2018; Rosato et al., 2019). Stereotypes that have been found to reinforce dementia-related stigma often center around people at late stages of dementia, where cognitive and functional impairment are most pronounced (Stites, Rubright, & Karlawish, 2018). Beliefs that people with dementia will face social isolation and discrimination—including health insurance discrimination—are prevalent in the United States and contribute to the atmosphere of fear, confusion, and “othering” that surrounds dementia (Stites et al., 2018).

While stigma related to dementia is a well-documented, harmful phenomenon, reducing stigma remains a challenge for dementia researchers and advocates. Firstly, the definition and measurement of stigma is inconsistent within the dementia literature. There are at least two subtypes of stigma: felt stigma and enacted stigma (Fletcher, 2019). Felt stigma describes an individual feeling that they are or will be stigmatized by others, while enacted stigma describes an individual behaving in a way that explicitly stigmatizes another person, such as explicit social exclusion or discrimination (Fletcher, 2019). Health related stigma can also be broken down into self-stigma (negative beliefs about one’s own disease), personal stigma (negative beliefs about another person with the disease), and perceived stigma (negative beliefs about what other people think about the disease) (Piver et al., 2013). There is also the issue of how to assess stigma in research. A recent review of dementia-related stigma research claims there is no standard measure of stigma that has been used with regards to dementia, and there are very few quantitative measures of dementia-related stigma (Herrmann et al., 2018).

A second challenge within the dementia-related stigma field is how to effectively reduce stigma. Efforts to reduce dementia-related stigma frequently utilize awareness or educational campaigns that are explicitly anti-stigma, or that attempt to raise awareness of the nuances of dementia and the people who live with it (Fletcher, 2019; Van Gorp & Vercruyse, 2012; Werner & Schiffman, 2018). However, more work is needed to determine an effective, long-lasting solution to the problem of dementia-related stigma. A review of mass media campaigns and interventions designed to reduce mental health stigma found that these campaigns and interventions resulted in small to moderate short-term effects that did not appear to be long-lasting (Gronholm, Henderson, & Thornicroft, 2017). While this review looked at anti-stigma campaigns and interventions pertaining to mental health broadly, similar mixed results have been reported regarding dementia-related stigma with mass media campaigns resulting in small to no effect on changing stigmatizing beliefs about dementia (Van Gorp & Vercruyse, 2012; Werner & Schiffman, 2018). There also is evidence that different demographic groups respond differently to dementia; for example, females in the United States felt more pity towards people with dementia, while older adults were more likely to expect that people with dementia would face discrimination and social isolation compared to younger adults (Stites et al., 2018). This raises the question of whether a one-size-fits-all campaign would adequately address stigma across demographic and individual differences (Stites et al., 2018).

Additional complexity of attempts to reduce dementia related stigma is discussed by Fletcher (2019) in a commentary on anti-stigma efforts within dementia research. He writes that the biomedicalization of dementia has been pointed to as a source of

dementia-related stigma—labeling behaviors associated with dementia as a disease, particularly an incurable disease in many cases—by some, and a way to reduce age-related stigma—differentiating aging and older adults from pathological memory loss and thinking difficulties—by others. Yet attempts to combat negative stereotypes about people with dementia can sometimes inadvertently reinforce felt stigma, as these campaigns draw more attention to the negative beliefs people might have about dementia. Fletcher (2019) also argues that simplistic positively-focused anti-stigma campaigns, although well-intentioned, may serve to implicitly reinforce felt stigma by means of “benevolent othering,” in which a group with less power—in this case, people with dementia—are portrayed by a group with more power—in this case, “healthy” members of the public—in such a way that elicits sympathy and highlights their “otherness.” Overly positive portrayals of dementia or use of celebrity spokespeople in mass media campaigns can lead to this issue, as they still highlight people with dementia as “other” and in need of help from a group with more power.

Although dementia-related stigma remains a challenging construct to define, measure, and reduce, it is clear that reduction of felt and enacted stigma is a worthy goal. As much as there is a consensus in the field, it seems that the way forward includes continued education on what dementia is, realistic portrayal of people with dementia—both their challenges and their strengths—and importantly, listening to concerns and ideas of people with dementia who have the best understanding of their own experiences.

Attribution of Controllability as a Facet of Stigma

Related to the construct of stigma is the concept of attribution of controllability. This concept stems from the social psychology theory of attribution, which describes how

people conceptualize the cause, stability, and controllability of behaviors or conditions (Hegarty & Golden, 2008). There is a subset of stigma research that focuses on controllability beliefs—is the individual or group affected in control of their condition, or is there is an external factor that is outside of their control—and how these intersect with stigmatizing beliefs. This research explores the theory that people are more likely to feel pity, sympathy, and other positive emotions when interacting with a person from a stigmatized group if they believe the individual has no control over their condition; negative responses are elicited when a person believes the stigmatized individual is responsible for their condition (Hegarty & Golden, 2008). For instance, a person classified as obese—a stigmatized condition—would be viewed with pity or sympathy if an individual believes the person is obese due to uncontrollable genetic and health factors. If the person is viewed as being obese because of poor diet and lifestyle choices, they will be blamed or otherwise judged negatively for their obesity (Hegarty & Golden, 2008). Thus, attribution of controllability is a potential factor that influences—or is influenced by—stigmatizing beliefs and behaviors.

The application of the theory of attribution of controllability as a facet of stigma has yielded complex results. Hegarty and Golden (2008) aimed to test if beliefs that a condition is uncontrollable justifies pre-existing stigma, or if beliefs that a condition is uncontrollable causes stigma. They used a vignette-based design attempting to manipulate controllability beliefs and assess stigma towards four groups: obesity, depression, homosexual orientation, and alcoholism. Their study found that manipulating controllability beliefs did not affect stigma, and that people with more prejudice endorsed a higher number of beliefs that the cause of these conditions were controllable (Hegarty

& Golden, 2008). Thus, pre-existing stigma may be justified by attributing a stigmatized condition to a controllable cause.

Kalsy et al. (2007) also employed a vignette-based design to assess controllability beliefs before and after a staff training educating professional caregivers of people with intellectual disability and dementia about the diagnoses and behavioral challenges that accompany them. The intervention consisted of providing information about Alzheimer's disease and dementia, intellectual disability such as Down syndrome, behavioral features at different stages of these conditions, and working through a case study. After the intervention, Kalsy et al. (2007) found that knowledge had increased, while controllability beliefs decreased. Upon learning more about the disorders, staff attributed causality of challenging behaviors more to external and uncontrollable factors—like the disorder itself—than to controllable factors (Kalsy et al., 2007).

While Kalsy et al. (2007) did not assess attitudes or stigma before and after their intervention, their study demonstrated that education may change attribution of controllability. Hegarty and Golden (2008) questioned if manipulating controllability beliefs affects stigma, although a limitation of their study was that it did not involve the intensity of intervention utilized by Kalsy et al. (2007). Another question brought up by both teams of researchers probes the “positive” or “negative” effects of high or low controllability beliefs. As Hegarty and Golden (2008) write, lower controllability beliefs are often associated with “positive” responses such as pity or sympathy, while higher controllability beliefs are often associated with “negative” responses such as blame and stigma. However, classifying pity as “positive” is an oversimplification, as pity reinforces a social distance and hierarchy, with people in the stigmatized group being placed below

the person from the majority or “powerful” group (Hegarty & Golden, 2008). Kalsy et al. (2007) also discussed the implications of their intervention decreasing controllability beliefs. They posited that this may have arisen from the emphasis within the educational intervention on the biological factors of the conditions, but that these findings confound theories that higher attribution of control is associated with optimism for enacting change in professional caregivers (Kalsy et al., 2017). Thus, the issue of whether high or low controllability beliefs are positive or negative remains complex, as some of the “positive” responses perpetuate harmful social hierarchies, while high controllability may actually be a belief that inspires hope and optimism in caregivers. What is clear is that attribution of controllability is a topic worthy of further exploration, especially as it pertains to stigma felt by groups who require caregivers, such as people with dementia.

Highlighting Gaps in the Literature

Thus far, this dissertation has reviewed two broad areas of dementia research: explanatory or informational models of dementia and perceptions of dementia. Both of these fields continue to evolve as interest grows in better capturing the psychosocial experiences of people with dementia, in recognizing strengths and positive qualities of people with dementia, and in learning about how the public perceives dementia from biological, psychological, and social lenses.

With regards to future directions in the realm of explanatory models of dementia, an explicitly positive psychology-informed biopsychosocial model would culminate years of research—especially that published by Kitwood (1997) and Sabat (2008)—and recent calls for measuring and capturing the positive experiences of people with dementia (Gaugler et al., 2019; Harris & Keady, 2008). Spector and Orrell’s (2010)

biopsychosocial model allows space for positive qualities and characteristics, but inherently it still focuses on delaying decline and negative outcomes. As Fletcher (2019) wrote in his article on pitfalls of dementia anti-stigma campaigns and research, the stance of directly combatting a negative perception can inadvertently lend credence to that perception and can even increase stigma. Extrapolating from this principle, it is possible that even a person-centered, biopsychosocial conceptualization of dementia that emphasizes reduction of excess symptoms may implicitly reinforce a skewed narrative that people with dementia only experience negative events; that they are defined by their symptoms or lack thereof; that the best outcome is compensation for limitations and delaying decline. What is missing from this approach is emphasis on recognition and encouragement of strengths, abilities, and positive events experienced by people with dementia.

Kitwood and Sabat's works address these gaps in many ways, but two issues remain. First, Sabat's (2008) biopsychosocial model is not what is referred to when researchers and clinicians use a biopsychosocial model; rather, the commonly discussed (e.g., Illife & Manthorpe, 2017) biopsychosocial model is more akin to that described by Spector and Orrell (2010). Second, Sabat's (2008) model lacks explicit emphasis within the framework itself on positive strengths, traits, and experiences of people with dementia. With the current negative culture surrounding dementia, implicit recognition of strengths may go unnoticed by researchers and clinicians.

Research on how the public understands dementia also indicates a large gap between the explanatory or informational models that are popular amongst academics and explanatory or informational models that are popular amongst the general population.

Laypeople continue to attribute dementia to normal aging, mental illness, stress, and spiritual beliefs (Tan et al., 2012). Even amongst laypeople who attribute dementia to a brain disease, there remains confusion and lack of knowledge about how dementia is conceptualized (Anderson et al., 2009). Importantly, studies looking at public understanding of dementia frequently assess understanding of the biomedical model of dementia; the biopsychosocial model of dementia is rarely mentioned in studies of public knowledge about dementia. If the biopsychosocial model is purported to more accurately describe the experience of dementia than the biomedical model, it seems imperative that the biopsychosocial model move into the public sphere. Current research is lacking that explores how the public understands a biopsychosocial model of dementia, and there is no research on how the public understands or reacts to a positive psychology-informed model of dementia.

A second issue addressed in this dissertation is how the public responds to dementia. Major constructs within this domain include attitudes and stigma, with attribution of controllability playing a part in stigma. The study of attitudes and stigma related to dementia remains complex, as there are inconsistencies in how these constructs are defined and measured. There are few studies of how attitudes and stigma related to dementia can be changed in the general public (Reynolds et al., 2017; Van Gorp & Vercruyse, 2012), and no published research on controllability beliefs about dementia amongst laypeople. Even among campaigns that aim to change stigma about dementia, more research needs to be conducted to learn how to effectively change beliefs to reduce stigma and increase positive attitudes without reinforcing harmful social hierarchies

between the “healthy” and powerful majority and the stigmatized and powerless minority (Fletcher, 2019).

Aims and Rationale of Dissertation

Aims

This dissertation first aimed to test how the informational model of dementia that is offered to members of the general adult population in the United States affects their perception of people with dementia. Three informational models were tested: a biomedical model, a biopsychosocial model, and a positive-psychology informed model. Second, this study aimed to explore factors that contribute to perception of people with dementia. Perception in this study is defined as attitudes, stigma, controllability beliefs, and behavioral responses to people with dementia. Third, this study aimed to assess the perceived credibility of each informational model of dementia. This third aim will provide preliminary information on whether a positive psychology-informed model of dementia might be accepted by the public, which could inform larger scale campaigns seeking to create a more positive culture surrounding people with dementia.

Rationale

This study broadly moves towards addressing an issue that hinders all elements of dementia research and care—culture. Intervening upon the culture in a facility or even a group of facilities may prove helpful in improving the experiences of some people with dementia, but those caregivers, professional and informal, are not immune from the broader societal culture in which they live. A global approach to changing the emphasis of the dementia narrative in our society has the potential to radically alter how people

with dementia are perceived and thereby treated by caregivers, facilities, communities, and policy.

This dissertation not only reflects recent trends within the field of dementia research (Gaugler et al., 2019; Harris & Keady, 2008), but also fits into larger social issues. Within recent decades, movements towards acceptance and inclusion of people with disabilities have arisen, especially as the internet has offered a more accessible platform for some people with disabilities to raise awareness, tell their stories, and protest (*Disability Inclusion*, 2019; United Nations, 2006; Ellis, Goggin, & Kent, 2015). Even more recently, especially with the advent of social media, movements like the “body positivity” movement have arisen, which aims to celebrate diversity of bodies, rather than stigmatize or exclude people who fall outside “normal” or “ideal” weight standards (Cohen, Newton-John, & Slater, 2020). The disabilities rights movement and body positivity movements represent just two areas in which there is a call for including and valuing people in historically stigmatized groups. Thus, a reframing of dementia in such a way that acknowledges the abilities and value of people who have long been stigmatized is a natural step towards a society that is more inclusive.

There is also an urgent need for better understanding of how scientific and public health information is disseminated and perceived. The issue of dissemination and perception of public health information has come to the forefront of global cultures during recent years with increases in mistrust of science (Kabat, 2017), anti-vaccine movements (Goldenberg, 2019), and in the wake of infectious diseases like Zika (Laurent-Simpson & Lo, 2019) and COVID-19 (Freeman et al., 2020). By assessing how laypeople are affected by and perceive the credibility of information presented to them

about dementia, a common health condition, this dissertation will add to the body of literature on the portrayal of public health information.

While it is undeniable that dementia is a syndrome caused by a disease process that greatly affects the life of the person with dementia and their family, encouraging what is positive is not mutually exclusive of addressing what is challenging. The findings of this dissertation aim to provide preliminary evidence on if a positive psychology-informed model of dementia is palatable to the public, and if the way dementia is framed matters in how people feel about this historically stigmatized group of people.

Procedure

The present study recruited participants through Amazon MTurk. Upon selecting the HIT posted for this study, participants were presented with an informed consent preamble. Upon consenting to continue with the study, participants were directed to SurveyMonkey to complete the study questionnaires and measures. Participants were randomly assigned to the biomedical model condition, the biopsychosocial condition, or the positive psychology-informed condition, so named based on which description of the dementia will be presented to the participant. Random assignment took place by participants selecting the top one of three randomly generated symbols as the first survey question. Depending on which symbol they selected, they were directed to one of the three survey conditions. Respondents read the brief description of dementia and then immediately answered three attention/comprehension questions; each participant answered the same comprehension questions regardless of the description they read to ensure the attention/comprehension questions do not prime participants to remember different pieces of information. Respondents then read the vignette. Following the

vignette, they responded to the survey questions and questionnaires (included in Appendix C) described in the Materials subsection, in the same order as they are listed in the Materials subsection. The entire study was designed to take approximately 20-30 minutes to complete, with a maximum time limit, as recommended by MTurk, of 60 minutes. Approval from the University of Louisville Institutional Review Board was acquired prior to data collection.

Hypotheses

Hypothesis Regarding the Effect of Model Condition on Perception of Dementia

Hypothesis 1. It is hypothesized that the informational model of dementia presented to participants will have an effect on participants' perceptions of a person with dementia as measured by responses to questionnaires following a vignette describing a person with dementia.

Directional hypotheses. The biomedical model condition will lead to a "malignant" perception of people with dementia, as defined by: poorest attitudes about dementia, highest stigma towards dementia, lowest controllability beliefs (external attribution of control), and more malignant behavioral responses to situation in the vignette (more likely to "avoid the person" in the vignette, higher agreement that "the person is behaving this way because of their Alzheimer's disease"). The biopsychosocial condition will lead to benign perception of people with dementia, as defined by: medium or neutral attitudes about dementia, medium level of stigma towards dementia, medium controllability beliefs, and benign behavioral responses to situation in the vignette (more likely to "inform" someone else of the woman's

behaviors, higher agreement that “the person behaves this way because no one has addressed her concerns”). The positive psychology-informed condition will lead to positive perception of people with dementia as defined by: best attitudes about dementia, lowest stigma towards dementia, medium controllability beliefs, and positive behavioral responses to the situation (more likely to “comfort” the woman in the vignette, higher agreement that “the person behaves this way because she is trying to communicate something the best way she can in the setting”)

Hypothesis Regarding Predictors of Perception of Dementia

Hypothesis 2. It is predicted that ageism, fear of Alzheimer’s disease, experience with people with dementia, emotional responses to the vignette, age, gender, race, and education will be associated with different perceptions of dementia, as defined by: attitudes, stigma, controllability beliefs, and behavioral response to vignette.

Directional hypotheses. Higher levels of ageism, fear of Alzheimer’s disease and less experience with people with dementia will predict more malignant perception of people with dementia, as defined in Hypothesis 1A. Emotional responses to vignette will also be predictive, with emotions such as pity, fear, annoyance, and helplessness predicting more malignant perception. Lower levels of ageism, more knowledge of AD, less fear of AD, and more experience with people with dementia will predict more positive perception of people with dementia. Emotional responses such as compassion and concern will predict more positive perception. Age, education, and gender may also be predictive, with older age, more education, and female gender associated with more positive perception. Race was included as an exploratory

variable, as there is a need for better understanding of how race/ethnicity are related to perceptions of dementia (Stites et al., 2018b).

It should be noted that there is conflicting evidence regarding whether experience with dementia and female gender predict positive or negative attitudes about dementia (O'Connor & McFadden, 2010; Rosato et al., 2019). Thus, predictions regarding these factors are exploratory.

Hypothesis Regarding Perceived Credibility of Informational Models

Hypothesis 3. It is predicted perceived credibility of the dementia model will a.) differ between groups, and b.) be associated with knowledge of Alzheimer's disease, fear of dementia, and experience with dementia. This aim of the study is very preliminary and exploratory at this stage, as research on perceived credibility of online health information in general is an emerging field, and there is little to no research on perceived credibility of dementia information (Sbaffi & Rowley, 2017). However, directional hypotheses are offered to guide this exploratory objective.

Directional hypotheses. Perceived credibility will be highest for the biomedical model and lowest for the positive psychology-informed model. Perceived credibility of each model will be predicted by knowledge of Alzheimer's disease, fear of dementia, and experience with dementia, with greater knowledge, more fear, and less experience with dementia associated with higher credibility for the medical model and lower credibility for the positive psychology-informed model.

CHAPTER II: METHODS

Participants

There were 270 individuals aged 18 and older recruited via Amazon MTurk. Inclusion criteria were English-speaking and residence in the United States. The study was posted separately for specific age groups (18-25, 25-30, 35-45, 45-55, 55+) in order to ensure distribution of ages across the adult lifespan. Surveys were closed such that 90 participants were recruited in ages 18-35, 90 participants were recruited in ages 35-55, and 90 participants were recruited in ages 55 and up. More participants began the survey than submitted the HIT on MTurk, which was possible due to the fact that the survey was hosted on SurveyMonkey through a link posted on MTurk. The total number of responses to the survey was 320. Upon examining the data, it appeared that many participants began the survey on SurveyMonkey but did not finish it or submit the HIT on MTurk, evidenced by incomplete data following the initial few questions. The final sample characteristics are discussed in Chapter III.

In order to assess the quality of the data, an attention/comprehension check was included following the explanatory description of dementia. All participants were asked the same three True/False questions pertaining to information about dementia provided in the description. The informed consent preamble included mention of these three questions, as participants who correctly answered all three were given a bonus of \$0.25.

Materials

Informational models of dementia include one of three, 3-paragraph educational descriptions of dementia. These descriptions (Appendix A) were written by the author of this study and reviewed by two subject experts. Participants were randomly assigned to read one of the three descriptions: the traditional biomedical model, the biopsychosocial model, and the positive psychology-informed model. Each description provides key information about symptoms of dementia and its neurological basis. The traditional medical model description of dementia aims to summarize information provided from organizations like the Mayo Clinic and Alzheimer’s Association of America; of note, these are among the first results when “dementia” is searched using an internet browser (*Dementia*, 2019; *What is Dementia?*, 2020). The biopsychosocial model description of dementia aims to provide information based on the model described by Spector and Orrell, 2010, which has been cited in over 100 studies since its publication. The positive psychology-informed model of dementia provides a unique perspective on dementia that is based on integration of recent research examining positive psychology constructs in people with dementia and pre-existing, positive biopsychosocial models (e.g., Hickman, Clarke, & Wolverson, 2018; Kitwood, 1997; Sabat, 2008; Seligman & Csikszentmihalyi, 2000; Shannon, Bail, & Neville, 2018; Wolverson, Clarke, & Moniz-Cook, 2016). Three brief comprehension questions followed each description to ensure participants read this element.

Vignette. All participants, regardless of which description of dementia they read, read a brief vignette immediately following the description and comprehension questions. The vignette (Appendix B), written by the author, describes a woman named Louise who has

been diagnosed with Alzheimer's dementia exhibiting a "challenging behavior." The vignette was developed following review of vignette-based research studies and recommendations (Dagnan, Hull, & McDonnell, 2013; Hughes & Huby 2004; Qualls et al., 2015; Stites et al., 2018).

Behavioral response survey questions followed immediately after participants read the vignette (Appendix C). Survey questions were developed by the author, and assessed participants' projected behavioral responses to the scenario in the vignette, attribution of the cause of Louise's behavior, and emotional responses to the scenario in the vignette. In total, there were 6 survey questions and 9 emotions to be rated by respondents. The behavioral and attribution survey questions utilized a 4-point Likert scale response framework. The ratings of emotional responses utilized a yes/no framework. Survey questions and emotions assessed were based on past studies utilizing vignettes (Qualls et al., 2015; Peterson et al., 1982) and vignette-based research recommendations (Hughes & Huby, 2004).

Controllability Beliefs Scale (CBS) is a 15-item, self-report measure of attribution of controllability regarding "challenging behavior" (Dagnan, Hull, & McDonnell, 2013). This scale was designed to be used by caregivers of people with challenging behavior, and it has been used with regards to older adults exhibiting challenging behavior (Dagnan, Grant, & McDonnell, 2004), adults with intellectual disabilities (Dagnan, Hull, & McDonnell, 2013), and older adults with intellectual disability and Alzheimer's disease (Kalsy et al., 2007). In a paper reporting the psychometric properties of the scale when taken by caregivers of people with intellectual disabilities, the CBS demonstrated very good reliability (Cronbach's $\alpha=0.89$) and convergent validity when compared to

measures of understanding self-injury behavior in people with intellectual disabilities and attributional style (Dagnan, Hull, & McDonnell, 2013). When used in a vignette-based study (Kalsy et al., 2007) with caregivers of older adults with intellectual disability and Alzheimer's disease, reliability remained good (Cronbach's $\alpha=0.84$). Participants rate each item on a 5-point Likert scale, ranging from 1=strongly agree to 5=strongly disagree; higher scores indicate higher attribution of internal control.

Dementia Attitudes Scale (DAS) is a 20-item, self-report measure of attitudes towards people with dementia (O'Connor & McFadden, 2010). Not only was it designed to test attitudes about dementia in general, but the authors also reported their intention for this scale to be used as a way to evaluate outcomes of interventions designed to promote a more positive culture of care amongst people working with individuals with dementia. In its development, the scale was administered to undergraduate students and certified nursing assistant students. It was found to have good internal reliability (Cronbach's $\alpha=0.78$) and demonstrated convergent validity when compared to scales of ageism and attitudes towards older people and people with disabilities. The DAS has since been used to assess explicit stigma towards people with dementia in young adults with no experience with dementia (Kane, Murphy, & Kelly, 2020). The DAS has two subscales, confirmed by factor analysis: social comfort and knowledge. Each item is rated on a 7-point Likert scale ranging from 1=strongly disagree to 7=strongly agree; higher scores indicate more positive attitudes.

STIG-MA scale is a 10-item, self-report measure of perceived stigma of Alzheimer's disease (Piver et al., 2013). It was adapted from the Explanatory Model Interview Catalogue, and it measures the respondent's beliefs about attitudes that other people have

about Alzheimer's disease. In its initial application, the STIG-MA scale demonstrated good reliability (Cronbach's $\alpha=0.83$). The authors of this measure identified cut-scores indicating "mild stigma," "moderate stigma," and "high stigma." The measure was completed by adults aged 25-75 years and older with varying levels of proximity to Alzheimer's disease and included members of the general public as well as healthcare professionals. Each item is rated "yes," "maybe," "do not know," and "no," with a value of 0-3 assigned to each response. Higher scores indicate higher perceived stigma.

Ambivalent Ageism Scale is a 13-item, self-report measure of ageist beliefs that includes hostile ageism and benevolent ageism subscales (Cary, Chasteen, & Remedios, 2017). Participants included in the measure development study were recruited via Amazon MTurk and were adults aged 18-57 years old, with a majority being White and Female. The AAS demonstrated excellent reliability (Cronbach's $\alpha=0.91$), with the benevolent ageism subscale demonstrating very good reliability (Cronbach's $\alpha=0.98$) and the hostile ageism subscale demonstrating good reliability (Cronbach's $\alpha=0.84$). The scale was also found to show convergent validity, as demonstrated by correlation with a well-established ageism scale. Each item on the AAS is rated using a 7-point Likert scale, with responses ranging from 1=strongly disagree to 7=strongly agree. Higher scores indicate higher levels of ageist beliefs.

Fear of dementia was assessed using an adaptation of the Fear of Alzheimer's Disease Scale (French et al., 2012). The original, 30-item self-report scale was developed to be used in older adults as a way to measure fear of AD. French et al. (2012) report the factor loadings of the thirty items, and found that the scale breaks into three factors: general fear, physical symptoms, and catastrophic attitudes. Given that the current study included

adults aged 18 and older, many of the questions on the scale that load onto the first two factors may not be relevant for many of the participants (ex: “When I misplace things, I sometimes think I may have Alzheimer’s disease”). The items in Factor 3, however, are general questions that assess catastrophic fears of Alzheimer’s disease that are applicable to any adult regardless of age. The current study included the five items from the original scale that make up the third factor, “Catastrophic Attitudes.” In French et al.’s (2012) sample of older adults, the internal reliability for this third factor was good (Cronbach’s $\alpha=0.80$). Respondents answered the 5-item adapted scale using a 5-point Likert scale framework as used in the original measure, ranging from never to always, with higher scores indicating greater levels of fear (French et al., 2012).

Alzheimer’s Disease Knowledge Scale (ADKS) is a 30-item, self-report measure of knowledge of risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management of Alzheimer’s disease (Carpenter et al., 2009). The measure was developed by adapting items from a variety of scales and research on knowledge about memory loss, Alzheimer’s disease, and aging. The ADKS was found to have good reliability (Cronbach’s $\alpha=0.71$) when administered to adults aged 22-87 years old. Carpenter et al. (2009) also demonstrated concurrent validity as indicated by changes on ADKS scores after dementia education, and convergent validity, as indicated by expected correlations between the ADKS and another measure of Alzheimer’s disease knowledge. Each item on the ADKS is rated “true” or “false.” A higher score is indicative of greater knowledge of Alzheimer’s disease.

Ten Item Personality Inventory (TIPI) was used to measure Big-Five personality dimensions (Gosling, Rentfrow, & Swann, 2003). The TIPI is a 10-item, self-report

questionnaire that was designed to allow researchers to briefly assess personality factors in studies where personality is not the primary focus. The TIPI utilizes two questions per Big-Five personality dimension: extraversion, agreeableness, conscientiousness, emotional stability, and openness to new experience. Although the internal reliability of each of the five dimensions is low (Cronbach's α ranges from 0.40 to 0.68), Gosling, Rentfrow, and Swann (2003) report adequate test-retest reliability and convergent validity when the measure was assessed in an initial sample of over 1,800 undergraduates and a subsample of 180 participants 6 weeks later. While not the most precise measure of personality, the TIPI allows for adequate measure of personality dimensions in cases where the length and intensity of other measures would preclude personality from being included in a study (Gosling, Rentfrow, & Swann, 2003). Participants respond to items on the TIPI using a 7-point Likert scale, ranging from "disagree strongly" to "agree strongly."

Social desirability was measured using the 13-item short form of the Marlowe-Crowne Social Desirability Scale. This shorter version of the original 33-item scale has been found to demonstrate good reliability (Cronbach's $\alpha=0.76$) and validity but is less burdensome to respondents than the original form (Reynolds, 1982). Each item is answered using a true/false framework, with higher scores indicating a stronger social desirability bias.

Perceived credibility of dementia model was measured using a four-item survey adapted from Flanagin and Metzger (2000). Perceived credibility of online health information is an emerging field, with a lack of consensus about how to measure the multidimensional construct of credibility. As such, there is no gold standard measure of perceived

credibility of information. Researchers often use items of particular relevance to their study, as the questions that are asked can actually impact perceived credibility (Eastin, 2001). Following a review of measures of perceived credibility, the measure utilized by Flanagin and Metzger (2000) has questions most appropriate to be adapted for the current study and demonstrates good internal reliability (Cronbach's $\alpha=0.78$). Participants were asked to rate the believability, accuracy, trustworthiness, and bias of the model of dementia they read about at the beginning of the study with a 7-point Likert scale response system (1=not at all, 7=extremely).

Demographic information was collected, including age, race and ethnicity, gender, and educational attainment. These demographic variables were selected based on past research examining factors associated with stigma and attitudes about dementia (O'Connor & McFadden, 2010; Rosato et al., 2019; Stites et al., 2018).

Personal/professional experience with dementia survey questions were included. Participants were asked, using a yes/no framework, if they have professional experience working with people with dementia, and if they have personal experience caring for a person with dementia. If participants answered "yes" to the professional experience question, they were prompted to write in an open text box their profession, followed by number of years worked in that profession. If participants answered "yes" to the person experience question, they were prompted to select whether they served as a primary caregiver; if "yes," they were asked to write how many years they served in this role.

Analysis Plan

All statistical analyses were conducted using IBM SPSS Statistics 28. Descriptive statistics were run on the demographic variables to better understand the respondents in each group. Internal reliability tests (Cronbach's alpha) were run on each set of questions or questionnaires, with the exception of questions regarding demographic and personal/professional experience with dementia.

The first aim of this study—to determine if perception of dementia is affected by how dementia is described—was tested using Multivariate Analysis of Variance (MANOVA). In this study, perception of dementia was defined by four variables: behavioral responses, controllability beliefs, attitudes, and stigma. Those four variables served as the dependent variables, while the dementia description (biomedical model, biopsychosocial model, or positive psychology-informed model) served as the independent variable. The proposed sample size of 270 participants ensures sufficient power (>0.80) to detect small to moderate effect sizes using a MANOVA. If the MANOVA detected a significant difference in perception of dementia between description of dementia conditions, a post-hoc test would be conducted to ascertain which of the three groups differ from each other.

The second aim of this study—to determine factors that predict perception of dementia—was assessed using multiple linear regressions. Separate regressions were conducted for each of the four dependent variables: behavioral responses, controllability beliefs, attitudes, and stigma. Each regression was conducted using the stepwise method. Although this method can yield results that are idiosyncratic to the specific sample, given the large number of variables and exploratory nature of these analyses, stepwise

regression was deemed the most interpretable method to serve the purpose of identifying variables that may warrant future study to better understand perception of dementia. The same variables were entered for each regression: ageism, fear of Alzheimer's disease, knowledge of Alzheimer's disease, personality, social desirability, age, race, gender, education, and personal/professional experience with dementia.

The third aim of this study—to explore the perceived credibility of each description of dementia—was assessed using an Analysis of Covariance (ANCOVA). The independent variable was the description of dementia, which has three conditions. The dependent variable was perceived credibility. Three covariates were included in this model: knowledge of Alzheimer's disease, fear of Alzheimer's disease, and experience with Alzheimer's disease, the latter of which was entered as number of years spent in a personal or professional role interacting with people with dementia. The proposed sample size of 270 participants was selected to ensure sufficient power (0.80) to detect a moderate effect size. Post-hoc analyses would follow should the ANCOVA indicate a significant difference in perceived credibility across the three descriptions of dementia groups.

CHAPTER III: RESULTS

Sample

Data cleaning

While 270 participants were recruited through MTurk, SurveyMonkey recorded 320 respondents. It was not possible to match SurveyMonkey respondents to MTurk workers due to privacy considerations, but possible reasons for this mismatch include respondents who began the study but chose to close it without completing it, or respondents who exceeded the 60-minute timeframe allotted by MTurk to submit the HIT. The data were cleaned during several waves to account for quality and to exclude participants with large amounts of missing data. Of the 320 respondents, 35 were excluded in the first wave due to having significant amounts of missing data after the first few questions (<50% of the survey complete), as it was assumed these participants did not attempt to finish the survey. A further 3 participants were excluded, as it appeared they did not complete the study either, given a total lack of response for the final 3-4 questionnaires and all of the demographic data.

Of these remaining 282 participants, 25 were excluded due to scoring a 0 or 1 on the attention check questions immediately following the description of dementia. The modal number of correct answers on these three true-or-false questions was 2. Given that the majority of respondents got 2 or more questions correct, and given that these questions were included to ensure participants read and understood the description of

dementia—a foundational element of the study--participants who scored below 2 were excluded.

Of these 257 participants, another 1 was excluded, as an answer was not recorded to indicate which description of dementia they read.

Of the 64 total respondents who were excluded, 20 were assigned to the biomedical model condition, 27 were assigned to the biopsychosocial model, and 16 were assigned to the positive psychology-informed model. Further information to better assess systematic differences in who quit the study or did not comprehend/attend to the description of dementia was unavailable, as these participants largely did not provide answers to demographic questions which were at the end of the study.

Following the listwise exclusion of participants with large amounts of missing data or questionable data quality due to failure on the attention check at the beginning of the survey, there remained random missing datapoints on questionnaire items in every case. Of note, missing data for demographics were not assessed, as these questions had larger numbers of missing data, and it would not make theoretical sense to impute demographic information. The analyses that included demographic variables excluded cases with these missing values listwise.

Missing data analysis of the questionnaire items showed the majority of participants had 1 item of missing data ($n=208$), while 4 participants had over 5% missing data. The 4 participants with slightly larger numbers of missing data—ranging 9 missing datapoints to 28—were in the biopsychosocial and positive psychology-informed groups. Descriptive analyses were conducted on a dataset with these 4 participants included, and on a dataset with these participants deleted listwise. In both of these

datasets, single mean imputation was used to address the random missing data throughout the rest of the sample. There were slight differences in mean, standard deviation, standard error, skewness, or kurtosis between these two datasets.

A major issue with single mean imputation is that it can lead to decreased variance because missing values are imputed with a single mean that does not include any “noise” that a complete dataset has (Little et al., 2014). This can introduce bias into the sample if the imputed means skew the results compared to the actual observed data. Given practical software constraints that hindered use of more complex multiple imputation methods, the 4 cases with larger amount of missing data were excluded listwise, as those participants stood out as different from the rest of the sample. This left a reasonably random and unbiased array of missing data amongst the rest of the participants. This reduces the risks of single mean imputation, but it should still be stated that this method decreases variance and thus can increase bias in the results. Yet due to the fact that the remaining instances of missing data appeared truly random, it was deemed that using the common (Little et al., 2014), although not ideal, data imputation method of single mean imputation was the best option for these analyses.

Sample Characteristics

Of the 252 remaining participants, 82 read the biomedical description of dementia, 88 read the biopsychosocial description of dementia, and 82 read the positive psychology-informed description of dementia. Participants who provided their age ($n=245$) ranged in age from 19 years old to 80 years old, with a mean age of 44.52 years old ($SD=16.03$). Regarding gender, 136 participants identified as male, 110 participants identified as female, and 1 participant identified as a gender other than male or female.

Most commonly, participants had earned a bachelor's degree ($n=136$) as their highest level of education, and 80.9% of participants were White ($n=203$). Table 1 includes more detailed information about sample demographics.

When asked about professional experience working with older adults with dementia, 111 participants selected “yes.” Some of the free text descriptions of work are not typical jobs that involve working with people with dementia (ex., “IT,” “data entry,” “software developer,” “employee”), so this number should be interpreted with caution as a likely overestimate. When asked about personal experience caring for a person with dementia, 129 respondents selected “yes,” with 98 participants indicating that they served as a primary caregiver. This high proportion, paired with the potential overestimation of professional experience working with people with dementia, makes it possible that the number of participants who said they served as a primary caregiver was also an overestimate. The majority of participants in this study had 0 years serving as a primary caregiver for a person with dementia ($n=111$), with an overall mean of 7.24 years as a primary caregiver ($SD=7.32$). Time spent serving as primary caregiver ranged from 0 to 41 years. In a few cases, participants said they were a primary caregiver, but provided a description of their situation in the free-text box rather than the number of years in this role. Those cases were treated as missing data in the analysis of years serving as a caregiver, and so were excluded from those analyses. Thus, the mean years serving as a primary caregiver for a person with dementia is likely a slight underestimate.

Primary Analyses

Reliability of measures

Before any analyses were conducted, reliability testing was run on each of the questionnaires used in this study. Table 2 presents the results of reliability testing using Cronbach's alpha. It should be noted that due to a technical error, 1 item on the Controllability Beliefs Scale (CBS) was not collected thus leaving the scale in this study with 14 items rather than 15. The item that was not captured was "They mean to make me feel bad." The reliability is reported based on the 14 rather than 15 items, and the rest of the analyses that include this measure should be interpreted with this error in mind.

Hypothesis 1

The first question this study addresses is whether perception of dementia differed depending on which description of dementia a participant read at the beginning of the study. Perception of dementia was defined by behavioral responses to a vignette, controllability beliefs, attitudes about dementia, and dementia-related stigma. Prior to running a MANOVA to test this hypothesis, reliability analyses were run to ensure the four dependent variables were reliable. As shown in Table 2, reliability ranged from adequate to excellent for the CBS, Dementia Attitudes Scale (DAS), and STIG-MA scale. The "behavioral responses" were 6 questions following a vignette describing a woman with Alzheimer's disease exhibiting a challenging behavior. Figures 1-6 show the frequency of the different possible responses to each of the six behavioral response questions. The questions were designed to measure "malignant," "neutral," and "positive" reactions to the vignette, with each type of reaction captured by two questions. The reliability for these three two-item "scales" was very poor ("neutral" Cronbach's

$\alpha=.077$, “positive” Cronbach’s $\alpha =.118$) or invalid (“malignant” Cronbach’s $\alpha =-.095$), suggesting that these questions do not accurately reflect malignant, neutral, or positive responses to the vignette. Limitations and improvements to this part of the study’s design are expanded upon in Chapter IV of this paper. These three sets of behavioral responses were included in the analysis, with the caveat that they likely cannot be interpreted at face value.

Assumption testing. The MANOVA statistical assumptions were tested prior to running the analyses (Pallant, 2011). The assumption of sample size being larger than the number of cells was met, with 18 cells and 252 participants. The assumption of normality was assessed through multiple methods. Q-Q plots were created for each of the dependent variables (6 in total, as behavioral responses were captured by three separate scales) to first assess for univariate normality. All q-q plots appeared approximately normal with the exception of the plot for the CBS, which indicated a bimodal distribution. A histogram confirmed a bimodal distribution of the CBS. The Mahalanobis distance was calculated using all the dependent variables to assess for multivariate outliers. Using a critical value of 20.52 ($df=5, p<.001$), five multivariate outliers were detected and removed from the sample. These statistical outliers were removed based on the tenet that the MANOVA is relatively robust to violations of normality in the absence of extreme outliers (Pallant, 2011). Since the CBS’ bimodal distribution raises questions about multivariate normality, and the sample size is slightly smaller than the central limit theorem suggests (20 observations per combination of dependent variable by factor), it was determined that removing these outliers would help the robustness of the MANOVA to accommodate mild to moderate variation from multivariate normality. A correlation

table showed that the data met the assumption of no multicollinearity, evidenced by all bivariate correlations between the variables being $r < .80$. The final assumption is that the population covariance matrices of each group are equal. Upon running the MANOVA, Box's M test was nonsignificant (Box's $M=52.412$, $p=.171$), suggesting equality of covariance matrices. Using the median statistic due to the potential non-normality of the data, Levene's F -test of equality of error variances was significant ($p=.036$) for the malignant behavioral response scale, and nonsignificant ($p > .05$) in the other five scales, suggesting adequate homogeneity of variance.

MANOVA Results. With the caveats outlined in the previous section regarding the statistical assumptions of the MANOVA, the analysis was conducted to ascertain if perception of dementia differed based upon which description of dementia participants read. The results showed that the null hypothesis—perception of dementia does not differ between description of dementia groups—failed to be rejected (Pillai's Trace=0.53, $F(12, 476)=1.080$, $p=.374$). Table 3 summarizes the marginal means for each of the six dependent variable scales.

Given the poor reliability and questionable normality distributions when the three subscales of behavioral responses were included, an exploratory MANOVA was conducted using the CBS, DAS, and STIG-MA as measures of perception of dementia. Excluding the three behavior response subscales increased the power and sample size, such that normality could be assumed based on the central limit theorem. Again, the results of this test were not significant, thus increasing confidence that perception of dementia did not differ based on the three models of dementia presented in this study (Pillai's trace=.021, $F(6, 482)=.863$, $p=.522$).

Given that there was not a statistically significant difference in perception of dementia between the biomedical, biopsychosocial, and positive psychology-informed models of dementia, no post-hoc analyses were conducted.

Hypothesis 2

The second question this study aims to explore is what variables are associated with perceptions of dementia, as defined by controllability beliefs (CBS), attitudes (DAS), stigma (STIG-MA), and behavioral responses to the vignette (malignant, neutral, positive). To explore this question, multiple linear regressions were conducted, with a separate set of regressions for each of these six scales. The same set of independent variables were included in each regression in a stepwise fashion due to the exploratory nature of this question. The independent variables included the description of dementia that was read, emotional responses to the vignette (Table 4 provides frequencies for each emotional response), knowledge of Alzheimer's disease, fear of Alzheimer's disease, ambivalent ageism, social desirability, personality traits, gender, education, race/ethnicity, personal experience caring for a person with dementia, and age. Table 2 lists the reliability of the measures used to capture these concepts which ranged from adequate to excellent. Tables 5-10 show bivariate correlation matrices for each of the six dependent variables and the independent variables.

Variables Associated with Controllability Beliefs. The first multiple linear regression conducted examined variables associated with controllability beliefs as measured by the CBS. A total of 230 respondents were included in this analysis, as participants with missing demographic data were excluded. Regarding the assumptions of multiple linear regression, the data for the CBS regression met the assumptions of no

multicollinearity (all $VIF < 10$, all bivariate correlations amongst variables $r < .80$), and normality of residuals (p-p plot of residuals do not show major deviations from normality, although there is evidence again of slight bimodal distribution). The scatterplot of residuals suggests the assumptions of linearity and homoscedasticity are questionable, with a slight linear trend to the datapoints rather than being randomly dispersed. Two outliers were identified based on residual z-scores beyond ± 3 standard deviations. The Mahalanobis distance and Cook's d values were within normal limits on these two cases. However, given the bimodal distribution of the CBS, these outliers were removed in an attempt to increase normality. This regression is still reported and discussed, albeit with caution given these potential violations of the assumptions of linearity and homoscedasticity of residuals.

Using the stepwise method due to the exploratory nature of this hypothesis and many of the variables, a total of 8 regression models were computed. The final model (Table 11) had a significant regression equation ($F(8,221)=111.057, p < .001$), and $R^2 = .801$. Participants' predicted controllability beliefs are equal to $56.403 - 8.091(\text{sympathetic emotional response}) + .164(\text{ageist beliefs}) - .541(\text{knowledge of Alzheimer's disease}) - .851(\text{agreeable personality trait}) - .116(\text{age}) - 3.654(\text{sadness emotional response}) + 4.420(\text{fearful emotional response}) - 2.647(\text{concerned emotional response})$. Controllability beliefs—with higher scores indicating beliefs that people with dementia have higher rather than lower control over their behavior—were associated with lack of sympathy, higher ageist beliefs, less knowledge of Alzheimer's disease, less agreeable personality, younger age, lack of sadness, fearfulness, and lack of concern. All of these variables were statistically significant ($p < .05$). Independent variables are listed in

descending order of effect on the regression, with lack of sympathy being the most associated with controllability beliefs, and lack of concern being the least—but still significantly—associated with controllability beliefs. These results do not generally support the directional hypotheses, as it was predicted more “malignant” independent variables—as seen in this equation—would be associated with lower rather than higher levels of controllability beliefs.

Variables Associated with Dementia Attitudes. The second multiple linear regression conducted examined variables associated with attitudes about dementia as measured by the DAS. A total of 230 respondents were included in this analysis as well. Regarding the assumptions of multiple linear regression, the data for the DAS regression met the assumptions of no multicollinearity (all $VIF < 10$, all bivariate correlations amongst variables $r < .80$), normality of residuals (p-p plot of residuals do not show major deviations from normality), linearity of residuals (central, rectangular pattern to residual scatterplot), and homoscedasticity (random dispersal of datapoints on residual scatterplot). There were no multivariate outliers identified based on Mahalanobis distance, Cook’s d , and residual z-scores.

Using the stepwise method, a total of 6 iterations were computed. The final regression model had a significant regression equation ($F(6,223)=22.772, p<.001$), and $R^2=.380$ (Table 12). Participants’ predicted dementia attitudes are equal to $35.398 + 1.136(\text{knowledge of Alzheimer’s disease}) + .250(\text{ageist beliefs}) + 7.929(\text{compassion emotional response}) + 1.402(\text{agreeableness}) + .896(\text{extraversion}) - 3.978(\text{indifferent emotional response})$. Dementia attitudes—with higher scores indicating more positive attitudes about dementia—were associated with more knowledge of Alzheimer’s disease,

more ageist beliefs, compassion, higher levels of agreeableness, higher levels of extraversion, and lack of indifference. Again, the independent variables are listed in descending order of impact on the model, with knowledge of Alzheimer's disease as the most associated, and lack of indifference as the least associated—but still significant—variable. These results generally support the directional hypotheses, with more “positive” variables associated with more positive attitudes about dementia, with the exception of ageism. However, Table 6 shows that ageism is not significantly correlated with the DAS, a discrepancy that is discussed further in Chapter IV.

Variables Associated with Stigma. The third multiple linear regression conducted examined predictors of stigma about dementia as measured by the STIG-MA. A total of 230 respondents were included in this analysis as well. Regarding the assumptions of multiple linear regression, the data for the STIG-MA regression met the assumptions of no multicollinearity (all $VIF < 10$, all bivariate correlations amongst variables $r < .80$), normality of residuals (p-p plot of residuals do not show major deviations from normality, although scatterplot of residuals appears slightly negatively skewed), linearity of residuals (central, rectangular pattern to residual scatterplot), and homoscedasticity (random dispersal of datapoints on residual scatterplot). Mahalanobis distance using a critical value of 22.46 ($df=6, p < .001$) of the final model identified two multivariate outliers. Cook's d for these values was less than 1, and the standardized residuals z-scores were within 3 standard deviations. An additional two cases were flagged as outliers due to residual z-scores beyond 3 standard deviations but had Mahalanobis distance and Cook's d values within normal limits. There were 4 potential outliers. Given the small number of outliers, generally normal distribution of residuals,

and Cook's d values that suggest these datapoints are not highly influential (Cook's $d < 1$), these values were left in the analysis to preserve the full sample of data (Pallant, 2011).

Using the stepwise method, a total of 7 iterations were computed. The final regression model had a significant regression equation ($F(7,222)=20.957, p < .001$), and $R^2 = .398$ (Table 13). Participants' predicted stigma scores are equal to $17.235 + 0.91(\text{ageist beliefs}) - .377(\text{social desirability}) - .314(\text{conscientiousness}) - .323(\text{extraversion}) - .054(\text{age}) - 1.575(\text{Asian/Asian American ethnicity}) + .552(\text{education})$. Dementia-related stigma—with higher scores indicating higher levels of stigma—was associated with more ageist beliefs, lower social desirability, lower conscientiousness, lower extraversion, younger age, non-Asian race/ethnicity, and higher education. Again, the independent variables are listed in descending order of impact on the model based on standardized beta coefficients, with ageism as the most associated variable, and education as the least associated—but still significant—variable. These findings generally support the directional hypotheses that more “malignant” variables would be associated with greater stigma. Of note, Table 8 shows that there is no significant correlation between non-Asian race/ethnicity and the STIG-MA scale. This discrepancy will be further discussed in Chapter IV.

Variables Associated with Behavioral Responses. The fourth set of multiple linear regression conducted examined variables associated with behavioral responses to the vignette: malignant, neutral, and positive behavioral responses. Figures 1-6 illustrate the frequency of responses to these behavioral questions. Because of how these data were collected, separate regressions were run for each of these three sets of questions. However, as previously stated, the reliability statistics of these scales are very poor, and

the assumption testing of each of these three scales was similar. Again, 230 respondents were included in this analysis. The data for malignant, neutral, and positive behavior responses all met the assumption of no multicollinearity (all $VIF < 10$, all bivariate correlations amongst variables $r < .80$). All three showed at least slight deviations from normality of residuals as evidenced by p-p plots, with the malignant subscale showing moderate deviation from normality. The major issues for these three subscales are in meeting the assumptions of linearity and homoscedasticity. All three showed very similar residual scatterplots, with a linear rather than random dispersal to suggest non-linearity and non-homoscedasticity.

For the malignant subscale, there was one outlier based on Mahalanobis distance critical value of 16.27 ($df=3, p < .001$). The Cook's d and residual z-score for this item were both within normal limits. Two values had residual z-scores outside of the cutoff of ± 3 ($z = 3.687; z = -3.192$), but had Mahalanobis distance and Cook's d values within normal limits. Given the deviations from normality in this scale, all three outliers were removed and the analyses run again, which revealed these outliers did in fact have an outsized influence on the model. The R^2 did not change significantly, but the predictor variables did. The neutral subscale did not flag any outliers based on Mahalanobis distance, Cook's d , or residual z-scores. The positive subscale flagged one outlier with a value above the Mahalanobis critical value of 20.52 ($df=5, p < .001$). This outlier was removed and the analyses run again, which resulted in the same values. Thus, this outlier was left in as it did not appear to have an outsized influence on the model.

Using the stepwise method, a total of 3 iterations were computed for malignant behavioral responses based on the sample of 228 participants. The final regression model

had a significant regression equation ($F(3,224)=28.695, p<.001$), and an $R^2=.278$ (Table 14). Participants' predicted malignant behavioral response scores are equal to $2.754 + .033(\text{ageist beliefs}) + .066(\text{knowledge of Alzheimer's disease}) - .355(\text{sympathetic emotional response})$. "Malignant" behavioral responses to the vignette about a woman with Alzheimer's disease were associated with more ageist beliefs, more knowledge of Alzheimer's disease, and lack of sympathy. The independent variables are listed in descending order of impact on the model based on standardized beta coefficients, with ageism as the most associated variable, and lack of sympathy as the least associated—but still significant—variable. These findings generally support the directional hypotheses that more "malignant" variables would be associated with malignant behavioral responses, with the exception of greater knowledge being associated with more malignant behavioral responses.

Using the stepwise method, a total of 3 iterations were computed for neutral behavioral responses. The final regression model ($n=230$) had a significant regression equation ($F(3,223)=18.600, p<.001$), and an $R^2=.198$ (Table 15). Participants' predicted neutral behavioral response scores are equal to $3.834 + .021(\text{ageist beliefs}) + .061(\text{fear of Alzheimer's disease}) + .493(\text{compassionate response})$. "Neutral" behavioral responses to the vignette were associated with more ageist beliefs, more fear of Alzheimer's disease, and compassion. The independent variables are listed in descending order of impact on the model based on standardized beta coefficients, with ageism as the most associated variable, and compassion as the least associated—but still significant—variable. These findings generally support the directional hypotheses, with a mix of "malignant" (ex.,

ageism, fear of Alzheimer's disease) and "positive" (ex, compassion) variables associated with neutral behavioral responses.

Using the stepwise method, a total of 6 iterations were computed for positive behavioral responses. The final regression model ($n=230$) had a significant regression equation ($F(5,222)=22.778, p<.001$), and an R^2 of .328 (Table 16). Participants' predicted positive behavioral response scores are equal to $1.990 + .034(\text{ageist beliefs}) + .465(\text{compassionate response}) + .044(\text{fear of Alzheimer's disease}) + .039(\text{knowledge of Alzheimer's disease}) + .056(\text{openness}) + .309(\text{positive psychology-informed model})$. "Positive" behavioral responses to the vignette were associated with higher ageist beliefs, compassion, more fear of Alzheimer's disease, more knowledge of Alzheimer's disease, higher levels of openness, and having read the positive psychology-informed model of dementia. The independent variables are listed in descending order of impact on the model based on standardized beta coefficients, with ageism as the most associated variable, and the positive psychology-informed model of dementia as the least associated—but still significant—variable. These findings show mixed results compared to the directional hypotheses, with some "positive" variables being associated with positive behavioral responses, while other variables are more "malignant," such as ageism and fear of Alzheimer's disease. Of note, the positive psychology-informed model was not significantly correlated with positive behavioral responses, which is discussed further in Chapter IV (Table 10).

Hypothesis 3

The third question this study aimed to explore was whether perceived credibility differed amongst the three descriptions of dementia. An ANCOVA was conducted to

address this question, with perceived credibility as the dependent variable, description of dementia group as the independent variable, and knowledge of Alzheimer's disease, fear of Alzheimer's disease, and years spent caring for a person with dementia as covariates. Perceived credibility was measured using 4 survey questions written specifically for this study, and did show a relatively low Cronbach's alpha (Cronbach's $\alpha=.617$)

Assumption Testing. The assumptions of ANCOVA were tested before running the analyses (Pallant, 2011) First, the covariates should not be influenced by the independent variable. In this study, it is possible that the description of dementia could have influenced people's knowledge and fear of Alzheimer's disease, while experience with dementia remains independent. However, measuring knowledge and fear using these scales before the description of dementia could have primed participants responses on the surveys that measure perception of dementia, which came before the measures of knowledge and fear. The descriptions differed in terms of language and framing rather than the facts that were given, so knowledge of Alzheimer's disease should remain independent of the description of dementia. Fear of Alzheimer's disease may have been impacted by the description of dementia, although the description was not designed to moderate fear in participants. Thus, this assumption was tentatively met, and further assumption testing continued.

Second, the covariates met the assumption of reliability, with at least adequate reliability as previously discussed. Third, the covariate fear of Alzheimer's disease ($r=.402, p<.01$) was correlated with credibility, while knowledge of Alzheimer's disease ($r=.045, p=.474$) and years caring for a person with dementia ($r=-.012, p=.854$) were not. Thus, knowledge and experience as a caregiver did not meet the assumption of

correlating to the dependent variable. Fourth, knowledge and fear of Alzheimer's disease and years caring for a person with dementia did not appear to meet the assumption of linearity based on scatterplots.

Another issue arises when testing the assumption of homogeneity of regression slopes. There was no significant interaction between knowledge of Alzheimer's disease and dementia description group ($F(3, 248)=1.588, p=.193$), nor between years caring for a person with dementia and the dementia description group ($F(3, 228)=.216, p=.885$). However, there was a significant interaction between fear of Alzheimer's disease and the dementia description group ($F(3, 248)=17.998, p<.001$) which violates the assumption of homogeneity of regression slopes. At this point, there are assumption violations for each of the three covariates. Knowledge and experience with dementia are not correlated to perceived credibility and do not have a linear relationship with the variable; and, fear of Alzheimer's disease fails the assumption of homogeneity of regression slopes. Thus, it is not recommended that an ANCOVA be used to analyze this data due to its failure to meet these statistical assumptions (Pallant, 2011). For the sake of this dissertation, the result of the ANCOVA is reported. A secondary analysis of a simple ANOVA testing if perceived credibility differed amongst the three groups was conducted as well in an attempt to provide more solid evidence to address this third research question.

ANCOVA Results. A one-way between-groups analysis of covariance was conducted to test if perceived credibility of a descriptive model of dementia differed based on which descriptive model participants read. Knowledge of Alzheimer's disease, fear of Alzheimer's disease, and years spent as a primary caregiver for a person with dementia were included as covariates to control for any effect they may have had on

perceived credibility. The data did not meet the assumptions of an ANCOVA. Upon running the ANCOVA, it did meet assumptions of homogeneity of error variance (Levene's F test $p > .05$). There was one outlier based on a Cook's d value greater than 1, but the residual z-score was within the ± 3 cutoff. A second analysis was conducted with this outlier removed, with no meaningful difference in results. Thus, the results reported are based on the dataset that includes this statistical outlier in order to better capture the full sample.

The results of this ANCOVA ($n=232$) were not significant ($F(2, 226)=2.590$, $p=.077$) with a small effect size (partial $\eta^2=.022$) thus failing to reject the null hypothesis that there is no difference in perceived credibility of dementia description based on which description participants read after controlling for knowledge of Alzheimer's disease, fear of Alzheimer's disease, and years caring for a person with dementia. There was a large effect of fear of Alzheimer's disease on perceived credibility (partial $\eta^2=.165$, $p<.001$).

Secondary Analysis: ANOVA. The failure of the covariates to meet the assumptions of an ANCOVA make the results of the test largely uninterpretable. In order to still attempt to answer the question of whether perceived credibility differs based on which description of dementia participants read, a one-way between-groups ANOVA was conducted, with perceived credibility as the dependent variable, and description of dementia as the independent variable. The data met the assumptions of random and independent sampling, and based upon sample size, met the assumption of normality. When checking for outliers using a boxplot, 5 outliers were identified. Upon examining these outliers, it was determined that 4 came from the biomedical description group, and

1 came from the biopsychosocial description group. They all skewed towards low levels of perceived credibility, with 4 cases scoring as low as possible on the scale. Given that these low datapoints did not appear to be due to error, analysis was conducted with and without the outliers in order to balance meeting the assumptions of the test while preserving potentially informative and valid data. Both analyses met the assumption of homogeneity of variance (Levene's F test $p > .05$).

ANOVA With Statistical Outliers. First, a one-way between-groups analysis of variance was conducted on the full sample ($N=252$). The results of this test showed that there was a significant difference in the average perceived credibility between the three models of dementia ($F(2,249)=3.387, p=.035$). There was a small effect size ($\eta^2=.026$).

Prior to running the analysis, a post-hoc test was selected to help elucidate differences between groups. Dunnett's t -test was selected, with the biomedical model as the control group, and with testing to see if the perceived credibility of the biopsychosocial model or positive psychology-informed model were smaller or larger than that of the biomedical model. This post-hoc test was selected because the biomedical model was designed to reflect the most commonly available information about dementia, thus representing a control of sorts. This post-hoc analysis showed that there was a significant difference in perceived credibility in the biopsychosocial and biomedical description groups (Dunnett's t -test $p=.021$). Looking at the mean credibility scores (Table 11), participants in the biopsychosocial group had higher scores on the measure of perceived credibility. There was no significant difference between the biomedical group and the positive psychology-informed group (Dunnett's t -test $p=.155$). These findings reject the null hypothesis that there would be no difference in perceived credibility

between the three groups, but do not support the directional hypothesis that the biomedical group would have the highest perceived credibility.

ANOVA Without Statistical Outliers. A second, a one-way, between-groups analysis of variance was conducted on the sample that excluded the 5 statistical outliers ($n=247$). Of note, 4 of these 5 cases were from the biomedical model group, and 1 was from the biopsychosocial group. They all appeared to be valid, albeit low, scores on the measure of perceived credibility. This analysis did not find a significant difference in average perceived credibility between the three description of dementia groups ($F(2, 244)=2.039, p=.132$). The effect size was small ($\eta^2=.016$). Given that there was no significant difference in perceived credibility between the three groups, post-hoc analyses were not conducted on this sample. Table 17 shows the marginal means for the analyses with and without the outliers. These findings fail to reject the null hypothesis that there would be no difference in perceived credibility between the three groups.

CHAPTER IV: DISCUSSION

Broadly, this study aimed to explore if and how the way that dementia is framed is related to perception of people with dementia amongst the general public in the United States. There is a scarcity of research on this topic, especially related to how the framing of dementia affects attitudes and stigma amongst the general population in the United States. Negative attitudes and stigma cause real harm in people living with dementia and their families, so it is imperative that we learn more about how to reduce stigma and improve empathic understanding of dementia amongst the general public. Yet, it is worth noting before discussing specific results that there are significant limitations in the interpretability of some of the tests in this study due to violations of statistical assumptions in multiple analyses. Limitations and future directions will be discussed in full in the next subsections.

The first and primary question this study addressed was if different informational models of dementia were related to differences in perception of dementia amongst adults in the United States. It was hypothesized that there would be a difference, with the most “malignant” perceptions related to the traditional biomedical model of dementia (Bond, 1972), “neutral” perceptions related to a biopsychosocial model of dementia, and “positive” perceptions related to a positive psychology informed model of dementia. These models of dementia were written by the author and based on commonly available information about dementia for the biomedical model (*What is Dementia?*, 2020; *What is Dementia?*, 2019), Spector and Orrell’s (2010) commonly cited biopsychosocial model of

dementia, a novel positive psychology-informed model of dementia based on work of Sabat (2008) and Kitwood (1997). As discussed in Chapter I, there is emerging data related to attitudes about dementia and dementia-related stigma. Stigma in particular is a complex construct, with beliefs about controllability of behaviors potentially contributing to higher or lower levels of stigma. Finally, behavioral responses based on a vignette were included in “perception” of dementia in the hopes of capturing a more “real-time” insight into participants’ reactions to the person with dementia in the vignette. These questions were designed to map on to the “malignant,” “neutral,” and “positive” perceptions of dementia.

The data collected in this study did not support the hypothesis that a multivariate conceptualization of perception of dementia would differ depending on which informational model of dementia participants read. The results of the MANOVA were not significant, even after excluding the problematic “behavioral response” variables. At a theoretical level, this result is surprising given previous research related to changing the conversation about previously stigmatized conditions (Bretton et al., 2015). Yet, studies documenting changes in stigma cite more intensive interventions to “change the conversation” (e.g., Broockman & Kalla, 2016; Knifton et al., 2010; Stuart, Koller, & West Armstrong, 2014). A three-paragraph description of dementia at the beginning of this study was likely not a strong enough intervention to change pre-existing beliefs about people with dementia. Another consideration relates to the time in which this study was conducted. In an age of misinformation and polarization, it is likely that presenting information once, in a relatively “dry” manner, is not enough to influence people’s beliefs (Marsh & Yang, 2018). Rather, information that is told through a story, that

triggers an emotional response, that coincides with pre-existing beliefs, or that comes from a trusted source may be more likely to influence beliefs and attitudes about the subject being presented (Marsh & Yang, 2018).

The second question addressed in this study was more exploratory in nature. As previously stated, there is a scarcity of information about factors that influence attitudes and stigma related to dementia. More knowledge of the factors that influence people's perceptions of dementia could be used as targets in public health interventions aiming to increase empathic understanding of dementia. In order to explore these questions, the constructs that comprised "perceptions of dementia" were analyzed in separate sets of linear regressions.

The first analysis explored the factors that related to controllability beliefs. Using the Controllability Belief Scale (CBS), higher scores coincide with higher belief that the person with dementia has control over their behavior. As discussed in Chapter I, there are positives and negatives to high versus low controllability beliefs. Higher controllability beliefs put more emphasis on the individual's ability to control their behavior, which may be interpreted as a positive perception that emphasizes the person's individuality more than their disease. However, in conditions like dementia where there undeniably is an effect of the disease on a person's behavior and abilities, overemphasis on individual control could lead to harmful under-recognition of the influence of the disease on the person.

In this study higher controllability beliefs were associated with generally more malignant predictors. Lack of sympathy, sadness, and concern in response to the vignette describing a woman with dementia (Louise) were significantly associated with higher

controllability beliefs. This makes sense in the context of believing Louise had more agency, and thus was choosing to behave in a way that was disruptive to others. Increased fear was also associated with higher controllability beliefs, which again, fits into a conceptualization of Louise as choosing to behave in a disruptive way. Younger age and less knowledge of Alzheimer's disease were associated as well, which could be interpreted as less personal and semantic experience with dementia leading to underestimation of the effects of dementia on a person's behavior. Increased ageism was a somewhat unexpected finding, as the ambivalent ageism captured by that scale suggests older adults have less control over their behavior and should be protected/infantilized. However, ageism could also be related to more negative beliefs about older adults, and thus lead to more individual blame when Louise disrupted the event. Finally, lower agreeableness was also associated with higher controllability beliefs. Inclusion of personality measures were exploratory, so further study would be needed to assess the reason for this relationship. It is possible that less agreeableness could lead to increased beliefs that negative behaviors of other people are intentional and controllable. While the direction of these variables maps onto theoretical predictions, it should be noted that the CBS was not normally distributed, and thus did not meet the assumptions of the multiple linear regression. These results should be confirmed in future studies.

The second construct was attitudes about dementia. For this regression, the data met all the statistical assumptions, and is thus one of the tests from this study that can be interpreted with confidence. In the Dementia Attitudes Scale (DAS), higher scores indicated more positive attitudes about people with dementia. The six significant independent variables accounted for 38% of the variance in attitudes about dementia in

this sample, which is a sizable proportion of this complex construct. Most of the variables were aligned with theoretical predictions. Compassion and lack of indifference in response to Louise are commonsense predictors of more positive attitudes. Agreeableness and extraversion were also related to positive attitudes. A more agreeable personality could indicate more patience or good-will towards others, and therefore generally positive beliefs about people. A more extraverted personality could also indicate more willingness to engage with people, which is touched upon in some of the DAS items. More knowledge of Alzheimer's disease being associated with more positive attitudes is an encouraging result, suggesting that increasing understanding of dementia could help improve beliefs about people with dementia.

Finally, higher ambivalent ageism was also associated with more positive beliefs based on the regression, but the two variables were not significantly correlated at a bivariate level. A scatterplot showed a dense distribution of datapoints in a positive linear trend, but with many datapoints dispersed in a non-linear fashion. It is possible the variance in the relationship between ageism and dementia attitudes was essentially "controlled for" in the regression by the other independent variables in the model, but that this uncontrolled variance resulted in a low bivariate correlation when looking at only ageism and dementia attitudes. Thus, it appeared that when controlling for the personality traits, emotional responses, and knowledge of Alzheimer's disease, ambivalent ageism accounted for a significant proportion of variance in dementia attitudes, such that increased ageism was associated with more positive attitudes. This surprising result could be explained by this scale measuring not only "hostile" ageism, but also "benevolent" ageism. While still stigmatizing and problematic, benevolent

ageism describes an overestimation of frailty and difficulty in old age in a way that cultivates sympathy. It could be that more sympathetic views of people with dementia due to higher benevolent ageism are related to more positive views of people with dementia. Further analysis of which items on the ambivalent ageism scale were associated with positive attitudes about dementia could test this hypothesis that benevolent ageism drove the relationship reported here. Future studies examining the relationship between ambivalent or benevolent ageism and dementia attitudes could yield valuable knowledge of how this seemingly negative trait of ageism relates to seemingly positive views of people with dementia.

The third construct explored through regression was stigma. Higher scores on the STIG-MA scale indicated more perceived stigma about Alzheimer's disease. This measure asked participants to imagine how they think others would respond if they had Alzheimer's disease, with items such as "Would your neighbors, your colleagues have less respect for you?" and "Would your family give you support right from the start?" Thus, this measure assessed how participants perceive dementia-related stigma in their communities. For this regression, the data broadly met all the statistical assumptions, and is thus another result from this study that can be interpreted with confidence.

The final regression model accounted for 39.8% of the variance in perceived stigma in this sample, which is again a significant proportion of the variance for a complex construct such as stigma. As expected, higher levels of ageism were related to higher perceived stigma. As ageism is a form of stigma, this relationship was unsurprising. Lower scores on the social desirability scale and less conscientiousness also related to higher levels of stigma, which could be due to these participants being more

willing to report their honest beliefs about perceived stigma. Interestingly, the STIG-MA scale overall was slightly negatively skewed. This finding when paired with the associations of higher stigma with less social desirability concerns and less conscientiousness raises the question of whether participants' true levels of perceived stigma are underreported in this sample.

Other significantly associated variables included younger age—which again could suggest less experience with dementia—less extraverted personality, non-Asian race/ethnicity, and higher education. The relationship between less extraversion and higher stigma is an exploratory finding that suggests increased research into how personality traits relate to perceived stigma of dementia. While non-Asian race was associated with higher perceived stigma, it is worth noting that the majority of participants in this study were White, thus making it difficult to draw meaningful conclusions about potential differences in stigma between participants with different racial identities. Furthermore, there was no significant correlation at a bivariate level, suggesting that the relationship found in the regression exists in the context of the other independent variables accounting for variance in stigma. Yet, this finding in the regression was somewhat surprising given past research about stigma in Chinese and Vietnamese immigrants in the United States that suggests the potential for higher levels of stigma due to cultural values around “loss of face” (Liu & Huang, 2018). However, in this study where participants' specific ethnicities and personal values are unknown, one potential explanation for this finding is that people from generally more collectivist backgrounds may perceive less stigma about dementia than people from more individualistic backgrounds (Werner et al., 2019). This finding may also be an artifact of

using the stepwise regression method, which can result in idiosyncratic independent variables depending upon the sample. Finally, higher education was associated with increased stigma. This finding did not support predictions that higher education would lead to less stigma due to having more knowledge about dementia, but because this survey focuses on perceived stigma in participants' social environments, it is possible that individuals with higher education may find a disease that affects cognition to be more isolating.

The final set of regressions examined predictors of three different levels of behavioral responses to the vignette describing Louise. As previously discussed, the reliability of these measures was very poor, and therefore any results from these survey questions should be re-tested using more robust measures. The malignant scale included items asking participants about likelihood to avoid Louise, and attribution of her behavior solely to her disease. This scale was associated with higher levels of ageism, more knowledge of Alzheimer's disease, and lack of sympathy. These findings make theoretical sense, with ageism and lack of sympathy perhaps leading to avoidance, while more knowledge could be related to overstating the effect of dementia on Louise's behavior. The neutral scale included items asking participants about likelihood to inform someone else in order to help Louise, and attributing her behavior (repeating questions loudly) to not having had her questions answered. More ageism and fear of Alzheimer's disease, and compassion related to the neutral responses. More ageism and fear of dementia could lead to participants being afraid to approach Louise, but a compassionate response could encourage them to find someone else to help her. Finally, the positive scale included items asking participants about likelihood to comfort Louise, and

attributing her behavior to attempts to engage with others. Increased ageism and fear of dementia were also associated with these responses, which were unexpected results. More expected were the independent variables of increased knowledge, compassion, and openness, where higher familiarity, a compassionate response, and an open personality style could increase the likelihood that a person would be willing to approach Louise and assume the best about her behavior. Finally, having read the positive psychology-informed model was related to positive behavioral responses in the regression, although there was no significant bivariate correlation. This result suggests that the positive psychology-informed model of dementia may have had a positive impact on participants' reaction to the person with dementia in the vignette when essentially controlling for the other independent variables in the regression. However, the unreliability of this scale makes it impossible to draw solid conclusions from these regressions, and thus further testing would be warranted to see if this relationship could be replicated.

The final research question addressed in this study examined if perceived credibility differed for the three descriptive models of dementia. This research question aimed to provide preliminary findings to better understand if more balanced, person-centered descriptions of dementia would be believed by members of the general population. The originally planned analysis to address this question was an ANCOVA in order to control for the potential effects of knowledge, fear, and personal experience with dementia on perceived credibility. However, there were multiple statistical issues with these covariates, making the results of the ANCOVA difficult to interpret. At face value, the ANCOVA showed that perceived credibility did not differ between the three groups, and that fear was a significant covariate, suggesting fear of Alzheimer's did influence

perceived credibility of the dementia description across all three groups. The non-significant ANCOVA would imply encouraging findings, suggesting people are open to believing even a positive psychology-informed description of dementia.

A secondary ANOVA was conducted to simply test if credibility differed amongst the three groups, and this analysis yielded a significant result when analyzing the full sample. Post-hoc tests showed that participants who read the biopsychosocial description of dementia found the model more credible than participants who read the biomedical model. Although not significantly different, the mean level of perceived credibility in the positive psychology-informed group was higher than in the biomedical group. When excluding outliers, there was not a significant difference in perceived credibility between the three groups, although the overall pattern of means was the same.

It was clear that removing the 5 outliers did affect the statistical significance and effect size of the difference between the groups, suggesting they did have a meaningful effect on the results. However, 4 of these 5 datapoints were from the biomedical group, suggesting a nonrandom pattern to these low scores. This nonrandom pattern suggests these scores represent meaningful and valid datapoints.

Using a more conservative approach and placing higher confidence in the analysis without the outliers, the results of a non-significant ANOVA suggest that credibility did not differ between the groups. This is an encouraging finding, as it again implies that information about dementia that is framed using a biopsychosocial or even positive psychology-informed perspective may be just as believable to the general public as the traditional biomedical approach. If using a more liberal approach to the statistical analyses and placing higher confidence in the analysis with the full sample, it appears

that a more balanced biopsychosocial description of dementia is deemed more accurate, trustworthy, unbiased, and overall credible than the traditional biomedical model.

Although by no means conclusive, these findings justify future exploration about the effects of public health information about dementia that comes from a more person-centered, strengths-based perspective.

Limitations

Limitations have been addressed throughout this paper, but will be summarized and expanded upon in this section. Limitations for this study can be considered in two categories: study design and statistical analyses.

In terms of study design, there are a number of factors to consider when interpreting the conclusions drawn from this study. First, data were collected using MTurk, a large online data collection platform. A benefit of this platform is the ability to easily recruit a large sample size that may be more diverse than recruiting for in-person participants in an area near a university. Another benefit was the ability to collect data remotely during the COVID-19 pandemic. However, MTurk can be subject to bots (Chmielewski & Kucker, 2020) or even to real people who are incentivized to complete tasks as quickly as possible to maximize payment given that each task on MTurk pays relatively little. While the reliability of most measures in this study were as expected, and efforts were made to exclude participants with large amounts of missing data and/or who scored a 0 or 1 on the three attention/comprehension check questions, it is still possible some of the participants in this study did not carefully read each question before answering. This is always a risk with survey-based studies, but it is somewhat amplified

through online data collection when there is no oversight of how participants are answering questions.

Second, the diversity of this sample was not representative of the general adult population in the United States. This sample was overwhelmingly White and highly educated. Of the 252 participants in the final sample following data cleaning, 203 were White, thus making it very difficult to determine any differences based on racial/ethnic background. The range of ages was better than expected, with participants up to age 80. Gender was also approximately equal between male and female, and one participant identified as a gender other than male or female. Given MTurk's national reach, it is unknown where the participants lived in terms of region of the country. Especially as perception of dementia can be influenced by culture, it is important to not overgeneralize these results to demographic groups that were not well-represented in this study.

A third limitation based on study design is the strength of the independent variable. The descriptions of dementia were designed to provide the same factual information using different language and framing. However, this is a very minor "intervention" compared to participants' pre-existing knowledge and experience with dementia. Thus, while there may not have been differences in perception of dementia based on the model participants read in this study, that does not mean the way dementia is framed could not affect perception of dementia if implemented on a larger scale.

Fourth, and perhaps the most significant limitation of the study design, is related to poor design or errors in implementation of the survey. The survey questions designed to assess behavioral responses to the vignette were written in such a way that made analysis difficult. Participants were essentially asked about responses that were implicitly

coded as “malignant,” “neutral,” or “positive” in six separate questions, rather than a continuous six-item scale. Because of how the questions were asked and scored, it was not possible to combine them into one scale, which may have improved the reliability of the questions and increased confidence in their validity. As it was, it is unclear if these questions truly captured “malignant,” “neutral,” or “positive” behavioral responses. The poor design of these questions casts doubt on the results of analyses using them. In an attempt to rectify this, a second MANOVA was conducted without these questions, which did not yield a different result. The regression analyses of these three sets of questions are also not sound, and the results should be interpreted with extreme caution, if at all. The survey questions to assess perceived credibility also had low reliability, with one item in particular (“how biased was the information;” reverse-scored) negatively affecting the reliability. Another error in hindsight was the way demographic information was collected. Asking for years of education would have made that variable easier to analyze, and would have included more nuance. There also seemed to be confusion about how to answer the questions about personal and professional experience with dementia. Some participants said they had professional experience with dementia, but wrote in professions that do not traditionally interface with people with dementia (e.g., IT, data entry). Also, when asked to free-type years as a primary caregiver for a person with dementia, some participants described their experience and thus there was no way to capture their caregiving experience in the regression. A final note in this section is that the CBS was missing one item. This error in the survey limits any comparisons between the results of the CBS in this study and in other studies, although the reliability of the CBS in this sample remained excellent. It is possible that this one missing item does not

substantially affect the validity of the scale as measuring controllability beliefs, but it is worth considering the results as related to the CBS with this caveat in mind.

The other main category of limitations is statistical analysis limitations. First and foremost, given practical constraints, single mean imputation was used to address the 1-2 missing items for each participant. Given the seemingly random dispersal—but universal presence—of missing data, the risks of single mean imputation were deemed acceptable. However, this method does reduce variance that can skew results, and may have contributed to some of the failure of statistical assumptions related to linearity, normality, and homoscedasticity.

Second, as previously discussed, there were issues with statistical assumptions in many of the analyses conducted. The data used for the MANOVA and ANCOVA failed multiple statistical assumptions, which calls into question the results from those tests. Even after removing the behavioral response questions from the MANOVA, the CBS did not meet the assumption of homoscedasticity or normality. The regression analyses for the behavioral responses are also likely unreliable given the problems with the survey questions themselves. Finally, the low reliability of the perceived credibility questions and the personality questions should be kept in mind when interpreting otherwise statistically sound results that include those variables. It should be noted that the personality subscales from the TIPI are documented to have low reliability in other studies (Gosling, Rentfrow, & Swann, 2003) partly due to their brevity, but they have been found to demonstrate test-retest reliability. The questions of perceived credibility were also drawn from other studies (Flanagin & Metzger, 2000), and demonstrate good face validity despite relatively low reliability of the 4-item set of questions.

Future Directions

Ageism, Attitudes, and Dementia-related Stigma

One variable was present throughout all six sets of regressions: ageism. In all cases, higher ageism predicted higher scores on the measure in question. This pattern raises interesting questions, especially as higher ageism not only predicted more malignant perceptions of dementia (CBS, STIG-MA, malignant behavioral responses), but it was also associated with a more positive attitude about dementia in the regression analysis of the DAS. It is possible that in this study, ageism was consistently associated with perceptions of dementia because of a conflation between old age and dementia. It is possible that older age and dementia are still implicitly conflated amongst the general population, such that ageist beliefs may essentially describe behaviors or experiences—like impaired memory or frailty—that are due to an underlying disease such as dementia (Fletcher, 2018). Given the fact that dementia was considered a normal part of aging as recently as the 20th century (Ballenger, 2017), this hypothesis seems plausible and warrants testing.

If old age and dementia are conflated, older adults with dementia may be subject to compounded stigmatization (Fletcher, 2018). Considering an intersectional viewpoint, older adults with dementia have social identities of being older in age, which carries a specific stigma, and of having dementia, which connotes its own set of stigma as a specific type of disability. Thus, it is possible that even if someone has a more positive attitude about dementia and less stigmatizing beliefs about dementia specifically, underlying ageism may influence how they interact with a person with dementia. Finally, further exploration of the role of benevolent ageism in attitudes about dementia could

yield useful information relevant to public health campaigns designed to reduce stigma. As Fletcher (2019) describes, anti-stigma campaigns may improve awareness and reduce negative attitudes about dementia, but they can also result in “benevolent othering” that still separates people with dementia from “us,” even if malice is not intended. This line of research could lead to important understanding of ways to more effectively address issues of stigma towards older adults with dementia by clarifying targets of intervention that could include general ageist beliefs.

Strengthen Intervention

With the caveat of the statistical limitations outlined above, the primary analysis in this study did not support the hypothesis that perception of dementia would differ depending on which descriptive model participants read. If we take this finding at face value, it is unsurprising that a brief, informational description of dementia would not have a significant impact on such a complex construct as perception of dementia. However, the results of the simple ANOVA to test differences in perceived credibility between the three groups showed that at the very least, participants’ credibility ratings did not differ between the three groups, and at best, participants who read the biopsychosocial model actually had the highest credibility ratings for their model. This finding suggests that future work into this area, perhaps from a public health lens, is warranted, as the public may be open to more balanced conceptualizations of dementia if they are made available.

Campaigns that are showing success in changing public opinion about historically marginalized groups, such as the body positivity movement and the disability advocacy movement, could be used as a framework to implement campaigns to address negative

perceptions of people with dementia. As Fletcher (2019) cautions against, though, current anti-stigma campaigns for dementia may actually cause higher instances of felt stigma for people with dementia and their families. Thus, rather than an anti-stigma campaign, dissemination of information about dementia that is balanced and includes mention of strengths as applicable could help improve public perception of dementia without “benevolent othering.” Depending upon better understanding of the interaction between ageism and stigma against people with dementia as discussed above, campaigns may also need to simultaneously address ageist beliefs as well as stigmatizing beliefs about dementia.

Future research could include creation of online content, whether websites or on social media, that disseminates biopsychosocial or positive psychology-informed information about dementia. To strengthen this intervention compared to the current study, it would be important to find ways to engage social media users with the content (Bretton et al., 2015), and to look at the longitudinal effects of these interventions. It would also be important to consider other ways of presenting information such as employing storytelling or trusted sources. More traditional approaches could be taken as well, for example providing a seminar or training that is based on a positive psychology framework to a group of participants, and testing their perceptions of dementia pre-and-post-test, and comparing that to a control group using the traditional biomedical model. This could add supporting evidence to similar pre-and-post-test interventions that have been conducted (Reynolds et al., 2017; Sabat, 2012).

A final vision for this line of research would be that it creates changes in the way dementia is portrayed by trusted sources such as the Centers for Disease Control, World

Health Organization, and Alzheimer's Association. Readily available public health information from trusted sources that adopts a more balanced view of dementia—one that accounts for individuals' retained strengths and personhood—has the potential to reduce the stigma and suffering of people living with dementia, their families, and the general population who may currently be very fearful of this syndrome.

Conclusions

The results of this study paint a complex picture of how perception of dementia is influenced. Due to the limitations described extensively throughout this paper, a number of the results cannot be interpreted with confidence. The tests with the most sound results are the regression analyses looking at predictors of dementia attitudes and perceived stigma of dementia, and the one-way ANOVA assessing differences in perceived credibility between the biomedical, biopsychosocial, and positive psychology-informed models. The regressions identified predictor variables that warrant further study, especially future work examining the relationships between ambivalent ageism and more positive attitudes of dementia, and ambivalent ageism and dementia-related stigma. Even the conservative, nonsignificant ANOVA looking at perceived credibility between the three groups is an encouraging result that provides justification for future research into changing the way dementia is described from a public health and cultural standpoint. This study and the questions it generated aim to add to the expanding field of research into how the social environment can be modified to improve the experiences of people with dementia and their families. In an ever-fracturing society, efforts to promote empathic and compassionate understanding of the experiences of marginalized individuals, including older adults with dementia, is a timely and worthwhile cause

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Table 1

Sample demographics

Demographic Variables	Frequency	Percentage
Age ($n=245$)	$M=44.52$	$SD=16.03$
Gender ($n=247$)		
Male	136	55.1
Female	110	44.5
Other	1	.40
Race ($n=251$)		
Asian/Asian American	16	6.3
Black	22	8.7
Hispanic	7	2.7
Multiracial	2	0.8
Native American	1	0.4
White	203	80.9
Highest education ($n=247$)		
Other	1	0.4
Some high school	2	0.8
High school	14	5.7
Some college	17	6.9
Associate's degree	16	6.5
Bachelor's degree	136	55.1
Master's degree	57	23.1
Doctorate	4	1.6

Table 2

Reliability scores of measures (N=252)

Measure	Cronbach's α	Number of Items
Behavioral Responses		
Malignant	-.095	2
Neutral	.077	2
Positive	.118	2
Controllability Beliefs Scale	.935	14
Dementia Attitudes Scale	.826	20
STIG-MA	.670	10
Ambivalent Ageism Scale	.965	13
Fear of Alzheimer's Disease	.830	5
Knowledge of Alzheimer's Disease	.733	30
TIPI—Full Scale	.633	10
Extraversion	-.093	2
Agreeableness	-.005	2
Conscientiousness	.211	2
Emotional Stability	.127	2
Openness	-.067	2
Social Desirability Scale	.659	13
Perceived Credibility	.617	4

Table 3

Marginal means of multivariate dependent variables (N=252)

Measure	Biomedical Model		Biopsychosocial Model		Positive Psychology-informed Model	
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>
Controllability Beliefs Scale	34.789	1.547	37.420	1.491	33.925	1.528
Dementia Attitudes Scale	93.873	1.566	94.557	1.510	93.722	1.547
STIG-MA	14.823	.592	14.788	.571	14.775	0.585
Malignant Behavioral Response	5.697	.123	5.857	.119	5.543	.122
Neutral Behavioral Response	5.880	.125	5.996	.121	5.941	.123
Positive Behavioral Response	5.696	.123	5.976	.118	6.002	.121

Table 4

Frequency of emotional responses to vignette (N=252)

Emotional Response	Frequency	Percent of Sample
Concerned	122	48.4
Indifferent	59	23.4
Annoyed	63	25.0
Pitying	67	26.6
Sympathetic	115	45.6
Compassion	107	42.5
Helpless	91	36.1
Sadness	134	53.2
Fearful	32	12.7

Note. Participants were able to select multiple emotional responses

Table 5

Bivariate correlations for Controllability Beliefs Scale

Independent Variable	Controllability Beliefs Scale	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	.682	<i>p</i> <.001
Knowledge of AD (<i>n</i> =252)	-.690	<i>p</i> <.001
Fear of AD (<i>n</i> =252)	.265	<i>p</i> <.001
Extraversion (<i>n</i> =252)	.127	<i>p</i> =.044
Agreeableness (<i>n</i> =252)	-.678	<i>p</i> <.001
Conscientiousness (<i>n</i> =252)	-.578	<i>p</i> <.001
Emotional Stability (<i>n</i> =252)	-.395	<i>p</i> <.001
Openness (<i>n</i> =252)	-.392	<i>p</i> <.001
Social Desirability (<i>n</i> =252)	-.135	<i>p</i> =.032
Male Gender (<i>n</i> =247)	.166	<i>p</i> =.009
Female Gender (<i>n</i> =247)	-.153	<i>p</i> =.016
Other Gender (<i>n</i> =247)	-.100	<i>p</i> =.117
Concerned (<i>n</i> =252)	-.500	<i>p</i> <.001
Indifferent (<i>n</i> =252)	.337	<i>p</i> <.001
Annoyed (<i>n</i> =252)	.329	<i>p</i> <.001
Pitying (<i>n</i> =252)	-.152	<i>p</i> =.016
Sympathetic (<i>n</i> =252)	-.680	<i>p</i> <.001
Compassion (<i>n</i> =252)	-.587	<i>p</i> <.001
Helpless (<i>n</i> =252)	.049	<i>p</i> =.439
Sadness (<i>n</i> =252)	-.344	<i>p</i> <.001
Fearful (<i>n</i> =252)	.180	<i>p</i> =.004
Educational Attainment (<i>n</i> =247)	.130	<i>p</i> =.042
Years as primary caregiver (<i>n</i> =232)	.229	<i>p</i> <.001
Age (<i>n</i> =245)	-.578	<i>p</i> <.001
Native American (<i>n</i> =247)	.043	<i>p</i> =.499
Asian (<i>n</i> =247)	.041	<i>p</i> =.520
Black (<i>n</i> =247)	.078	<i>p</i> =.224
Hispanic (<i>n</i> =247)	-.020	<i>p</i> =.750
White (<i>n</i> =247)	-.122	<i>p</i> =.055
Multiracial (<i>n</i> =247)	.006	<i>p</i> =.931
Biomedical Model (<i>n</i> =252)	-.035	<i>p</i> =.576
Biopsychosocial Model (<i>n</i> =252)	.113	<i>p</i> =.072
Positive Psychology Model (<i>n</i> =252)	-.080	<i>p</i> =.206

Table 6

Bivariate correlations for Dementia Attitudes Scale

Independent Variable	Dementia Attitudes Scale	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	-.080	<i>p</i> =.205
Knowledge of AD (<i>n</i> =252)	.426	<i>p</i> <.001
Fear of AD (<i>n</i> =252)	.136	<i>p</i> =.031
Extraversion (<i>n</i> =252)	.181	<i>p</i> =.004
Agreeableness (<i>n</i> =252)	.379	<i>p</i> <.001
Conscientiousness (<i>n</i> =252)	.331	<i>p</i> <.001
Emotional Stability (<i>n</i> =252)	.263	<i>p</i> <.001
Openness (<i>n</i> =252)	.251	<i>p</i> <.001
Social Desirability (<i>n</i> =252)	.075	<i>p</i> =.237
Male Gender (<i>n</i> =247)	-.070	<i>p</i> =.270
Female Gender (<i>n</i> =247)	.071	<i>p</i> =.267
Other Gender (<i>n</i> =247)	-.002	<i>p</i> =.971
Concerned (<i>n</i> =252)	.250	<i>p</i> <.001
Indifferent (<i>n</i> =252)	-.169	<i>p</i> =.007
Annoyed (<i>n</i> =252)	-.162	<i>p</i> =.010
Pitying (<i>n</i> =252)	.149	<i>p</i> =.018
Sympathetic (<i>n</i> =252)	.288	<i>p</i> <.001
Compassion (<i>n</i> =252)	.421	<i>p</i> <.001
Helpless (<i>n</i> =252)	-.005	<i>p</i> =.936
Sadness (<i>n</i> =252)	.099	<i>p</i> =.117
Fearful (<i>n</i> =252)	-.136	<i>p</i> =.031
Educational Attainment (<i>n</i> =247)	-.100	<i>p</i> =.119
Years as primary caregiver (<i>n</i> =232)	-.002	<i>p</i> =.978
Age (<i>n</i> =245)	.288	<i>p</i> <.001
Native American (<i>n</i> =247)	-.007	<i>p</i> =.917
Asian (<i>n</i> =247)	-.020	<i>p</i> =.759
Black (<i>n</i> =247)	.032	<i>p</i> =.619
Hispanic (<i>n</i> =247)	.022	<i>p</i> =.735
White (<i>n</i> =247)	-.018	<i>p</i> =.779
Multiracial (<i>n</i> =247)	.042	<i>p</i> =.508
Biomedical Model (<i>n</i> =252)	-.033	<i>p</i> =.598
Biopsychosocial Model (<i>n</i> =252)	.013	<i>p</i> =.838
Positive Psychology Model (<i>n</i> =252)	.020	<i>p</i> =.749

Table 7

Bivariate correlations for STIG-MA scale

Independent Variable	STIG-MA Scale	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	.465	<i>p</i> <.001
Knowledge of AD (<i>n</i> =252)	-.373	<i>p</i> <.001
Fear of AD (<i>n</i> =252)	.297	<i>p</i> <.001
Extraversion (<i>n</i> =252)	-.081	<i>p</i> =.199
Agreeableness (<i>n</i> =252)	-.465	<i>p</i> <.001
Conscientiousness (<i>n</i> =252)	-.451	<i>p</i> <.001
Emotional Stability (<i>n</i> =252)	-.369	<i>p</i> <.001
Openness (<i>n</i> =252)	-.228	<i>p</i> <.001
Social Desirability (<i>n</i> =252)	-.348	<i>p</i> <.001
Male Gender (<i>n</i> =247)	.102	<i>p</i> =.111
Female Gender (<i>n</i> =247)	-.086	<i>p</i> =.175
Other Gender (<i>n</i> =247)	-.119	<i>p</i> =.061
Concerned (<i>n</i> =252)	-.254	<i>p</i> <.001
Indifferent (<i>n</i> =252)	.223	<i>p</i> <.001
Annoyed (<i>n</i> =252)	.154	<i>p</i> =.014
Pitying (<i>n</i> =252)	-.099	<i>p</i> =.116
Sympathetic (<i>n</i> =252)	-.370	<i>p</i> <.001
Compassion (<i>n</i> =252)	-.312	<i>p</i> <.001
Helpless (<i>n</i> =252)	.149	<i>p</i> =.018
Sadness (<i>n</i> =252)	-.172	<i>p</i> =.006
Fearful (<i>n</i> =252)	.140	<i>p</i> =.027
Educational Attainment (<i>n</i> =247)	.018	<i>p</i> =.782
Years as primary caregiver (<i>n</i> =232)	.130	<i>p</i> =.048
Age (<i>n</i> =245)	-.351	<i>p</i> <.001
Native American (<i>n</i> =247)	.012	<i>p</i> =.852
Asian (<i>n</i> =247)	-.050	<i>p</i> =.436
Black (<i>n</i> =247)	.080	<i>p</i> =.208
Hispanic (<i>n</i> =247)	-.009	<i>p</i> =.887
White (<i>n</i> =247)	-.047	<i>p</i> =.459
Multiracial (<i>n</i> =247)	.051	<i>p</i> =.427
Biomedical Model (<i>n</i> =252)	.021	<i>p</i> =.735
Biopsychosocial Model (<i>n</i> =252)	-.005	<i>p</i> =.940
Positive Psychology Model (<i>n</i> =252)	-.017	<i>p</i> =.793

Table 8

Bivariate correlations for malignant behavioral responses

Independent Variable	Malignant Behavioral Responses	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	.476	<i>p</i> <.001
Knowledge of AD (<i>n</i> =252)	-.123	<i>p</i> =.052
Fear of AD (<i>n</i> =252)	.334	<i>p</i> <.001
Extraversion (<i>n</i> =252)	.146	<i>p</i> =.020
Agreeableness (<i>n</i> =252)	-.252	<i>p</i> <.001
Conscientiousness (<i>n</i> =252)	-.193	<i>p</i> =.002
Emotional Stability (<i>n</i> =252)	-.221	<i>p</i> <.001
Openness (<i>n</i> =252)	-.170	<i>p</i> =.007
Social Desirability (<i>n</i> =252)	-.178	<i>p</i> =.005
Male Gender (<i>n</i> =247)	-.007	<i>p</i> =.909
Female Gender (<i>n</i> =247)	.011	<i>p</i> =.858
Other Gender (<i>n</i> =247)	-.033	<i>p</i> =.610
Concerned (<i>n</i> =252)	-.113	<i>p</i> =.073
Indifferent (<i>n</i> =252)	.132	<i>p</i> =.036
Annoyed (<i>n</i> =252)	.205	<i>p</i> <.001
Pitying (<i>n</i> =252)	-.031	<i>p</i> =.627
Sympathetic (<i>n</i> =252)	-.253	<i>p</i> <.001
Compassion (<i>n</i> =252)	-.101	<i>p</i> =.110
Helpless (<i>n</i> =252)	.156	<i>p</i> =.013
Sadness (<i>n</i> =252)	-.015	<i>p</i> =.808
Fearful (<i>n</i> =252)	.033	<i>p</i> =.602
Educational Attainment (<i>n</i> =247)	-.029	<i>p</i> =.651
Years as primary caregiver (<i>n</i> =232)	.160	<i>p</i> =.015
Age (<i>n</i> =245)	-.099	<i>p</i> =.124
Native American (<i>n</i> =247)	.020	<i>p</i> =.759
Asian (<i>n</i> =247)	-.013	<i>p</i> =.834
Black (<i>n</i> =247)	.118	<i>p</i> =.063
Hispanic (<i>n</i> =247)	.033	<i>p</i> =.611
White (<i>n</i> =247)	-.109	<i>p</i> =.089
Multiracial (<i>n</i> =247)	.028	<i>p</i> =.664
Biomedical Model (<i>n</i> =252)	-.003	<i>p</i> =.968
Biopsychosocial Model (<i>n</i> =252)	.067	<i>p</i> =.292
Positive Psychology Model (<i>n</i> =252)	-.065	<i>p</i> =.302

Table 9

Bivariate correlations for neutral behavioral responses

Independent Variable	Neutral Behavioral Responses	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	.338	<i>p</i> <.001
Knowledge of AD (<i>n</i> =252)	.002	<i>p</i> =.971
Fear of AD (<i>n</i> =252)	.335	<i>p</i> <.001
Extraversion (<i>n</i> =252)	.089	<i>p</i> =.158
Agreeableness (<i>n</i> =252)	-.028	<i>p</i> =.662
Conscientiousness (<i>n</i> =252)	-.055	<i>p</i> =.387
Emotional Stability (<i>n</i> =252)	-.055	<i>p</i> =.387
Openness (<i>n</i> =252)	.038	<i>p</i> =.552
Social Desirability (<i>n</i> =252)	-.047	<i>p</i> =.458
Male Gender (<i>n</i> =247)	-.093	<i>p</i> =.145
Female Gender (<i>n</i> =247)	.092	<i>p</i> =.149
Other Gender (<i>n</i> =247)	.008	<i>p</i> =.905
Concerned (<i>n</i> =252)	-.022	<i>p</i> =.731
Indifferent (<i>n</i> =252)	.024	<i>p</i> =.708
Annoyed (<i>n</i> =252)	-.006	<i>p</i> =.920
Pitying (<i>n</i> =252)	.049	<i>p</i> =.434
Sympathetic (<i>n</i> =252)	-.069	<i>p</i> =.274
Compassion (<i>n</i> =252)	.036	<i>p</i> =.565
Helpless (<i>n</i> =252)	.177	<i>p</i> =.005
Sadness (<i>n</i> =252)	.102	<i>p</i> =.107
Fearful (<i>n</i> =252)	.020	<i>p</i> =.748
Educational Attainment (<i>n</i> =247)	-.062	<i>p</i> =.336
Years as primary caregiver (<i>n</i> =232)	.111	<i>p</i> =.092
Age (<i>n</i> =245)	-.084	<i>p</i> =.189
Native American (<i>n</i> =247)	.008	<i>p</i> =.905
Asian (<i>n</i> =247)	-.075	<i>p</i> =.239
Black (<i>n</i> =247)	.051	<i>p</i> =.426
Hispanic (<i>n</i> =247)	.080	<i>p</i> =.211
White (<i>n</i> =247)	-.023	<i>p</i> =.719
Multiracial (<i>n</i> =247)	-.026	<i>p</i> =.686
Biomedical Model (<i>n</i> =252)	-.038	<i>p</i> =.543
Biopsychosocial Model (<i>n</i> =252)	.010	<i>p</i> =.875
Positive Psychology Model (<i>n</i> =252)	.028	<i>p</i> =.654

Table 10

Bivariate correlations for positive behavioral responses

Independent Variable	Positive Behavioral Response	
	Pearson correlation	2-sided significance
Ageism (<i>n</i> =252)	.442	<i>p</i> <.001
Knowledge of AD (<i>n</i> =252)	-.044	<i>p</i> =.485
Fear of AD (<i>n</i> =252)	.389	<i>p</i> <.001
Extraversion (<i>n</i> =252)	.206	<i>p</i> <.001
Agreeableness (<i>n</i> =252)	-.115	<i>p</i> =.069
Conscientiousness (<i>n</i> =252)	-.032	<i>p</i> =.614
Emotional Stability (<i>n</i> =252)	-.026	<i>p</i> =.681
Openness (<i>n</i> =252)	.034	<i>p</i> =.594
Social Desirability (<i>n</i> =252)	-.045	<i>p</i> =.483
Male Gender (<i>n</i> =247)	-.012	<i>p</i> =.845
Female Gender (<i>n</i> =247)	.018	<i>p</i> =.776
Other Gender (<i>n</i> =247)	-.012	<i>p</i> =.845
Concerned (<i>n</i> =252)	.004	<i>p</i> =.946
Indifferent (<i>n</i> =252)	.028	<i>p</i> =.655
Annoyed (<i>n</i> =252)	.192	<i>p</i> =.002
Pitying (<i>n</i> =252)	.058	<i>p</i> =.360
Sympathetic (<i>n</i> =252)	-.040	<i>p</i> =.526
Compassion (<i>n</i> =252)	.046	<i>p</i> =.469
Helpless (<i>n</i> =252)	.118	<i>p</i> =.061
Sadness (<i>n</i> =252)	.003	<i>p</i> =.960
Fearful (<i>n</i> =252)	-.002	<i>p</i> =.969
Educational Attainment (<i>n</i> =247)	-.030	<i>p</i> =.634
Years as primary caregiver (<i>n</i> =232)	.151	<i>p</i> =.021
Age (<i>n</i> =245)	-.011	<i>p</i> =.868
Native American (<i>n</i> =247)	.009	<i>p</i> =.893
Asian (<i>n</i> =247)	.049	<i>p</i> =.441
Black (<i>n</i> =247)	.054	<i>p</i> =.402
Hispanic (<i>n</i> =247)	.003	<i>p</i> =.968
White (<i>n</i> =247)	-.080	<i>p</i> =.208
Multiracial (<i>n</i> =247)	-.026	<i>p</i> =.688
Biomedical Model (<i>n</i> =252)	-.126	<i>p</i> =.045
Biopsychosocial Model (<i>n</i> =252)	.037	<i>p</i> =.557
Positive Psychology Model (<i>n</i> =252)	.089	<i>p</i> =.161

Table 11

Regression model for Controllability Beliefs Scale

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	56.403	3.525		15.999	<.001
Sympathy	-8.091	1.058	-.295	-7.649	<.001
Ambivalent Ageism	.164	.027	.236	6.092	<.001
Knowledge of Alzheimer's Disease	-.541	.123	-.182	-4.407	<.001
Agreeableness	-.851	.201	-.167	-4.226	<.001
Age	-.116	.031	-.137	-3.721	<.001
Sadness	-3.654	.866	-.133	-4.220	<.001
Fearfulness	4.420	1.277	.109	3.460	<.001
Concern	-2.647	.985	-.096	-2.689	.008

Note. $R^2=.801$

Table 12

Regression model for Dementia Attitudes Scale

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	35.398	6.760		5.236	<.001
Knowledge of Alzheimer's Disease	1.136	.234	.350	4.852	<.001
Ambivalent Ageism	.250	.053	.329	4.720	<.001
Compassion	7.929	1.986	.263	3.992	<.001
Agreeableness	1.402	.359	.252	3.901	<.001
Extraversion	.896	.300	.163	2.987	.003
Indifferent	-3.978	1.993	-.111	-1.996	.047

Note. $R^2=.380$

Table 13

Regression model for STIG-MA scale

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	17.235	2.440		7.065	<.001
Ambivalent Ageism	.091	.017	.339	5.385	<.001
Social Desirability	-.377	.106	-.196	-3.557	<.001
Conscientiousness	-.314	.115	-.167	-2.725	.007
Extraversion	-.323	.107	-.167	-3.033	.003
Age	-.054	.020	-.165	-2.735	.007
Asian/Asian American ethnicity	-1.575	.563	-.152	-2.796	.006
Highest education	.552	.244	-.122	2.258	.025

Note. $R^2=.398$

Table 14

Regression model for malignant behavioral responses

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	2.754	.493		5.583	<.001
Ambivalent Ageism	.033	.004	.563	7.949	<.001
Knowledge of Alzheimer's Disease	.066	.019	.257	3.546	<.001
Sympathy	-.355	.155	-.151	-2.293	.023

Note. $R^2=.278$

Table 15

Regression model for neutral behavioral responses

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	3.834	.283		13.550	<.001
Ambivalent Ageism	.021	.005	.336	4.515	<.001
Fear of Alzheimer's Disease	.061	.019	.215	3.199	.002
Compassion	.493	.167	.198	2.959	.003

Note. $R^2=.198$

Table 16

Regression model for positive behavioral responses

Variables	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Constant	1.857	.537		3.455	<.001
Ambivalent Ageism	.036	.005	.601	7.536	<.001
Compassion	.516	.161	.216	3.200	.002
Knowledge of Alzheimer's Disease	.042	.019	.163	2.158	.032
Fear of Alzheimer's Disease	.039	.017	.144	2.247	.026
Openness	.054	.026	.119	2.044	.042
Positive Psychology- Informed Model	.293	.138	.117	2.126	.035

Note. $R^2=.328$

Table 17

Marginal means of perceived credibility, with (n=252) and without (n=248) outliers

Measure	Biomedical Model			Biopsychosocial Model			Positive Psychology-informed Model		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
Perceived Credibility— With Outliers	82	19.563	4.586	88	21.157	4.086	82	20.650	3.415
Perceived Credibility— Without Outliers	78	20.285	3.312	87	21.354	3.665	82	20.650	3.415

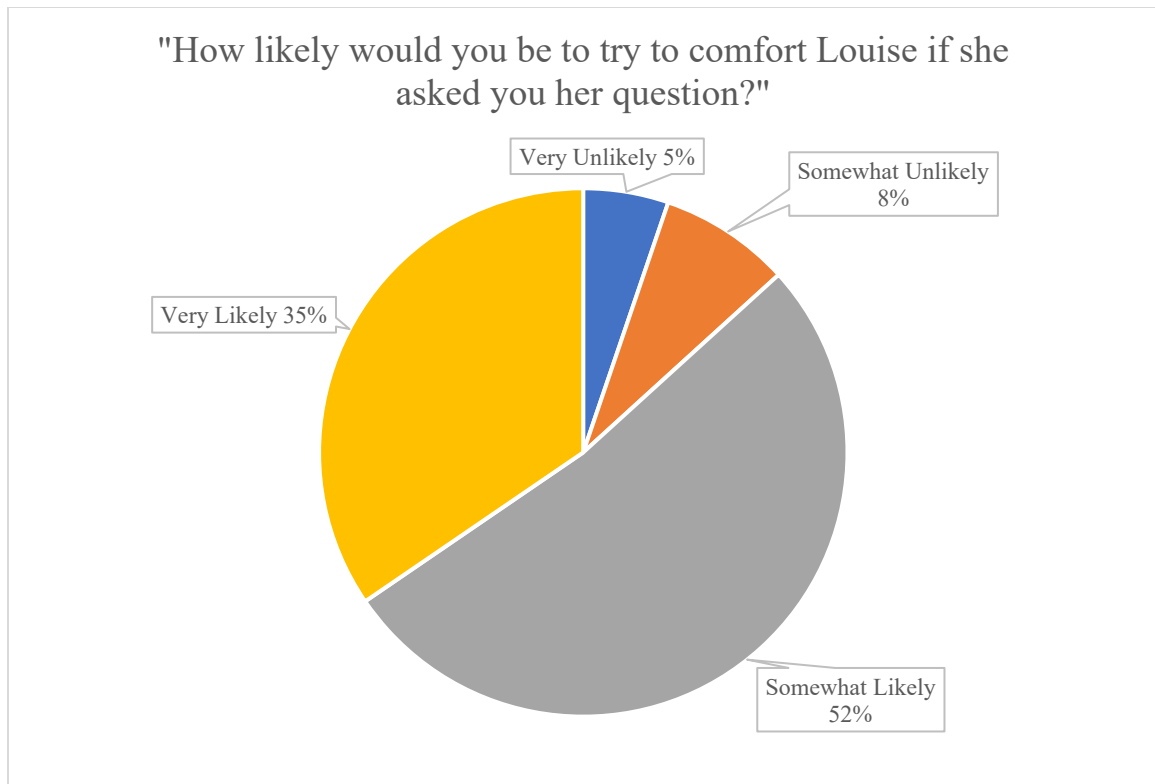


Figure 1. Percent of responses to behavioral response question 1, $n=249$. This item was coded as a “positive” behavioral response.

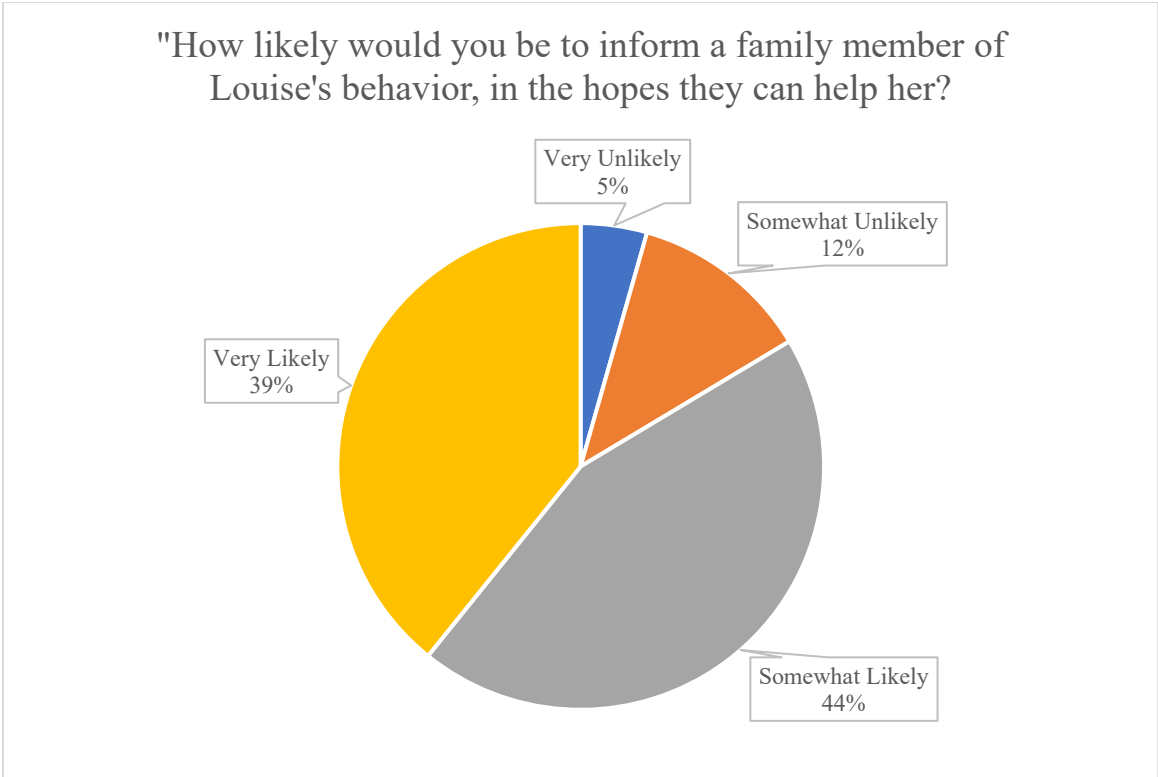


Figure 2. Percent of responses to behavioral response question 2, $n=250$. This item was coded as a “neutral” behavioral response.

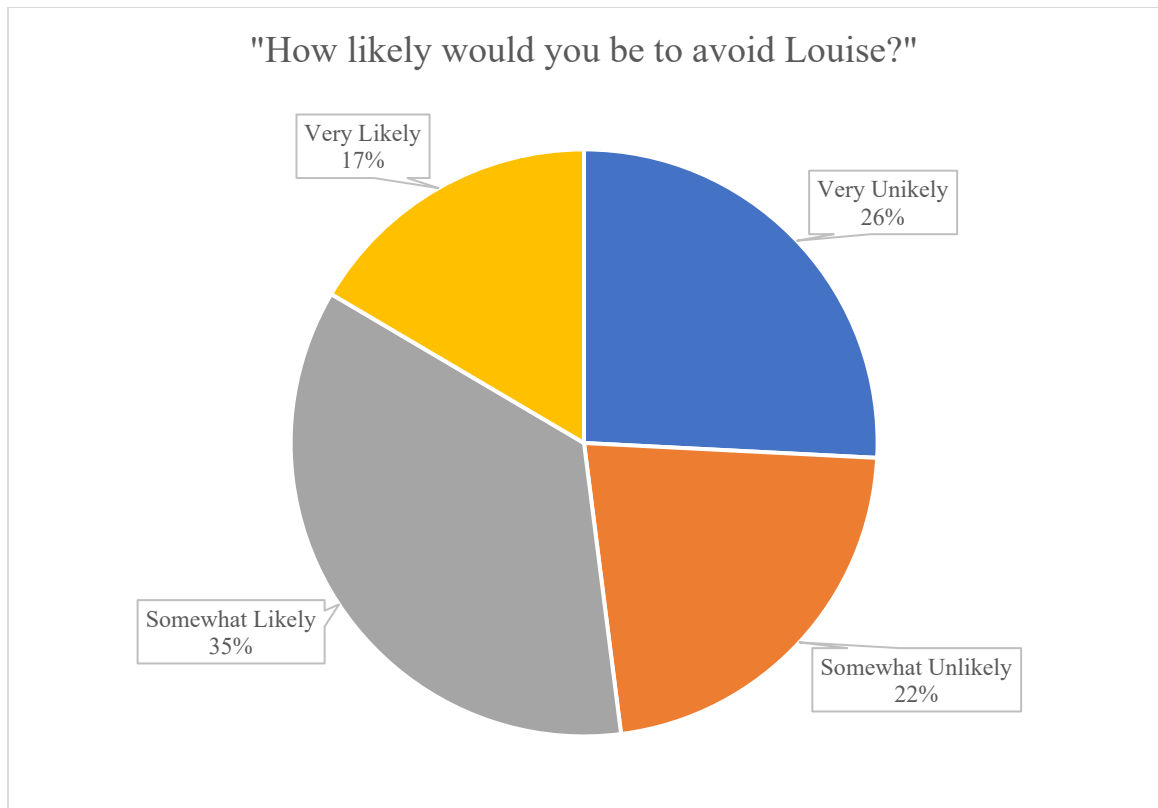


Figure 3. Percent of responses to behavioral response question 3, $n=248$. This item was coded as a “malignant” behavioral response.

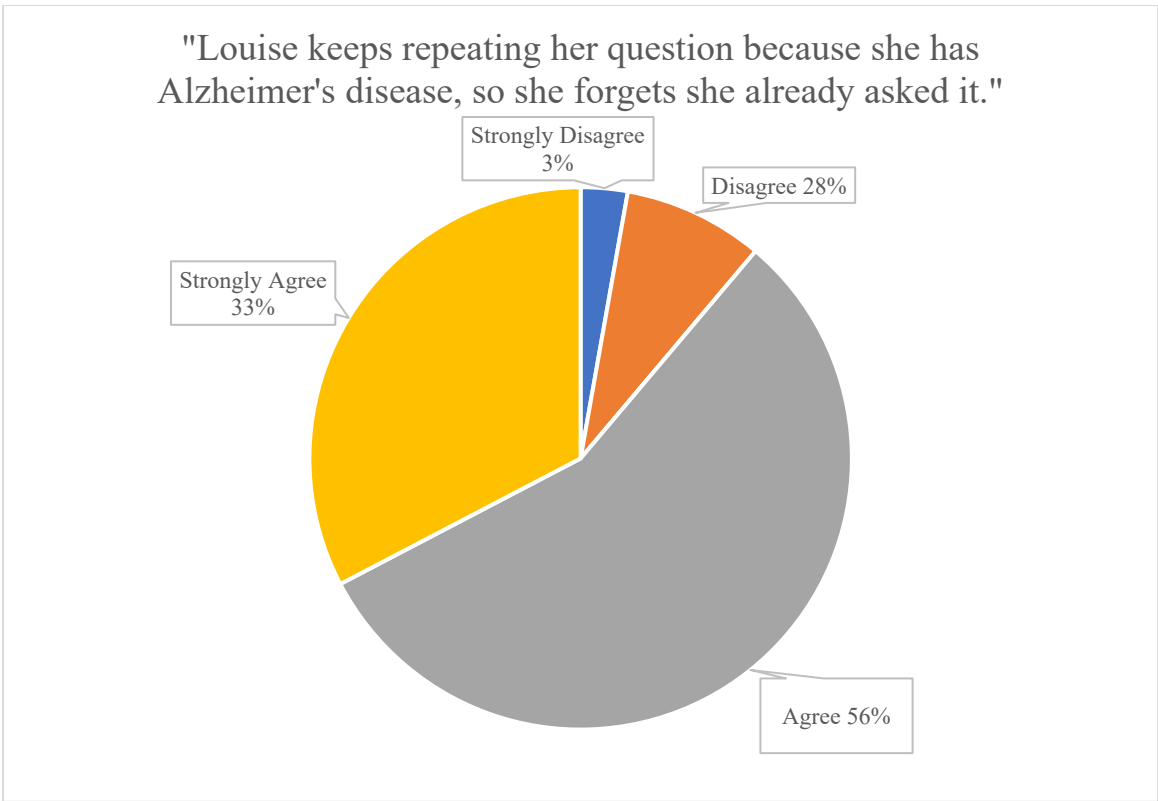


Figure 4. Percent of responses to behavioral response question 4, $n=251$. This item was coded as a “malignant” behavioral response.

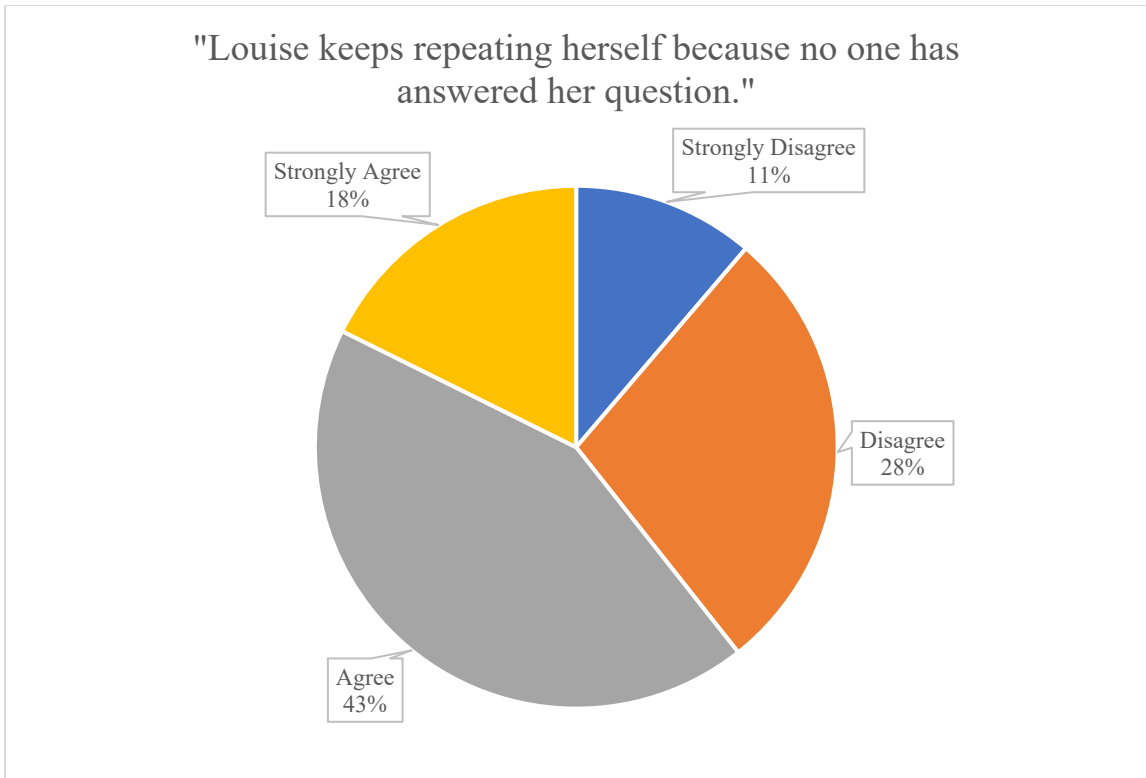


Figure 5. Percent of responses to behavioral response question 5, $n=249$. This item was coded as a “neutral” behavioral response.

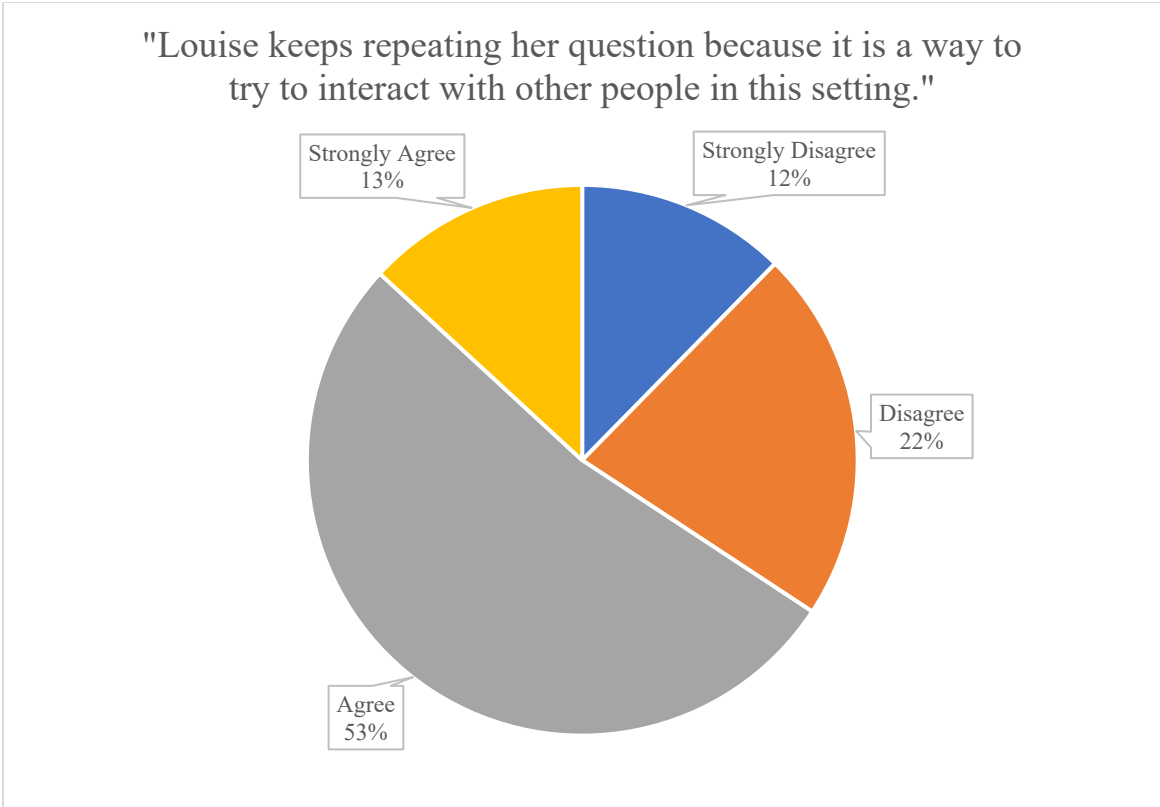


Figure 6. Percent of responses to behavioral response question 6, $n=251$. This item was coded as a "positive" behavioral response.

APPENDIX A: INFORMATIONAL MODELS OF DEMENTIA

A1. Biomedical Informational Model of Dementia

“Dementia is a condition with symptoms like impaired memory, language, and problem-solving abilities. These symptoms are severe enough to affect daily life. The most common cause of dementia is Alzheimer’s disease, a brain disease that worsens over time. Although there is still a lot we don’t know about Alzheimer’s disease, we believe it causes problems via the production of plaques and tangles in the brain. Depending on where these plaques and tangles are in the brain, patients may have different symptoms, like impairments in memory, language, thinking, or personality. Dementia can also make patients unable to perform self-care tasks like bathing or dressing, and unable to safely perform everyday activities like driving or cooking. As the disease worsens, many dementia patients are unable to live independently. They may end up living in a nursing home. Dementia can eventually be related to death.

Dementia usually occurs in people over the age of 65. However, sometimes people in their 40s or 50s can have dementia. It is important to know that dementia is not a normal part of aging. There is currently no cure for Alzheimer’s disease. Some medications may help improve symptoms temporarily. There are also ways to help symptoms of dementia that focus on providing emotional and physical comfort. These may look like redirecting the patient’s attention if they are upset or “acting out,” or creating a calm environment.

There are some ways to reduce your risk of developing dementia. These include not smoking, managing cardiovascular factors like high blood pressure, maintaining a healthy diet with enough vitamins, and staying physically, socially, and cognitively active. While these activities seem to reduce risk of dementia, more research is underway to learn more about how to prevent and treat dementia.”

Can dementia cause changes in language abilities?

Is dementia a normal part of aging?

Do people with dementia sometimes live in nursing homes?

A2. Biopsychosocial Informational Model of Dementia

“Dementia is a condition with symptoms like impaired memory, language, and problem-solving abilities. These symptoms are severe enough to affect daily life. Dementia is often related to Alzheimer’s disease, a brain disease that worsens over time. Although there is still a lot we don’t know about Alzheimer’s disease, we believe it causes problems via the production of plaques and tangles in the brain. Depending on where these plaques and tangles are in the brain, patients may have different symptoms, like impairments in memory, language, thinking, or personality. Health conditions, age, personality traits, and education can also affect symptoms. Even things like mood and the physical environment can change the experience of living with dementia. As dementia progresses, patients need more help with self-care activities like bathing or dressing. People with dementia may end up moving to a nursing home. Dementia can eventually be related to death.

Dementia usually occurs in people over the age of 65. However, sometimes people in their 40s or 50s can have dementia. It is important to know that dementia is not a normal part of aging. There is currently no medical cure for Alzheimer’s disease. Some medications may help improve symptoms temporarily. There are also behavioral interventions that can help people with dementia maintain functioning for longer. Some of these interventions also improve mood and quality of life. This may look like reminiscing in a group, or doing pleasant activities each day.

There are some ways to reduce your risk of developing dementia. These include not smoking, managing cardiovascular factors like high blood pressure, maintaining a healthy diet with enough vitamins, and staying physically, socially, and cognitively active. While these activities seem to reduce risk of dementia, more research is underway to learn about biological, social, and psychological factors that may help prevent and treat dementia.”

Can dementia cause changes in language abilities?

Is dementia a normal part of aging?

Do people with dementia sometimes live in nursing homes?

A3. Positive Psychology-informed Informational Model of Dementia

“Dementia is a condition where people have changes in memory, language, and problem-solving abilities. These changes are big enough to affect daily life. Dementia is often related to Alzheimer’s disease, a brain disease that advances over time. Although there is still a lot we don’t know about Alzheimer’s disease, we believe it causes changes via the production of plaques and tangles in the brain. Depending on where these plaques and tangles are in the brain, people may have different experiences. They could have problems with memory, language, thinking, or personality, but could keep abilities like humor and gratitude. The experience of living with dementia is affected by the way others treat them, individual factors, and the disease process. As dementia advances, people may need more help with self-care activities like bathing or dressing. People with dementia may move to a nursing home if a lot of assistance is needed. The disease associated with dementia can eventually be related to death.

Dementia usually occurs in people over the age of 65. Sometimes people in their 40s or 50s can have dementia. It is important to know that dementia is not a normal part of aging. There is currently no medical cure for Alzheimer’s disease. Some medications may help improve symptoms temporarily. Some psychosocial interventions can help people with dementia enjoy better mood, functioning, or quality of life. These include encouraging individual strengths and respecting the dignity of people with dementia. More research will help us learn how the social environment can help improve the lives of people with dementia.

There are some ways to help reduce the odds of developing dementia. These include not smoking, managing cardiovascular factors like high blood pressure, maintaining a healthy diet with enough vitamins, and staying physically, socially, and cognitively active.

Can dementia cause changes in language abilities?

Is dementia a normal part of aging?

Do people with dementia sometimes live in nursing homes?

APPENDIX B. VIGNETTE

Please read the following vignette and do your best to imagine yourself in this situation:

You are at a large family reunion taking place under a tent in a park. You are here with an older cousin, who is closer with the extended family than you are. You notice an older woman with short white hair, glasses, and a cane. You do not recognize her as a family member. She appears frustrated, and is walking slowly through the area, loudly asking “When can I go home? Is Johnny picking me up?” to seemingly every person she passes. Some people ignore her and look uncomfortable. Others reply, “I’m sorry, I don’t know” and go back to their conversations. People appear upset by her behavior, especially since it is almost time for toasts and dessert. Your cousin tells you she is a distant relative named Louise, and she has been diagnosed with Alzheimer’s dementia. Johnny was her husband, but he has passed away. Her caregiver is the person you saw make their way to the public restrooms on the other side of the park a few minutes ago. Your cousin tells you Louise is an avid gardener and bird watcher, but since the dementia has developed, she forgets her husband died years ago and easily loses her temper.

APPENDIX C: MEASURES

C1. Behavioral responses to vignette

Rate how likely you would be to engage in each of the following actions (1=Very Unlikely; 2=Somewhat Unlikely; 3=Somewhat Likely; 4=Very Likely):

How likely would you be to try to comfort Louise if she asked you her question?

How likely would you be to inform a family member of Louise's behavior, in the hopes that they can help her?

How likely would you be to avoid Louise?

To what extent do you agree with the following statements: (1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree):

Louise keeps repeating her question because she has Alzheimer's disease so she forgets she has already asked it.

Louise keeps repeating herself because no one has answered her question.

Louise keeps repeating her question because it is a way to try to interact with other people in this setting.

Select the emotion(s) you feel while in the room with Louise when she is repeating her question:

- | | | |
|-------------|-----|----|
| Concerned | YES | NO |
| Indifferent | YES | NO |
| Annoyed | YES | NO |
| Pitying | YES | NO |
| Sympathetic | YES | NO |
| Compassion | YES | NO |
| Helpless | YES | NO |
| Sadness | YES | NO |
| Fearful | YES | NO |

C2. Controllability Beliefs Scale (Dagnan, Hull, & McDonnell, 2013)

Please indicate how strongly you agree with each statement as it applies to the situation with Louise in the vignette you just read (1=agree strongly; 2= agree slightly; 3=unsure; 4=disagree slightly; 5=disagree strongly):

1. They are trying to wind people up
2. They can't help themselves
3. They are doing it deliberately
4. They know what they are doing
5. They have no control over their behavior
6. They could stop if they wanted
7. They are trying to manipulate the situation
8. They can think through their actions
9. They don't mean to upset people
10. They are in control of their behavior
11. They mean to make others feel bad
12. They are not to blame for what they do
13. They know the best time to challenge
14. They don't realize how it makes others feel

C3. Dementia Attitudes Scale (O'Connor & McFadden, 2010)

1=strongly disagree; 2=disagree; 3=somewhat disagree; 4=neither agree or disagree; 5=somewhat agree; 6=agree; 7=strongly agree

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

*reverse score

C4. STIG-MA (Piver et al., 2013)

If you were suffering from Alzheimer's disease...(YES MAYBE NO DO NOT KNOW)

1. Would you rather people did not know about your disease?
2. Would you tell the person you are closest to?
3. Would you lose self-esteem because of the disease?
4. Would this disease cause you shame or embarrassment?
5. Would your neighbors, your colleagues have less respect for you?
6. Do you think others would avoid you because of the disease?
7. Would your neighbors, your colleagues have less esteem for your family?
8. Do you think your wife/husband would stay with you and support you?
9. Do you think people you know at work or friends would ask you to stay away, even if you were taking medication for the disease?
10. Would your family give you support right from the start?

C5. Ambivalent Ageism Scale (Cary, Chasteen, & Remedios, 2017)

1=strongly disagree; 2=disagree; 3=somewhat disagree; 4=neither agree or disagree; 5=somewhat agree; 6=agree; 7=strongly agree

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.

C6. Fear of Alzheimer's Disease Scale, Catastrophic Attitudes subscale (French et al., 2012)

0=never; 1=rarely; 2=sometimes; 3=often; 4=always

1. I would rather die than develop Alzheimer's disease
2. Developing Alzheimer's disease would be the worst thing to happen to me
3. I believe that Alzheimer's disease is one of the worst diseases a person could develop
4. I would rather have a painful physical illness (e.g., cancer, AIDS) than develop Alzheimer's disease
5. I am afraid of developing Alzheimer's disease because of the burden I would be for my family

C7. Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009)

Alzheimer's Disease Knowledge Scale

Below are some statements about Alzheimer's disease. Please read each statement carefully and circle whether you think the statement is True or False. If you aren't sure of the right answer, make your best guess. It's important to circle an answer for every statement, even if you're not completely sure of the answer.

- | | | | |
|------|-------|-----|---|
| True | False | 1. | People with Alzheimer's disease are particularly prone to depression. |
| True | False | 2. | It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease. |
| True | False | 3. | After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years. |
| True | False | 4. | When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation. |
| True | False | 5. | People with Alzheimer's disease do best with simple, instructions given one step at a time. |
| True | False | 6. | When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away. |
| True | False | 7. | If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day. |
| True | False | 8. | In rare cases, people have recovered from Alzheimer's disease. |
| True | False | 9. | People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety. |
| True | False | 10. | If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease. |
| True | False | 11. | Most people with Alzheimer's disease live in nursing homes. |
| True | False | 12. | Poor nutrition can make the symptoms of Alzheimer's disease worse. |
| True | False | 13. | People in their 30s can have Alzheimer's disease. |
| True | False | 14. | A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse. |

- | | | |
|------|-------|--|
| True | False | 15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves. |
| True | False | 16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care. |
| True | False | 17. Eventually, a person with Alzheimer's disease will need 24-hour supervision. |
| True | False | 18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease. |
| True | False | 19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease. |
| True | False | 20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease. |
| True | False | 21. Alzheimer's disease is one type of dementia. |
| True | False | 22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease. |
| True | False | 23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things. |
| True | False | 24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline. |
| True | False | 25. Prescription drugs that prevent Alzheimer's disease are available. |
| True | False | 26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease. |
| True | False | 27. Genes can only partially account for the development of Alzheimer's disease. |
| True | False | 28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times. |
| True | False | 29. Alzheimer's disease cannot be cured. |
| True | False | 30. Most people with Alzheimer's disease remember recent events better than things that happened in the past. |

Source: Carpenter, B.D., Balsis, S., Ottingam, P.G., Hanson, P.K., & Gatz, M. (In press). The Alzheimer's Disease Knowledge Scale: Development and psychometric properties. *The Gerontologist*.

C8. The Ten-Item Personality Inventory (Gosling, Rentfrow, & Swann, 2003)

1=disagree strongly; 2=disagree moderately; 3=disagree a little; 4=neither agree or disagree; 5=agree a little; 6=agree moderately; 7=agree strongly

I see myself as:

1. _____ Extraverted, enthusiastic.
2. _____ Critical, quarrelsome.
3. _____ Dependable, self-disciplined.
4. _____ Anxious, easily upset.
5. _____ Open to new experiences, complex.
6. _____ Reserved, quiet.
7. _____ Sympathetic, warm.
8. _____ Disorganized, careless.
9. _____ Calm, emotionally stable.
10. _____ Conventional, uncreative.

Scoring (“R” denotes reverse-scored items): Extraversion: 1, 6R; Agreeableness: 2R, 7; Conscientiousness; 3, 8R; Emotional Stability: 4R, 9; Openness to Experiences: 5, 10R.

C9. Marlowe-Crowne Social Desirability Scale—13-item Short Form (Reynolds, 1982)

True/False

1. It is sometimes hard for me to go on with my work if I am not encouraged
2. I sometimes feel resentful when I don't get my own way
3. On a few occasions, I have given up doing something because I thought too little of my ability
4. There have been times when I felt like rebelling against people I authority even though I knew they were right
5. No matter who I'm talking to, I'm always a good listener
6. There have been occasions when I took advantage of someone
7. I'm always willing to admit it when I made a mistake
8. I sometimes try to get even, rather than forgive and forget
9. I am always courteous, even to people who are disagreeable
10. I have never been irked when people expressed ideas very different from my own
11. There have been times when I was quite jealous of the good fortune of others
12. I am sometimes irritated by people who ask favors of me
13. I have never deliberately said something that hurt someone's feelings

C10. Perceived credibility measure (adapted from Flanagin & Metzger, 2000)

1=not at all; 2=not very; 3=slightly; 4=neither; 5=moderately; 6=very; 7=extremely

1. How believable was the information you read about dementia at the beginning of the study?
2. How accurate was the information you read about dementia at the beginning of the study?
3. How trustworthy was the information you read about dementia at the beginning of the study?
4. How biased was the information you read about dementia at the beginning of the study?

Bias item reverse scored

C11. Demographic Questions

1. What is your age? ____ years old
2. What is your gender? Male Female Nonbinary Other
3. What is your race/ethnicity? American Indian or Alaska Native Asian or Asian American Black or African American Hispanic, Latino, or Spanish Origin Middle Eastern or North African Native Hawaiian or Pacific Islander White Other
4. What is your highest level of education? Some high school High school Some college Associate's degree Bachelor's degree Master's degree Doctorate degree Other

C12. Experience with Dementia

1. Do you have professional experience working with older adults with dementia?

Yes/No

If yes, what is your profession? _____

How many years have you worked in that profession? _____

2. Do you have personal experience caring for a person with dementia?

If yes, did you serve as a primary caregiver? Yes/No

If yes, how many years did you provide care for this person? _____

CURRICULUM VITAE

Diana T. DiGasbarro Hedrick
Diana.hedrick@va.gov

EDUCATION:

- 2017- Present** **Ph.D., Clinical Psychology—University of Louisville**
Dissertation: *Changing Public Perception of Dementia: The Effect and Credibility of Three Informational Models*
Louisville, Kentucky
- 2021 – Present** **Doctoral Internship—Edith Nourse Rogers Memorial Veteran’s Hospital**
Geropsychology primary track
Bedford, Massachusetts
- 2019** **M.S., Clinical Psychology—University of Louisville**
Louisville, Kentucky
- 2017** **B.A., Psychology with Honors—Georgetown University**
Minor in Cognitive Science
Washington, D.C.
- September 2015 -** **Study Abroad, University of St. Andrews**
December 2015 Coursework in psychology, European history, art history
St. Andrews, Scotland, United Kingdom

CLINICAL INTERVENTION EXPERIENCE:

- 2021 – Present** **Edith Nourse Rogers Memorial Veteran’s Hospital**
Geropsychology Outpatient Clinic
Supervisor: Brian Zuzelo, Psy.D.
- Conduct intakes, provide individual therapy services to older adult Veterans in outpatient geropsychology mental health clinic
 - Treatment modalities include behavioral activation, cognitive-behavioral therapy, psychoeducation
 - Client challenges include depression, mild cognitive impairment, dementia, and Parkinson’s disease
 - Create and implement therapy group for Veterans with recent diagnoses of dementia. Group to offer support, emotional processing, and psychoeducation
 - Receive weekly individual supervision

2021 – Present

Edith Nourse Rogers Memorial Veteran’s Hospital

Community Living Center

Supervisor: Lisa Bloom-Charette, Ph.D.

- Provide individual therapy services to older adult Veterans in residential inpatient setting
- Treatment modalities include cognitive behavioral therapy for insomnia, cognitive behavioral therapy, mindfulness-based intervention, psychoeducation
- Client challenges include insomnia, depression, chronic pain, adjustment disorders, PTSD, stroke, aphasia, schizoaffective disorder
- Participate in weekly interdisciplinary care team meetings with staff and families
- Receive weekly individual supervision

2021 – Present

Edith Nourse Rogers Memorial Veteran’s Hospital

Mental Health Clinic

Supervisor: Joshua Berger, Ph.D.

- Conduct Orientation and Treatment Planning sessions to determine Veteran’s goals and make appropriate referrals
- Provide individual therapy services to Veterans across the lifespan
- Treatment modalities include acceptance and mindfulness-based interventions, cognitive behavioral therapy, dialectical behavioral therapy-informed intervention
- Client challenges include insomnia, anxiety, bipolar disorder, excoriation disorder, eating disorders, adjustment disorders
- Receive weekly individual supervision and weekly interdisciplinary group consultation

2020 – 2021

Frazier Rehab Institute—NeuroRehab Program

Supervisor: Amy Gonshak, Ph.D.

- Adapt and implement cognitive-behavioral and mindfulness techniques for use in individual and group therapy with clients at an outpatient neurological rehabilitation program
- Client challenges include aphasia, motor, vision, memory, and executive function deficits, anxiety, depression, and difficulty adjusting to brain injury
- Clients aged 16-85 years old with traumatic brain injury, stroke, and other acquired brain injuries
- Coordinate care via interdisciplinary rounds with occupational therapists, speech therapists, physical therapists, and case managers
- Discuss client progress, therapy recommendations, and answer family questions during Team and Family meetings

- Receive weekly individual supervision

2020 – 2021

University of Louisville Psychological Services Center

Integrated Interventions Specialty Team

Supervisor: Richard Lewine, Ph.D.

- Tailor therapeutic modalities to client needs using an integrated therapeutic approach
- Integrated approach combines evidence-based techniques from mindfulness and acceptance-based therapies, cognitive-behavioral therapy, dialectical behavioral therapy, and interpersonal and social rhythms therapy
- Implement individualized treatments with clients experiencing suicidal ideation, mood disorders, serious mental illness, chronic health conditions, and migraines
- Receive group and individual supervision

2018- 2020

University of Louisville Psychological Services Center

Mindfulness and Acceptance-Based Interventions Specialty Team

Supervisor: Paul Salmon, Ph.D.

- Implemented mindfulness-based therapies for clients with mood disorders, anxiety disorders, eating disorders, trauma history, chronic pain, and migraines
- Led meditations with clients including body scans, breathing meditations, loving kindness meditations, gratitude meditations, and inviting in difficult emotion meditations
- Integrated mindfulness and acceptance techniques with other forms of therapy, such as cognitive-behavioral therapy and exposure therapy
- Received group, individual, and peer supervision

2018- 2019

Masonic Communities of Kentucky—Louisville Campus

Supervisor: Suzanne Meeks, Ph.D.

- Provided behavioral activation, supportive therapy, and cognitive-behavioral therapy for older adults in short and long-term care residential facility
- Conducted cognitive assessment, and provided report, feedback, and recommendations to client and family member
- Client abilities varied in terms of hearing, vision, mobility, and cognitive functioning
- Client diagnoses included generalized anxiety disorder, major depressive disorder, insomnia, Parkinson’s disease, and Alzheimer’s disease
- Coordinated care with the Social Services and Activities departments

- Received individual supervision

**May 2018 -
October 2018**

Kindred Transitional Care and Rehabilitation—Wedgewood

Supervisor: Suzanne Meeks, Ph.D.

- Learned to provide BEACTIV treatment in long-term care setting for older adults with cognitive impairment and depression
- Provided BEACTIV therapy for an older adult with cognitive and language impairments due to stroke
- Received individual supervision

2017- 2018

University of Louisville Psychological Services Center

Eating Disorders Specialty Team

Supervisor: Cheri Levinson, Ph.D.

- Learned to use cognitive-behavioral therapy, dialectical behavior therapy, family-based therapy, and acceptance and commitment therapy with clients with eating disorders
- Conducted eating disorder intake assessments
- Implemented evidence-based interventions for eating disorders, specific phobias, and depression
- Led eating disorder recovery groups with 2-6 clients per group
- Facilitated transfer of client with severe eating disorder at high risk of medical complications to inpatient treatment
- Received group, individual, and peer supervision

CLINICAL ASSESSMENT EXPERIENCE:

2021 – Present

Edith Nourse Rogers Memorial Veteran’s Hospital

Capacity Assessment

Supervisor: Malissa Kraft, Psy.D., Stacey Larson, Ph.D., J.D.

- Conduct capacity assessments in response to consults across Bedford VA hospital system
- Address capacity issues related to medical decision-making, financial decision-making, independent living
- Conduct brief neuropsychological batteries to inform capacity evaluations

2019- 2021

University of Louisville Psychological Services Center

Adult Assessment Practicum

Supervisor: David Wunsch, Ph.D.

- Conduct semi-structured interviews and standardized assessments for adults at outpatient clinic
- Administer, score, and interpret results of assessments
- Provide clients with feedback, written report, and recommendations

- Referral questions include psychological diagnostic evaluation for ADHD, bipolar disorder
- Assessment measures include: MCMI-III, WAIS-IV, Connors' Continuous Performance Test 3rd Edition, Connors' Adult ADHD Rating Scale—Observer Report and Self Report, BAI, BDI-II, BHS, BSS, Mood Disorder Questionnaire

2018- 2021

University of Louisville Psychological Services Center

Child Assessment Practicum

Supervisor: Bernadette Walter, Ph.D.

- Conduct semi-structured interviews and standardized assessments for children at outpatient clinic
- Administer, score, and interpret results of assessments
- Provide clients with feedback, written report, and recommendations
- Referral questions include Advanced Program eligibility for gifted and talented students, behavioral problems in school
- Assessment measures include: WISC-V, WIAT-III, Scales for Identifying Gifted Students—Home Rating Scale, Child Behavior Checklist, Achenbach Teacher Report Form, Vanderbilt Parent and Teacher Assessment Scales, Multidimensional Anxiety Scale for Children, in-school observation

2019 - 2020

Comprehensive Neuropsychological Services

Neuropsychological Assessment Practicum

Supervisors: Brenda Parker, Ph.D., and Anne Book Miller, Ph.D.

- Conducted semi-structured interviews with clients and collateral informants, standardized assessments, and review of medical records for children and adults at private practice
- Administered, scored, and interpreted battery of neuropsychological tests
- Wrote reports including diagnostic impressions and recommendations
- Referral questions and conditions addressed included seizure disorders, head injuries, dementia, memory problems, psychiatric disorders, developmental delays, ADHD, genetic disorders, and intellectual disabilities
- Client ages ranged from 5-90 years old. Many clients came from rural Kentucky and were diverse regarding socioeconomic status and race
- Assessment measures included: MMSE, WAIS-III, WAIS-IV, WISC-IV, WISC-V, WMS-III, WASI-II, WRAT4, D-KEFS, MMPI-2, MACI-II, RBANS, CAVLT-2, RAVLT, Boston Naming Test, Mattis Dementia Rating Scale-2, GDS,

BDI-II, BAI, fluency tasks, and complex attention tasks

May 2018 -
September 2018

**University of Louisville Physicians Healthcare Outpatient
Center**

Neuropsychological Assessment Practicum

Supervisors: Liz Cash, Ph.D. and Whitney Rebholz, Ph.D.

- Conducted semi-structured interviews with clients and collateral informants, standardized assessments, and review of medical records for older adults at outpatient medical clinic
- Administered, scored, and interpreted battery of neuropsychological tests
- Wrote reports describing functional status, findings from collateral interview, diagnostic impressions, and recommendations
- Referral questions and conditions addressed included memory problems, mild neurocognitive disorder, dementia, and major depressive disorder
- Clients were older adults referred by geriatric physician, and were diverse regarding socioeconomic status and race
- Assessment measures included: WRAT4, Mattis Dementia Rating Scale-2, CVLT, Benton Visual Form Discrimination Test, Boston Naming Test, simple and complex attention tasks, verbal fluency tasks, GDS, GAD-7, PHQ-9, Symptoms of Dementia Scale, FrSBE

PEER-REVIEWED PUBLICATIONS:

Hedrick, D., Simon, D., Mast, B. T. (2022). Working with Families. In S. Bush & B. Yochim (Eds.), *Handbook of Geriatric Neuropsychology Practice Essentials*. Taylor and Francis.

Mast, B. T., Molony, S. L., Nicholson, N., Keefe, C. K., **DiGasbarro, D.** (2021). Person-centered assessment of people living with dementia: review of existing measures. *Alzheimer's & Dementia: Translational Research and Clinical Interventions*.

DiGasbarro, D., Midden, A., Van Haitsma, K., Meeks, S., & Mast, B. (2020). Reliability and Validity of the Adult Hope Scale among Nursing Home Residents with and without Cognitive Impairment. *Clinical Gerontologist*, 43(3), 340-349.
<https://doi.org/10.1080/07317115.2019.1656696>

Mast, B. T., & **DiGasbarro, D.** (2018). Capacity Assessment Across Functional Domains in Later Life. In *Oxford Research Encyclopedia of Psychology*. Oxford University Press. <https://doi.org/10.1093/acrefore/9780190236557.013.409>

PRESENTATIONS:

DiGasbarro, D. (2021, March). *Changing Public Perception of Dementia: The Effect and Credibility of Three Informational Models*. Oral presentation at Graduate Student Regional Research Conference, 14th Annual meeting. Virtual.

DiGasbarro, D., Whitaker, C., & Mast, B. (2020, November). *Positive Behaviors and Strengths of People with Dementia*. Poster accepted for presentation at the Gerontological Society of America Annual Scientific Meeting, Virtual.

Flaherty, L., Girgis, C., **DiGasbarro, D.,** Mohanty, D.D., LaFaver, K. (2020, September). *Perceived Stigma in Patients with Functional Movement Disorder: A Qualitative Study*. Poster presented at the International Parkinson and Movement Disorder Society Virtual Congress.

DiGasbarro, D., Molony, S. L., Nicholson, N., Keefe, C. K., & Mast, B. T. (2020, August). *Person-centered Assessment in People with Dementia: A Review of Existing Measures*. Poster presented at the American Psychological Association Annual Convention, Virtual.

DiGasbarro, D., Van Haitsma, K., Meeks, S., & Mast, B. (2019, November). *Optimism, Quality of Life, and Cognition in Recent Nursing Home Residents*. Poster presented at the Gerontological Society of America 71st Annual Scientific Meeting, Austin, TX. <https://doi.org/10.1093/geroni/igz038.419>

DiGasbarro, D., & Mast, B. (2018, November). *Predictors of Older Adults' Estimated Probability of Future Nursing Home Admission*. Poster presented at the Gerontological Society of America 70th Annual Scientific Meeting, Boston, MA. <https://doi.org/10.1093/geroni/igy031.3612>

COMMUNITY PRESENTATIONS:

Gonshak, A., **DiGasbarro, D.** (2021, April). *Recovery from Brain Injury: the Long and Winding Road*. Presentation given at the Brain Injury Alliance of Kentucky Annual Summit, 2021. Virtual.

OTHER PUBLICATIONS:

DiGasbarro, D., & McDuffie, D. (2020, October). A Gap in the Literature: Racial Disparities in Voting Access and Participation Amongst Older Adults. *Clinical Geropsychology News*, 27(3), 26-28.

RESEARCH EXPERIENCE:

2020 – Present **University of Louisville: Doctoral Dissertation**
Dissertation Committee Chair: Benjamin Mast, Ph.D., ABPP
Dissertation Committee Members: Susan Buchino, Ph.D., Sara Bufferd, Ph.D., Suzanne Meeks, Ph.D., Bernadette Walter, Ph.D.

- Dissertation Title: *Changing Public Perception of Dementia: The Effect and Credibility of Three Informational Models*
- Proposal accepted September, 2020
- Study will assess if portrayal of dementia affects perception of dementia amongst laypeople using a vignette method
- Three portrayals of dementia will be tested based upon the following models of dementia: medical model, biopsychosocial model, positive psychology-informed model
- Perception of dementia defined by behavioral responses, stigma, attribution of controllability, and attitudes
- Additional predictors of perception of dementia to be assessed include knowledge of Alzheimer's disease, fear of Alzheimer's disease, ageism, personality, demographics, and personal experience with dementia
- The perceived credibility of each model will also be assessed, with the hopes of determining if a positive psychology-informed model of dementia is palatable to the general population in the United States
- Data will be gathered using Amazon MTurk

2017-Present

University of Louisville: Aging and Neuropsychology Lab

Mentor and Supervisor: Benjamin Mast, Ph.D., ABPP

- Graduate student research assistant
- Areas of research include capacity assessment in older adults, measuring positive psychology constructs in older adults with dementia, person-centered assessment of people with dementia, positive strengths and behaviors of people with dementia, and family involvement in geriatric neuropsychological assessment
- Assist in project development, IRB application, data analysis, and writing
- Prepare manuscripts, chapters, and poster presentations based on pre-existing datasets, literature reviews, and novel research

2016-2017

Georgetown University: Center for Aphasia Research and Rehabilitation

Supervisor: Rhonda Friedman, Ph.D.

- Undergraduate research assistant and psychology honors student
- Senior honors thesis: *Differences in Semantic Fluency Task Performance between Three Variants of Primary Progressive Aphasia*
- Transcribed aphasic patients' responses to

neuropsychological assessments using international phonetic alphabet, measured reaction time, performed error coding

**June 2015 -
August 2015**

Washington University: Emotion and Relationships Lab

Supervisor: Tammy English, Ph.D.

- Undergraduate research assistant during summer term
- Worked on project examining effects of emotion regulation in married couples in their 20s-80s
- Performed data entry and checking, video coding following specific coding protocol, literature searches

RESEARCH PROJECTS IN PROGRESS:

2019 - Present

Perceived Stigma in Patients with Functional Movement Disorders: A Qualitative Study

Primary Investigator: Kathrin LaFaver, M.D.

Co-investigators: Lauren Flaherty, M.S., Diana DiGasbarro, M.S., Christina Girgis, M.D., Diksha Mohanty, M.D.

- Developed thematic codebook with Christina Girgis, and performed coding of transcribed interviews with people with functional movement disorders
- Assisted in development of poster for presentation at conference
- Manuscript in progress

TEACHING AND SUPERVISORY EXPERIENCE:

2020 – 2021

University of Louisville: Psychological Services Center

Integrated Interventions Specialty Team

Supervisor: Richard Lewine, Ph.D.

- Peer supervisor to junior graduate student therapists on clinical team
- Meet for 2-4 hours per month

2019, 2020

University of Louisville: Clinical Interviewing

Supervisor: Barbara Stetson, Ph.D.

- Along with three other Clinical Graduate Teaching Assistants (CGTAs), taught summer clinical interviewing course to first-year graduate students
- Led classes on: Interviewing Skills, Problem Identification and Cultural Formulation, Dangerousness and Risk Assessment Across the Lifespan, and Intake Interviewing and Report Writing
- Assisted with classes on: Affect and Mental Status Exam, Goal Identification, and Multicultural Considerations in Interviewing
- Created and graded assignments, and supervised first-year

students following role-plays

- Utilized traditional education format in 2019 and remote-learning format in 2020 due to COVID-19

**January 2020-
April 2020**

University of Louisville: Intellectual and Cognitive Assessment

Supervisor: Bernadette Walter, Ph.D.

- Along with three other CGTAs, taught semester-long course on the administration, scoring, and interpretation of the WAIS-IV and WISC-V to first-year graduate students
- Demonstrated administration of subtests and supervised students as they practiced in class
- Graded and supervised students following practice administration of WAIS-IV and WISC-V with community volunteers

2019

University of Louisville: Aging and Neuropsychology Lab

Supervisor: Benjamin Mast, Ph.D., ABPP

- Supervised undergraduate research assistants
- Trained undergraduate students to gather data for project testing psychosocial measures and a brief life review intervention for people with dementia in a nursing home
- Observed and supervised undergraduate research assistants during interviews and life review sessions with research participants

**January 2019-
April 2019**

University of Louisville: Quantitative Methods in Psychology

Supervisor: Maria Kondourova, Ph.D.

- Teaching assistant for in-person, semester-long course
- Taught two lab weekly lab sections of 10-15 students each
- Created and graded homework assignments and exams, and held office hours

June 2018

University of Louisville: Introduction to Psychology

Supervisor: Benjamin Mast, Ph.D., ABPP

- Teaching assistant for online summer course through Blackboard
- Graded assignments

2017-2018

University of Louisville: Introduction to Psychology

Supervisor: Edna Ross, Ph.D.

- Teaching assistant for in-person, semester-long course
- Proctored exams, held office hours, and graded assignments and exams

WORK EXPERIENCE:

2021

LINC-AD Evaluation Tool Pilot

Project facilitators: Cynthia Port, Martha Tierney, Sam Fazio, Sheryl Zimmerman

- Consulted for authors of novel evaluation tool to measure person-centeredness of assessment measures as part of NIH-funded LINC-AD project
- Piloted evaluation tool, PC-MET, to assess the person-centeredness of existing measures used with people with dementia
- Provided feedback to authors about the current version of the PC-MET, including suggested edits, questions, and feasibility
- Served as 1 of 3 raters (myself, Benjamin Mast, Sheila Molony), with interrater reliability to be analyzed

2019 - 2021

University of Louisville Psychological Services Center

Supervisor: Bernadette Walter, Ph.D.

- Clinical Graduate Teaching Assistant
- Coordinate initiation of treatment and assessment services for individuals contacting the clinic, including individuals in crisis
- Collaborate with external agencies for incoming and outgoing referrals, outreach, and client case management
- Conduct psychotherapy intake evaluations, and assist in treatment referral within clinic or with external agency
- Serve as first point of contact for management of crisis situations within the clinic
- Provide peer supervision to graduate student therapists, including assistance with intakes, assessments, therapy services, and crisis management
- Facilitate adherence to clinic operating procedures
- Responsible for clinic operations including opening and closing procedures, payment records, scheduling, database management, and chart audits
- Meet with clinic director on a weekly basis to discuss incoming clients, assignation of cases to graduate student therapists, and other clinic business, including clinic operating procedures during COVID-19

2019 – 2020

University of Louisville Clinical Psychology Colloquium Series

Supervisor: Bernadette Walter, Ph.D.

- Organized Clinical Psychology Colloquium Series held in the fall and spring semester
- Invited professionals from the community to present to the Clinical Psychology doctoral programs' students, faculty

members, and other interested departments about issues in psychology

- Secured 5 speakers for the Fall 2019 series and 3 speakers for the Spring 2020 series, with topics including substance use disorders, telehealth, grief, and family therapy
- Moderated clinical panel with graduate student therapists titled “Psychotherapy with Clients with Comorbid Medical Conditions”
- Developed and led clinical workshop covering “Time Management in Psychotherapy”

**May 2016 -
August 2016**

Association for Psychological Science

- Summer intern in the Membership Department in Washington, D.C.
- Staffed annual convention in Chicago, conducted data mining projects to bolster membership, and researched grants

SERVICE ACTIVITIES:

2022 – 2023

Council of Professional Geropsychology Training Programs (CoPGTP)

- Appointed CoPGTP Student Representative for 2022-2023 term

2020 - Present

Society of Clinical Geropsychology, American Psychological Association, Division 12, Section II

- Co-editor of the society newsletter, *Geropsychology News*, for three-year term
- Request submissions from executive team, committee chairs, and members for newsletter content
- Edit submissions and create newsletter for publication three times per year
- In partnership with newsletter co-editor, Danielle McDuffie, M.A., created recurring Social Justice Corner column devoted to social justice and diversity issues within geropsychology

2019- 2021

University of Louisville: Multicultural Training Committee

- Student member of committee formed in the Department of Psychological and Brain Sciences to enhance training in multicultural competency for Clinical Psychology doctoral program graduate students
- Committee goals include: define multicultural training experience, identify and disseminate training opportunities to graduate students and faculty, implement tracking

program, and gather participation data

2018-2020

University of Louisville: Department of Psychological and Brain Sciences

- Conducted interviews and assisted with interview day activities for Clinical Psychology doctoral program applicants in 2018, 2019, 2020
- Coordinated transportation for all applicants interviewing for the Clinical Psychology doctoral program in 2019

TRAINING AND CERTIFICATES:

2021

LGBTQ+ Affirming Healthcare Certificate

- Earned certificate offered through the University of Louisville School of Medicine
- Certificate requires attending four training presentations and completion of patient simulation in spring 2021
- Learn to use LGBTQ+ affirming practices as a healthcare provider
- Training topics include intersectionality, gender identity, and Black trans individuals' experiences and recommendations in healthcare settings

2020

American Heart Association Basic Life Support Certification

- Completed Basic Life Support course in August, 2020
- Trained in adult, child, and infant CPR and use of AED

2019

Operation Immersion

- Stayed at Kentucky National Guard base for four-day immersive training designed to teach mental health providers to work with service members, veterans, and family members (SMVF)
- Participated in field exercises, lectures, and panel discussions to develop of cultural competency in working with SMFV
- Learned about military structure and culture, suicide risk assessment in SMFV, sleep disturbances in SMFV, and acceptance and commitment therapy for moral injury

2018

Body Project

- Completed 13.5 hours of training to implement the Body Project, a program that promotes healthy body image on college campuses
- Co-leader of a Body Project group, consisting of two 2-hour long sessions with approximately 10 participants, in September 2018

HONORS AND AWARDS:

2020 **University of Louisville Graduate Student Council Research Fund**

Awards up to \$500 for graduate student research activities

2020

University of Louisville Graduate Student Council Travel Fund

Awards up to \$350 for conference registration and travel

MEMBERSHIPS:

2019- Present **Society of Clinical Geropsychology, American Psychological Association, Division 12, Section II**

2016- Present **Association for Psychological Science**

COMPUTER SKILLS:

Microsoft Word	Microsoft Excel	Microsoft PowerPoint
IBM SPSS	IBM SPSS-Amos	Blackboard
Launchpad	Adobe Photoshop	CPRS
VA Video Connect	Microsoft Teams	Zoom
Webex		