

A Look into Public Outreach and Intervention to Create Dementia Friendly Communities

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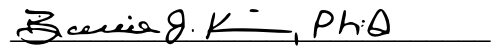

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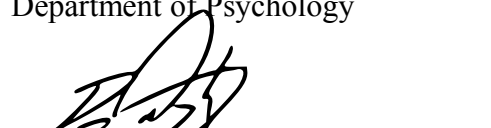

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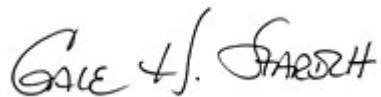

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Table of Contents

	Page
Title Page.....	1
Acknowledgements	3
List of Figures.....	5
Abstract	6
Chapter	
I. Introduction.....	7
II. Literature Review.....	11
III. Method	61
Participants.....	60
Measures	61
Procedure	63
IV. Results	65
V. Discussion	69
References	80

List of Figures

Figure	Page
Figure 1	68

Abstract

The complications associated with dementia are among the leading causes of death for older adults, impacting over 5.8 million people in the United States. It is on the incline and is expected to double, affecting 13.9 million people by 2060. This has a severe impact on older adults, their families, and the overall community. Increasing awareness and education for dementia can aid in furthering community support while increasing empathy towards individuals with dementia. Community programs and interventions have been utilized in the past to assist in increasing awareness for other mental health disorders, diseases, and for marginalized/ vulnerable groups of people. One method is through utilizing these means of community outreach and awareness interventions. Implementing interventions such as virtual reality simulations of dementia symptoms as well as educational/ empathy building techniques like Feil Validation theory have been used in the past to assist in increasing health professional awareness and empathy for dementia. However, these forms of interventions have not been used significantly with community members outside of those in the health profession who interact with individuals with dementia more consistently in cafes, restaurants, and other common community settings. The purpose of this study is to examine pretest attitudes towards dementia with community employee participants, provide an intervention through a virtual reality experience of dementia accompanied with Validation training to participants, to allow participants an opportunity to implement/ interact with caregivers and those diagnosed with dementia, and to measure posttest attitudes about ADRD (Alzheimer's Disease and Related Dementia).

Chapter One

Introduction

A Look into Public Outreach and Intervention to Create Dementia Friendly Communities

Dementia is a disease that is affecting older adults, their families, and the community and society at large. By the year 2060, it is anticipated that 13.9 million individuals will be diagnosed with dementia (Alzheimer's Association, 2019c). For older adults, a diagnosis of dementia is becoming one of the leading causes of death in the world (Alzheimer's Association, 2019c). As a result, the need for community education and interventions related to dementia can have a far reaching impact.

Dementia is a general term used to characterize diseases that influence memory, language, problem solving, and other related cognitive skills (Alzheimer's Association, 2019c). Despite being regularly seen in older adults, it is not part of the normal aging process and is unique in its rapid deterioration of mental faculties (Alzheimer's Association, 2019c). Symptoms of dementia start out slowly and gradually progress over time at a rate much faster than the rate of the natural aging process (Alzheimer's Disease International, 2019). The progression of dementia symptomology impairs the individual to the point that behavior and mood change noticeably and permanently, as no present cure exists for dementia (Mittrani et al., 2006)

One method of offering assistance to the increasing rate of diagnosis of dementia in society is through community outreach and increasing awareness about this vulnerable population. Community psychology is a model that has been used to increase awareness in a variety of disorders and promote mental health in general. Focusing on community education on a large scale as well as applying different interventions to raise awareness of the needs of individuals with mental health difficulties can effectively increase community acceptance and

overall knowledge of mental health in society (Tebes, 2010). Currently, research is needed within community psychology to examine and restructure the relationship between the community and marginalized groups, including individuals with dementia (Roy et al., 2016). While working from this theoretical framework, it is necessary to develop an understanding that all societies and communities, marginalized and non-marginalized groups alike, are linked together through the shared idea of diversity (Tebes, 2010).

When utilizing the community psychology approach with underserved and underrecognized populations such as individuals with dementia and other minority groups, it is helpful to incorporate and emphasize diversity within the research framework. Incorporating diversity into the research process assists community psychology by increasing social justice as well as by empowering underrepresented and oppressed groups (Stivala, 2017; Tebes, 2010). Community psychology desires to assist societies in incorporating the following goals: first, creating balance and acceptance within the community, and second, establishing respect for diversity from all societies (Stivala, 2017; Tebes, 2010).

A few existing campaigns and interventions have aimed to increase dementia awareness in specific communities. These interventions can be found in countries such as the United States, Japan, the United Kingdom, and Wales. However, there appears to be a lack of information in the literature on dementia awareness and education programs for the general public, especially in the United States, as the majority of the existing dementia awareness programs have been created for healthcare professions and family members that function as caregivers to the individual diagnosed with dementia (Shanley et al., 2004). Few established community organizations exist for dementia education and training; however, community events have been formed to educate caregivers and families on care techniques, communication with healthcare professionals,

managing healthcare and insurance, and legal and financial decisions (Colorado Department of Human Services, 2017). Utilizing these resources and educating the community can allow for a greater access to care, an increase in quality of life for the individual with dementia, as well as increased public knowledge and empathy towards dementia. Despite the existing community outreach programs nationally and internationally, further awareness and structured interventions are needed throughout the entirety of the United States (Bartolo et al., 2010), as a lack of community-wide approaches exist to support individuals with dementia and their corresponding caregivers.

Interventions exist to train specific parts of the community to think beyond treatment and some employ empathy building skills where they may be lacking. One such intervention used is a virtual reality (VR) simulation that aims to increase empathy levels regarding the experiences of persons with dementia (Adefila et al., 2016). The Savvy Caregiver Program (SCP) is another psychoeducational program for caregivers whose goal is to provide caregivers with a training program that could be offered by a variety of organizations (Hepburn et al., 2003). STAR-C is another program that aims to increase the well-being of family caregivers and their care receivers through the implementation of interventions (Teri et al., 2005). These interventions all serve to solidify the need for communal resources, empathy, and support for people with dementia and in turn their caregivers.

Validation theory has been shown to be effective when used by caregivers to foster more effective communication among caregivers and persons with dementia (Feil, 1993a). This theory has the potential to ensure that the community is equipped with the skills to effectively communicate with a person with dementia. Additionally, validation can assist and help the person with dementia feel that they are being understood within the social and community

context, further decreasing the feeling of being discriminated against or stigmatized for the disease. Validation facilitates communication between caregivers and individuals with dementia and prompts caregivers to think beyond treatment (Adefila et al., 2016). The effectiveness of using validation with caregivers and individuals in the health professions has been found to be effective on a large scale (Morris et al., 2018; Söderlund et al., 2016). It is of further interest to explore the extent that validation can influence and impact the community.

The current study sets out to investigate and explore the lack of a community psychology approach in utilizing validation and empathy building activities focused on community members as opposed to medical personnel and paid or familial caregivers. The study aims to increase knowledge and empathy towards individuals with dementia through educational and experiential means. The researchers hypothesized that through intervention and education, knowledge about dementia would be increased in the community. Researchers also hypothesized that through intervention and education, social comfort towards persons with dementia would be increased within the community.

Chapter Two

Literature Review

A Look into Public Outreach and Intervention to Create Dementia Friendly Communities

Impact of Dementia in the United States

More than 5.8 million people are living with some form of dementia in the United States of America (Batsch et al., 2012; Department of Human Services, n.d.; Mittelman & Bartels, 2014). This figure is expected to more than double to 13.9 million individuals being diagnosed with dementia by the year 2060 (Centers for Disease Control and Prevention, 2018b). Dementia diagnosis is becoming one of the leading causes of death in the world (Alzheimer's Association, 2019c). The impact of dementia is reaching an all time high in the United States. Every 65 seconds, a person in the United States is diagnosed with dementia, leading to an estimated 290 billion dollars in medical costs for the nation (Batsch et al., 2012). One in every three older adults dies from Alzheimer's or another type of dementia, killing more people than breast cancer and prostate cancer combined (Alzheimer's Association, 2019c). Dementia is a nationwide epidemic that is affecting older adults, their families, and thus the community and society at large. As a result of this growing epidemic, the need for education and intervention related to dementia within the community is needed.

Dementia

Dementia is a general term used to characterize diseases that influence memory, language, problem solving, and other related cognitive skills (Alzheimer's Association, 2019c). Disorders that are grouped under dementia consist of a range of abnormal brain changes. The changes that result from these disorders affect cognitive abilities, behavior, feelings, and relationships of individuals diagnosed (Alzheimer's Association, 2019c). Dementia is a leading

cause of disability and dependency among the older generation (World Health Organization, 2014). Individuals diagnosed with dementia experience symptoms that influence and hinder normal activities and relationships (Dementia Society of America, n.d.).

Dementia is common in older individuals; however, it is not part of the normal aging process (Alzheimer's Association, 2019c). As a result, it is important to distinguish between memory loss associated with the natural aging process and memory loss associated with the onset of dementia. The natural aging process includes memory loss and progressive difficulties in communication with others. As the natural aging process begins, cognitive abilities decrease as the brain also begins to age; this can result in mild issues with memory recall and issues in remembering names (Jansen et al., 2011). However, the development of dementia and its symptomatology stands apart from the natural aging process. Dementia is significantly different and more impairing overall when compared to the natural aging process (Almeida et al., 2002; Vachon, 2016). Symptoms of dementia are much more progressive, meaning symptoms start out slowly and gradually increase over time at a rate much faster than the rate of the natural aging process (Alzheimer's Association, 2019c). It is common as older adults age to experience problems with memory, attention, and focus. However, individuals diagnosed with dementia undergo severe brain changes that can be measured through lab tests, physical examinations, and through the collection of medical history and thus are considered abnormal (Ducharme et al., 2016). Over time, symptoms worsen and eventually can result in negative cognitive and noncognitive manifestations (Cohen-Mansfield et al., 2013; Maidment et al., 2008).

Alzheimer's disease is the most common form of dementia, making up approximately 60-70% of all cases (Alzheimer's Association, 2019c). Alzheimer's is a disease in which cognitive abilities of individuals decrease such as language, executive functioning, and memory

dysfunction (Alzheimer's Association, 2019c). Alzheimer's disease also impacts a multitude of behavioral and motor abilities like eating, walking, and talking (Alzheimer's Association, 2019c). Other forms of dementia include frontotemporal dementia, vascular dementia, Lewy body disease, and mixed dementia (Clark et al., 2017). All of these forms of dementia develop differently in the brain and can be distinguished from each other based on symptom presentation, lab tests, and clinical evaluation. Educating the community about the various types of dementia can help to increase understanding of symptomatology. However, the different forms of dementia produce relatively similar symptoms. All forms of dementia ultimately lead to severe impairment in functioning that influences the individual diagnosed; this impairment progresses and impairs to such an extent that behavior and mood change noticeably and permanently (Terracciano et al., 2018). These forms of dementia are commonly seen in the older adult population of individuals of 65 years or older but can also be diagnosed in those younger than 65 years (Alzheimer's Association, 2019c). Two specific diagnoses for dementia are recognized: Early Onset (EO) and Late Onset (LO). EO is diagnosed in individuals younger than age 65 whereas LO is diagnosed in individuals ages 65 or older (Wawrziczny et al., 2016).

Progressive Nature of Dementia

The progressive development of cognitive and noncognitive symptoms are not characteristic of natural aging and impair the quality of life for individuals with dementia. One example of such manifestation includes delirium. Delirium is a common neurobehavioral symptom that over 89% of older adults with dementia experience (Kolanowski et al., 2014). Delirium, along with the other symptoms of dementia, negatively develops over time and is characterized by incoherent thoughts and speech, illusions, and restlessness (Tanaka et al., 2015; Wright et al., 2015). Further cognitive symptoms of dementia include difficulties with memory

and problems with focusing and paying attention. Noncognitive symptoms of dementia can include mood disturbances such as psychosis, personality changes, agitation, aggression, pacing, wandering, altered sexual behavior, changed sleep patterns, and appetite disturbances (Cohen-Mansfield et al., 2013; Forester & Oxman, 2003; Maidment et al., 2008). These manifestations of dementia do not occur in the natural aging process and are unique to dementia and its forms (Song et al., 2018). Progressive symptoms are divided into three separate stages: early, middle, and late stages (Song et al., 2018). Symptoms can also be categorized as mild, moderate and severe as well, and with each stage, symptoms become progressively worse; however, it is important to note that the progressive symptoms of individuals with dementia can look different throughout the entire population (Tremont et al., 2006) and as a result, possessing knowledge on the symptomology can offer insight and assistance towards caring for individuals diagnosed with dementia.

Community outreach and increasing awareness about individuals with dementia can assist in supporting this vulnerable population. Many community programs focus on other mental and physical health disorders outside of dementia; however, these community-based approaches can be useful and function as a template and a potential model for future research and intervention aimed at increasing community awareness and intervention for dementia.

Community Psychology

Community psychology places focus on integrating the multiple, systemic layers of individuals' lives. These layers include incorporating individuals' social, cultural, economic, political, and environmental contexts (Society for Community Research and Action, 2019a).

Community psychology first began as a research-driven field of psychology but the attention has

shifted to intervening in order to help promote mental health awareness and assist those who are underserved and underrecognized within the community (Townley et al., 2018).

Community psychology is a multifaceted approach that extends past the contemporary and general psychological studies regarding theories and processes (Graham & Ismail, 2011). Community psychology examines the diversity of the human experience, including contextual features and how those factors can influence an individual's mental health. Two main ideas that are associated with this field of study are, first, that people must be observed within the correct, corresponding social and cultural context, and second, that this context is one of the root causes of diversity within human expression, behavior, and overall experience (Mankowski et al., 2011). In order to address the difference of expression and diversity, community psychology requires flexibility in approach when examining a specific population (Collins et al., 2018). When examining varying populations, community psychology conducts research with this same principle in practice (Fryer, 2008; Reyes Cruz & Sonn, 2011). Collecting and analyzing data utilizing a community psychology framework offers a set of values that is helpful for researching the relationship dynamic between societal issues and problems along with the independent functioning within a community (Mankowski et al., 2011). Furthermore, this field also offers strategies for the creation of interventions and constructive changes on the societal and systemic levels (Mankowski et al., 2011).

Collectivistic versus Individualistic Psychology

Fryer (2008) asserted that the field of community psychology arose along with the birth of the civil rights movement, the war on poverty, and the movement for awareness of mental health. This movement for increasing awareness of mental health became the main goal for the field of community psychology (Townley et al., 2018). Increasing awareness includes a

multifaceted approach that focuses on identifying the differences among cultural contexts, individuals, and communities (Fryer, 2008). Prior to the use and implementation of community psychology, contemporary psychology largely approached people as being comparable on a larger scale; that is, different societies and contexts were observed and researched with no emphasis or attention given to the corresponding cultural dynamics of that specific population (Mankowski et al., 2011). Researching and comparing groups in this way is known as an individualistic approach to understanding human behavior (Mankowski et al., 2011). This individualistic approach to psychological studies was the most commonly used form of research prior to the birth of community psychology (Mankowski et al., 2011).

Understanding societal problems within varying cultural and societal contexts poses potential complications when using an individual-oriented modality (Townley et al., 2018). Comparing cultures within the same context prior to the implementation of a community-based approach resulted in the failure of many mental health policies and practices over time in certain cultural contexts, as well as the overall segregation of people that were deemed mentally ill when compared to the cultural norms of the societies around those individuals (Mankowski et al., 2011). The increasing numbers of disproportionate hospitalizations of cultural minorities was a cause of concern for many professionals who were utilizing individualistic-focused research and psychology during this time (Mankowski et al., 2011; Townley et al., 2018). The formation of a collectivistic approach within the community psychology context allowed for an alternative to the social isolation and discrimination that individuals were experiencing. Community psychology provided an extension and changes from the previous individualistic approach by recognizing and researching the discrepancies of mental health policies and practices while also emphasizing cultural dynamics and the importance of being culturally aware and sound

(Mankowski et al., 2011; Reyes Cruz & Sonn, 2011). Promoting psychological well-being was the primary focus while still allowing for the continuing development of understanding different cultural communities (Mankowski et al., 2011). This idea is integral in the conceptualization of how to approach dementia within the community at large. Utilizing community psychology as an approach to exploring and educating others about dementia offers a unique perspective for researchers.

When integrating a collectivistic and community psychological approach to research intervention, a shift occurs in the community's approach to psychology and mental health awareness (Mankowski et al., 2011). This shift can be categorized as a change in mindset in which a greater emphasis exists on understanding mental health and the development of disorders. Furthermore, the collectivistic approach takes into account that mental health and related disorders progress and are impacted by more factors than just biological influences (Mankowski, Galvez, & Glass, 2011; Perkins, 2009a, 2009). This mindset also offered a shift towards a new perspective for the topic of mental health within the community. This movement increased awareness for the community by introducing environmental influences and how these influences impact the human psyche (Perkins, 2009a). The shift from individualistic to a community-based approach in psychology is linked to one of the main features associated with community psychology: the necessity and concern for intervention possibilities (King & Shelley, 2008; Mankowski et al., 2011; Reyes Cruz & Sonn, 2011).

Integrating the collectivistic approach to the study of dementia allows for an opportunity to increase community awareness on mental health (Alzheimer's Association, 2019a). Swaffer (2014) discussed the impact of the collectivistic approach to dementia in assisting in decreasing the stigma experienced by individuals who are diagnosed with dementia. This stigma is

characterized by different acts that result in the individual with dementia being negatively labeled, losing status and power, and experiencing discrimination and stereotyping in the community (Swaffer, 2014). The conceptualization of stigma is twofold: a perceived feeling that is coming from external factors such as other people or groups of people as well as a more internal sense of shame that results in a loss of the individual's sense of self due to the symptoms of dementia (Swaffer, 2014). Individuals diagnosed with dementia who encounter this stigma can be negatively impacted. Research has shown that this in turn decreases individuals' likelihood to seek a formal diagnosis and treatment as well as social support (Swaffer, 2014). Approaching the topic of dementia through the utilization of the collectivistic and community psychological approach can help raise awareness for dementia and also decrease the level of stigmatization in society towards this disease.

Need for Further Community Mental Health Awareness

Community psychology is a model that has been used to approach increasing awareness in a variety of disorders and in promoting mental health in general. Community psychology has been found to be effective through its perspective and methodology in which societal and communal education on the importance of mental health can have a means to be introduced, shared, and discussed through publication and psychoeducation efforts in the public (Tebes, 2010). Focusing on community education on a large scale as well as applying different interventions to raise awareness for mental health can effectively increase community acceptance and overall knowledge of mental health in society (Tebes, 2010). The prevalence of mental illness and the lack of mental health awareness in the United States stands as a leading epidemic that is impacting the community at increasing rates (Mental Health America, 2019). It is estimated that every year, one out of five adults in the United States experiences symptoms

related to mental illness (Mental Health America, 2019; National Alliance on Mental Illness, 2019b; National Institute of Mental Health, 2019). Approximately 75% of lifetime mental disorders occur before 24 years of age (Gagnon et al., 2017). In order to accurately meet the needs of individuals experiencing mental health concerns, early intervention is necessary as challenges with mental health issues begin to arise for these (Gagnon et al., 2017). Targeting and using the community in these interventions can be effective in increasing awareness of mental health (Gagnon et al., 2017).

The lack of community mental health awareness leads to decreased public acceptance (National Alliance on Mental Illness, 2017). Individuals diagnosed with mental illnesses experiencing higher rates of homelessness, involvement in the criminal justice system, and incarceration within the United States (National Alliance on Mental Illness, 2019b). Only about 22% of individuals with serious mental illnesses are employed, with less than half of those individuals holding full time jobs (National Alliance on Mental Illness, 2017). The National Institute of Mental Health defines serious mental illness as a mental, behavioral, or emotional disorder that results in an impairment in overall functioning (National Institute of Mental Health, 2019). This impairment greatly limits major life activities. The limited employment of this population can, in part, be associated with the stigma surrounding mental health which thus lends credence to the need for greater community awareness of mental health through community programs and interventions (National Alliance on Mental Illness, 2017). However, marginalized groups have also experienced the same alienation as individuals with severe mental illness. Increasing community awareness about individuals with severe mental health problems and marginalized groups can assist in decreasing the stigma associated with mental health and diversity as well as promote empathy and acceptance within the community (Townley et al.,

2018). Utilizing community psychology as the framework for increasing community awareness can offer a means to accomplish this goal.

Community Psychology and its Emphasis on Social Awareness in Marginalized Groups

Since its inception, community psychology has stood apart from other psychological fields due to the emphasis of promoting community mental health, societal changes, and the reform of mental hospitals through innovative and constructive research as well as increasing awareness of specific groups and mental health (Mihelicova et al., 2018; Reyes Cruz & Sonn, 2011). These ideas have been especially present in the role that community awareness interventions have had in marginalized groups and populations. Marginalized groups can be defined as specific groups that are systematically excluded from full participation in community settings and often lack the needed resources that are available to more mainstream groups (Garrett, 2019). Currently, an interest and need exist within community psychology to examine and restructure the relationship between the community and marginalized groups (Roy et al., 2016). Increasing community awareness about marginalized groups is one way that community psychology aims to promote social justice, education, and quality interventions within the community. These groups include, but are not limited to, the following: LGBTQA+ groups, senior citizens, racial and cultural minorities, individuals with Autism Spectrum Disorder, and the homeless. With regard to the LGBTQA+ population specifically, community psychology has played a significant role in promoting acceptance for the population within the community. The study of mental health and increasing awareness in the community has decreased the stigmas associated with the LGBTQA+ population; specifically promoting that through various forms of research that homosexuality is not associated with criminality or mental illness (McFarland, 2018). In turn, communities have stepped up to continue to promote awareness and equality

through protests, advocacy groups, pride parades and events, which in turn lead to the legalization of gay marriage in 2015 (Editors, 2019). These efforts on the part of the field of psychology and the community have paved the way for acceptance and equality that would not be possible without community endorsement of mental health knowledge, empathy, and advocacy, as these are the hallmarks of community psychology.

While working from this theoretical framework, it is necessary to develop an understanding that all societies and communities, marginalized and non-marginalized groups alike, are linked together through the shared idea of diversity (Tebes, 2010). When utilizing the community psychology approach with underserved and underrecognized populations such as individuals with dementia and other minority groups, it is necessary to incorporate and note diversity within the research framework. Community psychology allows for the recognition of this important idea (Tebes, 2010). Understanding diversity as it relates to mental health acknowledges that communities and societal groups all have a uniqueness that researchers must strive to understand in order to provide proper research and analysis (Society for Community Research and Action, 2019b; Tebes, 2010). Incorporating diversity into the narrative only furthers the agenda for community psychology by increasing social justice as well as by empowering underrepresented and oppressed groups (Stivala, 2017; Tebes, 2010). Community psychology desires to assist societies in incorporating the following goals: first, balance and acceptance within the community, and second, respect for diversity from all societies (Stivala, 2017; Tebes, 2010).

Academic journals have been written which emphasize the community psychology approach within psychological research while also promoting awareness and respect for different societies. The Society for Community Research and Action (SCRA) was created by the

American Psychological Association in order to have a unique collection of information and literature about community psychology (Case et al., 2014; Society for Community Research and Action, 2019b). The SCRA has created a space for research that focuses on increasing community awareness on diversity and promoting mental health care and education. The SCRA has fostered an environment in which researchers and others alike can come together and investigate to learn more about community psychology. The SCRA is responsible for the publication of the American Journal of Community Psychology (AJCP), a journal in which quantitative, qualitative, and mixed methods research studies are published (Society for Community Research and Action, 2019b). Another widely used journal for the field of community psychology is the Journal of Community Psychology (JCP) (Graham & Ismail, 2011). These journals both publish community-based articles and research that aims to increase community awareness and education. Furthermore, these articles and journals provide a bridge between research and intervention within societies (Wang et al., 2016). Utilizing the findings from these journals aids with constructive changes within societies through policy reform and improving health outcomes by increasing access to health services (Wang et al., 2016).

Research demonstrates that significant physical and mental health benefits result from being included in community relationships like social networks and other similar groups (Graham & Ismail, 2011). In turn, an individual's quality of life can be positively or negatively impacted by their involvement in the community and community acceptance (Omoto, 2005). Thus, it is important to promote awareness about the population and its needs while simultaneously increasing empathy from the community. Foster-Fishman, Cantillon, Pierce, and Egeren (2007) showed that individuals who saw their communities as having a problem, being ready for change, and having the capacity to change were more likely to be involved in

community efforts to remedy the problem. The study found that the highest predictor of community involvement within the study was community members' perceptions of the problem. This study solidifies the importance of a community knowing that dementia exists, understanding the impact it has on the community and the individual, and having empathy for both in order to be actively involved in promoting change for the community and those with dementia within it. Therefore the community psychology model serves as a framework in order to address the needs of individuals with dementia through informing the community about the problems that people with dementia face, and in turn promoting change for the betterment of the community and persons with dementia.

Dementia Awareness in Communities

A lack of literature exists on dementia awareness and education programs for the general public, at large, as the majority of the existing dementia awareness programs have been created for healthcare professions and family members that function as caregivers to the individual diagnosed with dementia (Shanley et al., 2004). Programs that focus on increasing dementia awareness and understanding accomplish this through different types of intervention within various community settings. Few existing campaigns and interventions have aimed to increase dementia awareness in specific communities. Dementia awareness can be characterized by an increase in public knowledge and understanding towards dementia symptoms and related disorders that assist in decreasing the stigma associated with dementia as well as discriminatory behavior through promoting positive and effective interactions with individuals diagnosed with dementia (Phillipson et al., 2019). Dementia awareness desires to promote advocacy for individuals diagnosed and living with dementia through public campaigns and interventions within the community (Phillipson et al., 2019). Individuals with dementia experience challenges

in communication in day to day interactions as a result of the severe and progressive symptomatology associated with the disorder (Shanley et al., 2004). Through the implementation of dementia awareness in communities, the problems that individuals with dementia face can potentially be reduced if the general public had a basic and functional understanding of dementia and were educated on how to interact, treat, and show respect for people diagnosed with dementia (Shanley et al., 2004).

Intervention Studies on Dementia Awareness

Programs exist which specifically target intervention in the lives of the individual diagnosed with dementia. These programs center on non-pharmacological interventions that take place at the community level. Ranging from cultural events that educate the public about dementia to training people within the community to better understand the needs of individuals with dementia, non-pharmacological interventions for individuals with dementia are among the most effective tools for dementia awareness and integration within this population (Zeisel et al., 2016b). Utilizing this form of intervention may improve quality of life for individuals with dementia through a variety of ways. Non-pharmacological interventions strive to assist communities in making functional living spaces for individuals with dementia (Zeisel et al., 2016b). Doing so improved reports of wellbeing for individuals with dementia as well as created less costly means of psychological and medical intervention (Phillipson et al., 2019; Zeisel et al., 2016a). Community psychology promotes these forms of communal intervention and implementation. Targeting the community as the main means of increasing dementia awareness challenges society and creates a cultural shift (Phillipson et al., 2019). This cultural shift requires a significant amount of community involvement that extends past a short campaign or a few dementia awareness programs. This is one potential reason why intervention among community

members is not as popular as intervention is among healthcare workers or caregivers (Alzheimer's Disease International (ADI), 2016); (Phillipson et al., 2019).

Programs aimed at dementia awareness occur on the international level. Japan has implemented a 10 year dementia awareness campaign that is aiming to decrease the stigmatization associated with dementia through the use of changes in vocabulary (World Health Organization & Alzheimer's Disease International, 2012). Through intervention at the governmental level, the leaders of Japan replace a previously demeaning word used to refer to dementia with a more respectable term (World Health Organization & Alzheimer's Disease International, 2012). Along with the diction change, training has been offered for over 2 million individuals to promote advocacy and increase overall understanding for people living with dementia (World Health Organization & Alzheimer's Disease International, 2012). Likewise, in the United Kingdom, public interest exists in normalizing the dementia experience and addressing and challenging the common misconceptions associated with dementia (Phillipson et al., 2019). The Dementia Friends program is an initiative that focuses on raising awareness and understanding of dementia on the national level (Alzheimer's Disease International (ADI), 2016). The United Kingdom has further implemented the SHIELD (Support At Home: Interventions to Enhance Life in Dementia) program that aims to improve self-efficacy and competency for caregivers to those with dementia by examining the impact of volunteering with caregivers as well as exploring the overall themes and takeaways from the caregiver and the individual with dementia (Brooks et al., 2014). The thoughts and experiences of these volunteers as well as the level of perceived communal support was gathered through semi-structured interviews (Brooks et al., 2014). Caregiver support coupled with community education on dementia provided an increased sense of connection within the community as well as

strengthened social identity not only for the caregivers but for the individual with dementia as well (Brooks et al., 2014). However, this is one of the only studies of its kind; therefore, further research is recommended in order to explore these effects. In Wales, intervention and community awareness for dementia is also of special interest. The Respect, Empathy, and Dignity (RED) group was developed in response to researchers' desire to educate the public on dementia (Chalk & Page, 2016). RED focuses on building dementia-friendly communities by offering resources and training for interacting with individuals with dementia as well as partnering with larger existing corporations to increase awareness of dementia (Chalk & Page, 2016). Offering easy access to useful resources about dementia for the communities of Northern Wales created a voice for these individuals who find it challenging to communicate for themselves (Chalk & Page, 2016).

On the national level in the United States, there also exist a few community programs on dementia awareness. The Garrison Institute on Aging (GIA) is an interdisciplinary organization within the Texas Tech University Health Sciences Center that utilizes community psychology to assist in increasing awareness and integration of education around dementia. The GIA provides education on healthy aging, collaborative community outreach efforts, and caregiving to bring awareness to Alzheimer's disease and dementia (Reddy et al., 2015). The GIA accomplishes this goal through non-profit, educational outreach programs held in local, easily accessible areas such as health fairs, hospitals, and farmers' markets (Reddy et al., 2015).. This program provides families with free services such as the "Healthy Lubbock" event to promote health exercise and nutrition, informational booths at various local events in rural or low-income neighborhoods, free brain autopsies of deceased loved ones for confirmation of the clinical diagnosis of dementia, and educational seminars in local community centers and university campuses (Reddy et al.,

2015). The GIA also provides services for the caregivers to the individual with dementia or Alzheimer's, including available resources for community activities on daily living, health care consultations, financial advice and advocacy, and social interaction which extends beyond support groups (Reddy et al., 2015). All of these opportunities come at no cost to the families as they are sustained by the support of community volunteers (Reddy et al., 2015). As many of these organizations are non-profit, funding is primarily dependent on donations, contributions, community sponsorships, and government grants. This means that for programs such as the GIA and SHIELD, funds for supporting these community outreach programs are severely limited, which may hinder the longevity of already existing programs (Kerr-Tar Regional Council of Governments, n.d.; Reddy et al., 2015). In turn, if community settings are not aware of the effectiveness or implementation of these programs, dementia support and intervention within the community could potentially cease to be significant or present in research.

Other studies have approached dementia awareness through assessing how communal factors such as acceptance and participation influence the lives of individuals with dementia as well as the overall family dynamics. Bartolo, De Luca, Serrao, Sinforiani, Zucchella, and Sandrini (2010) conducted a study consisting of 118 pairs of individuals with dementia and caregivers in order to measure and assess the forms of burden caregivers carry when they partake in different community programs like neurorehabilitation and outreach groups. The Caregiver Burden Inventory, the Beck Depression Inventory (BDI), and Quality of Life (EuroQol-5D) measures were utilized to analyze any correlation between the specific forms of caregiver burden, stress, depression, and overall quality of life (Bartolo et al., 2010). The domains of caregiver burden which were analyzed included objective burden, developmental burden, physical burden, social burden, and emotional burden (Bartolo et al., 2010). Caregiver burden

correlated positively with caregiver depression; however, the burdens correlate negatively with their quality of life (Bartolo et al., 2010). Regarding the domains of burden, objective burden was ranked the highest whereas emotional burden was reported as the lowest (Bartolo et al., 2010). Further, 67% of the caregivers in the study requested future interventions which would specifically reduce their burden (Bartolo et al., 2010). Caregiver burden, regardless of form or domain, directly relates to the manifestation of depression or depressive symptoms in caregivers of individuals with chronic neurology (Bartolo et al., 2010). Moreover, this study further articulates the need for individual as well as community interventions which may prevent and manage stressful situations that caregivers face when they attempt to engage in community programs with the individual who receives care. A commonality throughout various outreach and awareness organizations is the lack of research to support the desperate need for effective community interventions (Colorado Department of Human Services, 2017; Kerr-Tar Regional Council of Governments, n.d.; Oregon Department of Human Resources, n.d.). The lack of research that provides concrete evidence of this need intervenes not only with the well-being and care available for individuals with dementia, but also for caregivers and families. The collective support of a community impacts the overall well-being of the family caregiver (North Carolina Department of Health and Human Services, n.d.). In turn, this impacts the quality of care provided to the individual with dementia. This beneficial symbiotic relationship can be implemented with countless other families that have an individual with dementia if knowledge and understanding are continually perpetuated and documented within the community.

Existing Community Programs

Several associations and groups for mental health have been created in order to raise awareness and provide education. Programs like these center around increasing engagement and insight for mental health and disorders within the community as well as marginalized groups. These programs focus on how community members can become advocates as well as stay informed and accommodated for mental health, as the prevalence of these disorders within the community increases. One national program that aims to increase community awareness on mental health is the WhyCare? Campaign (National Institute of Mental Health, 2019). Launched in May 2019, the WhyCare? Campaign emphasizes the impact that caring can have on individuals with mental illnesses (National Institute of Mental Health, 2019). This campaign also seeks to increase mental health education to allow for easier identification of warning signs associated with various mental illnesses as well as resources and access to care for those individuals with mental illnesses (National Institute of Mental Health, 2019). Community programs use several different platforms to increase community engagement, involvement, and awareness. Founded in 2002, NAMIWalks is another national program founded in over 100 communities that is designed to bring awareness to mental health (National Alliance on Mental Illness, 2019c). Every year, 5K NAMIWalks events are hosted to not only bring about mental health awareness, but to also raise money for local, regional, and state NAMI organizations (National Alliance on Mental Illness, 2019c). Additional organizations such as the National Association of Councils on Developmental Disabilities (NACDD) promote civic engagement for those who are part of a marginalized mental health community. The goal behind NACDD is to create support, involvement, and community cohesion towards marginalized individuals with disabilities (National Association of Councils on Developmental Disabilities, n.d.). This engagement includes creating space to provide individuals with developmental disabilities a

productive role to play within the community through the creation of jobs and volunteer opportunities (National Association of Councils on Developmental Disabilities, n.d.). This group has also created an initiative in order to help those with developmental disabilities understand voting rights and engage in the community from a political standpoint as well, an area that has been neglected previously in community research (National Association of Councils on Developmental Disabilities, n.d.). Organizations like NACDD promote the well-being of not only the person with a disability, but also caregivers and the community at large (National Association of Councils on Developmental Disabilities, n.d.). Allowing opportunities for communal involvement for the individual with disabilities as well as educating the general public on disabilities creates a relationship in which both parties benefit, this is an important and integral concept that lies in community psychology and the reason for the creation of community programs.

Community Programs Relating to Dementia

The NACDD provides one of many examples of ways in which organizations can promote education and involvement for individuals who have mental health difficulties or present to be different within the larger community context. Using this model as well as other similar community programs, these ideas can be applied specifically to individuals with dementia. Targeting involvement within the community can be beneficial not only to the community in its entirety, but it can also help promote a meaningful existence within the lives of those diagnosed with dementia and their caregivers.

Throughout North Carolina, Oregon, Colorado, and Massachusetts exist a limited number of effective outreach and awareness programs which provide various forms of assistance to familial caregivers of those who are afflicted with Alzheimer's disease or dementia. A few of

these notable organizations include Project C.A.R.E. (Caregiver Alternatives to Running on Empty) in North Carolina (Land of Sky Regional Council, 2012); the Family Caregiver Support Program (FCSP) which has chapters in North Carolina and Oregon (Kerr-Tar Regional Council of Governments, n.d.); the National Family Caregiver Support Program (NFCSP) which has a prominent chapter in Colorado (Colorado Department of Human Services, 2017); the Community Services and Supports Unit located in Oregon (Oregon Department of Human Resources, n.d.); Compass Memory Support in Massachusetts (Senior Living Residences, 2019); the University of Colorado Colorado Springs (UCCS) Aging Center (Senior Living Residences, 2019); as well as the Boston University Alzheimer's Disease Center (Mental Health America, 2019). Numerous benefits have been provided to caregivers by the existing programs as well as benefits provided to the individuals who have dementia or Alzheimer's disease. The primary objectives of these outreach programs is to empower the entire families that have been impacted by an individual with dementia or Alzheimer's disease and improve overall quality of life (Colorado Department of Human Services, 2017; Oregon Department of Human Resources, n.d.). These associations provide consultation, resources for support groups throughout the state, information about related services, funding assistance, training and education, respite care resources, local agencies within the state which provide family support, connections to Alzheimer's Association chapters within the state, supplemental services, funding for research, and legal services and advocacy. Associations like these provide a multitude of different resources available for the community.

One of the most common benefits provided by these community organizations is the establishment of support groups for families within the community. Providing and having access to social support groups assist in the recovery and mental health of the entire family that has an

individual who is diagnosed with dementia (Senior Living Residences, 2019). If no support groups are available in the immediate or local areas for these individuals and families, the organizations provide resources for support groups in various cities within the state that can be accessed (Colorado Department of Human Services, 2017; Senior Living Residences, 2019). Even though many programs have provided a means for these resources, increasing educational and awareness opportunities can assist in furthering the development of these programs and increase the range of services to a larger degree, thus allowing for greater assistance. Another communal and societal benefit is the availability of family consultants who are proficient in dementia care. These consultants are experts in providing resources to caregivers for in-home modification assessments, resolving family issues, assistance in decision making related to care, coordinating caregivers with financial aid, and connecting caregivers and families to local resources within the community (A Place for Mom, 2019; Aging and Disability Resource Connection of Oregon, 2014; Kerr-Tar Regional Council of Governments, n.d.; Land of Sky Regional Council, 2012). Another role that consultants also play is as advisors of planning future care, including hospice, end of life resources, and palliative care (Colorado Department of Human Services, 2017).

The aforementioned community programs additionally provide assistance, information, and resources for families with an individual with dementia. Other existing programs help caregivers and families find types of respite care (A Place for Mom, 2019; Aging and Disability Resource Connection of Oregon, 2014; Colorado Department of Human Services, 2017; Kerr-Tar Regional Council of Governments, n.d.; Land of Sky Regional Council, 2012; Oregon Department of Human Resources, n.d.). Respite care provides families with temporary relief to further reduce stress and exhaustion through community intervention and assistance. Volunteers

and nursing assistants within the organizations offer time to be with the individual with dementia, several services within adult day service programs, and overnight care within residential settings (A Place for Mom, 2019; Aging and Disability Resource Connection of Oregon, 2014; Colorado Department of Human Services, 2017). However, funding to help pay for temporary relief like respite care is limited (Kerr-Tar Regional Council of Governments, n.d.). Community outreach programs are also aware of the financial strain that comes with providing full time care for individuals who have dementia or Alzheimer's disease (Aging and Disability Resource Connection of Oregon, 2014; Colorado Department of Human Services, 2017; Oregon Department of Human Resources, n.d.). Funding assistance is offered and provided when available for individuals who qualify for in-home personal care, adult day services, group respite or overnight residential respite care (A Place for Mom, 2019; Colorado Department of Human Services, 2017; Kerr-Tar Regional Council of Governments, n.d.; Land of Sky Regional Council, 2012). Additionally, training and educational resources are available for family caregivers within community organizations (Aging and Disability Resource Connection of Oregon, 2014; Colorado Department of Human Services, 2017; Kerr-Tar Regional Council of Governments, n.d.; Land of Sky Regional Council, 2012).

Although few established community organizations for dementia education and training exist, community events have been formed to educate caregivers and families on care techniques, communication with healthcare professionals, managing healthcare and insurance, and legal and financial decisions (Colorado Department of Human Services, 2017). These community events also provide connections to the Alzheimer's Association chapters within each state for access to a broad range of other available programs and educational resources which exist both locally and in other counties (Kerr-Tar Regional Council of Governments, n.d.; Land of Sky Regional

Council, 2012). These organizations also have supplemental services available on a limited basis such as home modifications, assistive technology, emergency response systems, and necessary supplies (Aging and Disability Resource Connection of Oregon, 2014; Colorado Department of Human Services, 2017; Kerr-Tar Regional Council of Governments, n.d.; Oregon Department of Human Resources, n.d.). Additionally, families may be eligible for legal services assistance, advocacy efforts, and transportation as available (A Place for Mom, 2019; Aging and Disability Resource Connection of Oregon, 2014; Oregon Department of Human Resources, n.d.). Through the work and time dedicated by community intervention, families with an individual diagnosed with dementia as well as the individual have resources available that would not be otherwise present. Utilizing these resources and educating the community in the surrounding areas can allow for a greater access to care, an increase in quality of life for the individual with dementia, as well as increased public knowledge and empathy towards dementia. Few programs exist which are available that have aimed at accomplishing this in the United States.

The North Carolina Department of Health and Human Services highlighted the qualities of Project C.A.R.E. (Land of Sky Regional Council, 2012). This is the only dementia-specific, state-funded program in the United States for familial caregivers of those afflicted with dementia or Alzheimer's disease (Land of Sky Regional Council, 2012). Established in 2001, Project C.A.R.E. provides a multitude of services such as counseling, caregiver education and training, advocacy, as well as partnerships with other outreach programs to heighten awareness and increase assistance options for families (North Carolina Department of Health and Human Services, n.d.). Project C.A.R.E. is a leader in the advocacy and outreach in communities and centers on creating connections within the community to families and individuals diagnosed with dementia. A prominent presence of this organization in dementia and Alzheimer's communities

exists as it focuses on community outreach, involvement, and implementation. These communities are provided with resources targeted at fulfilling the unmet needs of families with an individual with dementia. The goal is to increase community involvement within these families to ideally increase understanding, acceptance, support, assistance, and overall embracement in the community at large (North Carolina Department of Health and Human Services, n.d.). This program differs from the other organizations because of the ample opportunities and resources available through Project C.A.R.E. in order to take direct action in implementing community services. The National Family Caregiver Support Program (NFCSP) and the Oregon Community Services and Supports Unit are aware of the necessity for community involvement in providing collective care for families and the individual diagnosed with dementia (Colorado Department of Human Services, 2017; Oregon Department of Human Resources, n.d.). Community outreach and involvement programs are needed and in high demand, and this is reflected in the services of the aforementioned community programs. However, as a result of lack of overall community awareness, interest, or empathy, sometimes supportive groups in other cities and accessible online resources are the most that can be provided for individuals with dementia (Administration for Community Living, 2019; North Carolina Department of Health and Human Services, n.d.).

Another program which provides accommodations is the Purple Table initiative. This program provides an environment of advocacy and encourages community partnership for dementia awareness and integration. The Purple Table is a training program utilized to create more conducive environments in restaurants for those who have dementia and other various cognitive conditions (Purple Tables, 2017). Various restaurants that register to be a part of the Purple Table project undergo specific training to learn effective forms of communication,

empathy, understanding, and patience in order to meet the unique needs of clients who have dementia as well as their families and/or caregivers (Purple Tables, 2017). Additionally, registered restaurants provide numerous accommodations for the clientele such as a quieter table, additional attention, extended service time, a table closer to the restrooms, and so forth (Purple Tables, 2017). When the employees within a participating restaurant have been effectively trained, families can make a Purple Table reservation for a comfortable and enjoyable experience which may otherwise be challenging, frustrating, and overwhelming in another establishment (Purple Tables, 2017).

Dementia-friendly communities. Dementia Friendly America (DFA) is a national leader for implementation and creation of social and community support for people living with dementia (Dementia Friendly America, 2015). Since its inception, DFA has led the way for the creation of dementia friendly communities. Dementia-friendly communities aim at counteracting the social and communal isolation that individuals with dementia experience through specific communities that provide support for the individual with dementia (Caregiving MetroWest, n.d.). As a result of the progressive and debilitating nature of dementia symptoms, individuals diagnosed have been seen to withdraw from the community as the condition progresses (Alzheimer's Association, 2019b). The communities are specific villages, towns, or cities that foster and promote quality of life for the individual with dementia through continuous education about dementia and the promotion of dementia awareness (Dementia Friendly America, 2015). Dementia-friendly communities provide safe and informed spaces that help individuals diagnosed with dementia flourish in the community. These communities involve several different community settings: banks, law enforcement centers, employers, health care centers, local restaurants, libraries, etc. (Dementia Friendly America, 2015). Communities that utilize the

dementia-friendly model focus on four aspects of intervention: improving social inclusion for those who are diagnosed with dementia, challenging the stigma in society towards those diagnosed with dementia, improving dementia care and services, and promoting awareness (Alzheimer's Disease International, 2019). Globally, there has been an initiative to create dementia-friendly communities in several different areas, specifically North America and the Netherlands (Swaffer, 2014).

In North America, the Minnesota Model is a movement to create dementia-friendly communities (Caregiving MetroWest, n.d.). The team members and researchers were able to utilize the already existing, albeit limited, community-based services and programs for individuals with Alzheimer's disease (Caregiving MetroWest, n.d.). Researchers utilized the DFA model and focused on creating a community-wide approach in which everyone within various businesses were trained, informed, and aware of appropriate ways to interact with individuals who have dementia (Caregiving MetroWest, n.d.). The people were also encouraged to be respectful towards individuals with dementia, as well as families and caregivers. In this community-wide educational program, community members learned ways in which dementia and Alzheimer's disease are socially isolating for both the individual diagnosed and family members (Caregiving MetroWest, n.d.). This is due to the experiences of feeling embarrassed in community and the subsequent preference to stay home in order to avoid the pressure of having to explain behaviors to a community that does not understand or accept dementia symptoms (Caregiving MetroWest, n.d.). This project further extended the awareness by explaining how the increase in social isolation and frustration within caregivers further increases the potential for depression (Caregiving MetroWest, n.d.).

On a global level, the Netherlands have attempted to identify and combat these very personal issues and the lack of visibility, activism, and inclusion for caregivers as well as persons with dementia (Holland et al., 2017). The Netherlands have a dementia-specific village that attempts to remedy the isolation that people with dementia experience. The village is designed so that individuals diagnosed with dementia can live in a familiar setting that reflects personal style. The residents that live in these villages are also placed near other individuals who have similar interests, further reflecting a typical community setting. The village is equipped with stores, pubs, gardens, and other establishments (Holland et al., 2017). The residents are able to walk around and participate in these community establishments as well, and are encouraged to do so. The village also employs over 200 individuals trained on how to effectively and appropriately interact with individuals who have dementia. The Netherlands also has living facilities for individuals 55 and up, called Apartments for Life, that are designed to accommodate aging individuals over time in order to help these individuals remain in the home. The apartments are designed with wheelchair and stretcher accessibility, room for medical equipment, and furniture that can be adjusted to aid in activities of daily living (eating, dressing, bathing, etc) for older adults and adults with dementia.. Some apartment complexes incorporate childcare facilities and restaurants to promote community interactions for the residents (Holland et al., 2017). Another example of how the Netherlands is pronounced in the area of dementia awareness within the community is through the existing elder care facilities. Staff in some facilities provide in-home services to individuals in the community, and select facilities even provide day care services to those with dementia. Other facilities are often built very close to each other and allow the residents to dine and freely interact with individuals in the adjacent facility. The effect that this village has had on the Netherlands has been impactful. Community members reported lower

rates of depression, anxiety, and an overall increase in perceived health. Community members also improved in scoring on memory and attention enough that it has created a rise in interest in other countries, such as Switzerland and Germany (Holland et al., 2017). These findings further support the idea of increasing social support in the community for individuals with dementia. It provides strong validation for the implementation of dementia friendly communities, increases access to care, and the necessity of further interventions for this vulnerable and at risk population.

Through the implementation of dementia villages and promoting overall communal inclusion and awareness for dementia, the residents are offered a sense of normalcy and dignity that has not been previously emphasized in other countries (Holland et al., 2017). The Netherlands provides a revolutionary way to promote awareness and holistic wellness for those with dementia. This approach to care has the potential to change the lives of many individuals around the globe (Holland et al., 2017). Utilizing the DFA model, the trainings and accommodations of the Purple Table reservations, and implementing the skills and resources learned from the Netherlands and other similar dementia friendly communities, communities all across the globe can create more dementia aware communities that embraces and advocates for the needs of people with dementia while furthering community understanding on the purpose and value that these individuals have within the community (Purple Tables, 2017; Rahman & Swaffer, 2018).

Lack of Community Awareness and Intervention for Dementia

Despite the existing community outreach programs nationally and internationally in North Carolina, Oregon, Colorado, Massachusetts, and the Netherlands, a great need exists for further awareness and structured interventions throughout the entirety of the United States

(Bartolo et al., 2010). There is a lack of community-wide approaches that aim to support individuals with dementia and their corresponding caregivers. These individuals continue to have fear and anxiety when entering into different community settings based on fear of rejection, perceived feelings of shame, and beliefs about discrimination (Abdollahpour et al., 2015; Adefila et al., 2016; Bekhet & Avery, 2018; Hepburn et al., 2003; Lang & Fowers, 2019; Morris et al., 2018; Tay et al., 2016; Teri et al., 2005; Vachon, 2016). Community psychology offers a way for these individuals to exist as a part of the community without the fear of rejection or isolation, the lack of understanding from others, or overall embarrassment (Caregiving MetroWest, n.d.). Programs like the GIA outreach initiatives are specifically created in order to fill the gaps in research related to Alzheimer's disease and dementia, caregiver services, and community awareness that are often neglected by state and federal government (Reddy et al., 2015). Efforts are made to increase health information literacy as well as the overall quality of life for families (Howrey, 2018). These types of educational and intervention efforts can be applied to all marginalized and discriminated members of the mental health community. This is especially of interest due to the increasing population around the world being affected by dementia-related diagnoses (Centers for Disease Control and Prevention, 2018b).

While organizations directed at increasing awareness about Alzheimer's in the United States exists, civic engagement and awareness in the community lack for individuals with dementia and/or caregivers within these programs (Jennings et al., 2016). Many communities embrace a youth-centered society (Lytle & Levy, 2017). Therefore, being more understanding of disabilities and diseases that affect younger people is more likely than that of older people, especially older people with dementia. Lytle and Levy (2017) attempted to measure undergraduate and community attitudes about older people and measure the effects of

psychoeducation and exposure on these attitudes in two experimental studies. The researchers implemented an online study that assessed the attitudes of the participants using the Positive Education about Aging and Contact Experiences (PEACE) model through the following measures: attention and mood checks; ageism measures; positive and negative age stereotypes; feeling thermometer; aging anxiety; anxiety about interacting with older adults; behavioral intentions; anti-age discrimination petition; aging knowledge; and demographics. Participants in all experimental conditions reported decreased negative attitudes towards older adults and increased aging knowledge at the end of the study. The study implies that in order to decrease ageism in the future, it is important to challenge inaccurate information about older adults as well as to increase factual knowledge about them. This study and the PEACE model could be applicable to other populations as well as other disorders through an online or in-person means of providing education and exposure (Lytle & Levy, 2017). Educating the community and exposing the community to older adults, especially those with dementia, have been identified by caregivers and persons with dementia as a way to increase their quality of life (Jennings et al., 2016).

Goals for care and quality of life have been identified by individuals with dementia and their caregivers. Jennings et al. (2016) set out to identify these goals. Five focus groups of 43 participants including 7 individuals with dementia and 36 caregivers were interviewed for the research. Five domains of care were identified by the participants including: medical, physical quality of life, social and emotional quality of life, access to services/support, and caregiver support (Jennings et al., 2016). Among these domains there were specific goals identified by caregivers and people with dementia separately. Caregivers identified that ensuring the safety of the person they provide care for as well as managing the stress that accompanies caregiving are

two of the most universal goals (Jennings et al., 2016). Persons with early stage dementia identified that meaningful activities were of importance to them, such as having a job and being included in family gatherings. Both groups identified the need to revise the goals as the disease progresses. Additionally, these goals must be customized for each person and their specific needs (Jennings et al., 2016). A variety of settings should thus attempt to learn about and integrate these self-identified goals into the care provided for this population (Jennings et al., 2016).

Although various services are provided to caregivers and care recipients from individual domains, a lack of interpersonal connection and communication is evident between different professions such as social workers, local and federal government agencies, and health care professionals (Howrey, 2018). Research indicates that local health sciences librarians may be potential liaisons for promoting awareness of this division as they provide advocacy, resources, and education in community outreach for caregivers and care-receivers (Howrey, 2018).

According to Howrey (2018), health sciences librarians have the ability to collaborate with various forms of healthcare professionals, universities, researchers, and local agencies in order to create community outreach connections to family caregivers. Utilizing these potential partnerships with local community establishments and agencies as well as government officials, medical librarians can provide recommendations and resources for family caregivers and care recipients (Howrey, 2018). This can be done by implementing outreach programs and creating accessible in-house libraries and online resources (Howrey, 2018).

One form of existing community advocacy provided is the Care Corps Demonstration Act of 2017, which places volunteers within local communities to work with older adults who have variations of mental disorders and disabilities who need assistance in living independently (Howrey, 2018). Another is the RAISE Family Caregivers Act of 2017 House bill which grants

the secretary of the Department of Health and Human Services the ability to develop a national strategy for supporting family caregivers (Howrey, 2018). The idea behind this form of advocacy is to provide support to family caregivers and create more awareness within the community by formulating recommendations and specific community outreach activities annually (Howrey, 2018). The resource building consisted of creating web pages that are easily accessible and simple to navigate. These websites would have local community resources for services catered specifically for caregivers of older adults and the care recipients with various disabilities (Howrey, 2018). Additionally, the websites contain links to online articles related to health care and social service professionals (Howrey, 2018). The advocacy and resources provided to family caregivers supplies them with education about local outreach and awareness programs which celebrate, praise, and validate their experiences as well as their role as caregivers. Health sciences librarians have the ability to utilize National Family Caregivers Month in November to develop local community educational training programs for caregiver support groups such as AARP TEK Careversations workshops and Today's Caregiver Fearless Caregiver Conferences (Howrey, 2018). Health sciences librarians assess the particular needs of caregivers and older adults by conducting surveys throughout local communities, updating and improving family caregiver education websites, creating local workshops, and reviewing the existing health sciences literature to fill the gaps (Howrey, 2018).

Howrey (2018) noted how health sciences library program development would be most effective and well implemented in local community groups. This is because networking within local communities expedites the learning process for the librarians and provides insight into the existing gaps and available resources which heavily impact the quality of care for caregivers and care receivers. Further, it allows various members of the community to come together and serve

others in a mindful and empathetic way. Howrey (2018) further suggested the most crucial aspects which must be considered when working with family caregivers. These suggestions include respect of the caregivers and care receivers, timely coordination and integration of care, providing all necessary information and education, physical comfort, emotional support, involvement of community, continuity and consistency, as well as overall accessibility to services (Howrey, 2018). Thus far most research is targeted at caregiver well-being. Caregivers are significantly impacted by the isolation and lack of resources in the community which in turn creates significant negative impacts for individuals with dementia themselves (Vasileiou et al., 2017).

Impact of the Challenges of Caregiving on the Community

The symptoms associated with early, middle, and late stages of dementia increase in severity as the diagnosis of dementia worsens in the individual (Song et al., 2018). The progression of dementia creates challenges in day-to-day living for the individual with dementia, which in turn impacts the caregiver as well as the community in which these individuals reside. As the dementia symptoms develop, daily activities become difficult to perform and complete successfully without outside assistance or help of any kind. Activities of daily living (ADLs) are specific activities that are conducted everyday in order for an individual to function (Jutten et al., 2019). These activities include bathing, dressing, grooming, eating, mouth care, and toileting. The progressive clinical course of dementia hinders these activities as a result of intense cognitive and noncognitive decline (Jutten et al., 2019; Song et al., 2018). ADLs slowly become more difficult to complete as those with dementia decline over time, beginning with little challenges at first and eventually progressing to an inability to complete or perform any ADLs.

Necessary tasks such as washing hair, getting dressed, or wearing a jacket in cold weather are all ADLs that an individual with dementia might forget as the disease progresses. Those diagnosed with dementia develop a vital need for a caregiver due to the challenges associated with the disease.

The challenges specific to providing care to an individual with dementia fall into the categories of social and psychological. Regarding the social aspect of caregiver strain, one's relations with family, friends, and coworkers can potentially shift and lead to a sense of isolation within the home as well as within the community (Abdollahpour et al., 2015; Bejjani et al., 2015; Flasbeck & Brüne, 2019; Hepburn et al., 2003; Kuo et al., 2014; Lee et al., 2017). Psychological challenges include social withdrawal from family, friends, and the community, lack of time available to reach out for social support, and feelings of loneliness as caring for the person with dementia becomes more demanding (Vasileiou et al., 2017).

Social challenges. It is not uncommon for family members of an individual with dementia to feel angry about the diagnosis, to feel guilty about not being able to provide better care, or to feel as if a loved one is being taken or is separate from the family (Dauphinot et al., 2015). Given that care for an individual with dementia is most often provided by a spouse or adult child (Schulz & Martire, 2004), these aforementioned feelings can lead to the caregiver becoming estranged from their social support system, the rest of the family, and the community entirely (Mitrani et al., 2006). This shift in dynamics can increase caregivers' burden, stress levels, frustration, and rates of depression (Qualls, 2016; Scharlach et al., 2006; Semple, 1992; Sörensen et al., 2006; Strawbridge & Wallhagen, 1991; Tay et al., 2016; Tremont et al., 2006; Trujillo et al., 2016; Yu et al., 2018). In turn, this shift has been seen to create mental and emotional trauma for the caregiver (Liu et al., 2015; Nam, 2016; Takai et al., 2009; Truzzi et al.,

2012). Furthermore, caregivers also report that the quality of care provided is impacted to the individual with dementia as well as a reported impact on the overall quality of life and emotional well-being for the individual with dementia (Dauphinot et al., 2015; Elnasseh et al., 2016; Lieberman & Fisher, 1999; Scharlach et al., 2006). Oftentimes, these families have little knowledge and understanding of the disease as it begins to manifest, which is also reflected within the communities (Liu et al., 2015; Nam, 2016; Takai et al., 2009; Truzzi et al., 2012). Without outside support, resources, advocacy, or education from the community, the family and the individual with dementia can feel isolated and lost.

Due to the absence of dementia awareness and education within the community, caregivers and the individual with dementia may lack the opportunity to advocate for personal mental health and well-being (Chattillion et al., 2013; Hepburn et al., 2003). If these individuals feel socially withdrawn and separated from society, education on dementia and increasing dementia awareness becomes challenging. Understanding the signs and symptoms that can accompany dementia, such as depression and anxiety, further aid the understanding of the disorder in general (Yu et al., 2018). Additional research found a limited comprehension of the impact of depression among caregivers, the individual with dementia, and the community (Cheng et al., 2017; Lee et al., 2017). The limited awareness of what an individual with dementia endures can negatively impact the quality of care provided and can lead to the isolation of both the caregiver and the individual with dementia and can lead to burnout (Takai et al., 2009).

Psychological challenges. Caregiving places a psychological toll on caregivers, and little research has been conducted on finding ways to reduce this burden that could also serve to reduce the overall mental health concerns of the caregiver (Liu et al., 2008; Weisman de Mamani et al., 2018). This is another area in which community education is imperative; however,

research is lacking in its identification of caregivers of individuals diagnosed with dementia and the feelings of isolation and withdrawal that are experienced. The few studies that have been conducted reveal that loneliness and isolation are frequent factors associated with the caregiver's life (Mark, 2016; Sherman et al., 2013; Vasileiou et al., 2017). Specifically, loneliness is characterized by a negative experience that takes place when an individual's social network and relationships are deficient or lacking in some way. This can occur in two forms: emotional loneliness or social loneliness (Vasileiou et al., 2017). A caregiver's social network as well as the social connections in life tend to decrease as the symptoms of dementia progresses and increases in the individual diagnosed with dementia. Social and emotional loneliness can negatively impact the caregiver and have been seen to impact higher order cognitive processes for the caregiver (Cacioppo & Hawkley, 2009). As caregivers become more lonely, isolation develops as the caregivers begin to lack time and fail to reach out for social support and contact. While this occurs, coping skills decrease as stress levels increase in the life of the caregiver, and researchers have observed symptoms similar to depression manifest and worsen as time passes and as the disease progresses (Cacioppo & Hawkley, 2009; Song et al., 2018). Readily available community support groups could aid in alleviating the social and emotional loneliness that is experienced. Additionally, these support groups could also serve as an educational resource for individuals within the community to learn more about dementia and the challenges associated with providing care to an individual with dementia.

As indicated in the research, a significant lack of time is devoted towards caregiver self-care (Abdollahpour et al., 2015; Bekhet & Avery, 2018; Lang & Fowers, 2019; Tay et al., 2016). Many aspects of the caregiver's personal well-being are negatively impacted by the demands of their position. A few of the potential effects associated with these demands include stress,

depression, and anxiety (Heponiemi et al., 2006). Research shows that fewer daily stressors result in fewer emotional fluctuations (Heponiemi et al., 2006). These are all effects that could potentially be lessened by more readily available support groups, resources, and education about dementia.

When caregivers are not mindful of their own care and well being, they lack an ability to recognize the potential risks and various stressors which may negatively impact their physical, emotional, and psychological health (Adefila et al., 2016; Hepburn et al., 2003; Morris et al., 2018; Teri et al., 2005; Vachon, 2016). One such experience that caregivers are at an increased risk for is burnout. Caregiver burnout is a common phenomenon that occurs as a result of experienced strain without the opportunity for recovery, and it can result in lasting physical, mental, and emotional impacts (Centers for Disease Control and Prevention, 2019; Takai et al., 2009; Truzzi et al., 2012). Constantly being in the role of a caregiver leads to caregiver burnout when no perceived level of communal or societal support is available. Burnout can increase the risk of depression, decrease overall satisfaction with life, and lead a caregiver to losing their sense of self (Centers for Disease Control and Prevention, 2019; Dauphinot et al., 2015; Heponiemi et al., 2006; Liu et al., 2015; Sørensen et al., 2006; Takai et al., 2009; Truzzi et al., 2012). This is yet another area that could be aided with the greater availability of community support groups, resources, and education about dementia.

Research has shown a negative association between empathy and burnout among professional caregivers (Wilkinson et al., 2017). Empathy is the ability to share and understand another individual's feelings while also keeping an objective outlook (Flasbeck & Brüne, 2019). Compassion and empathy are the basis of caregiving but have been found to be lacking in the care of older adults in part due to burnout (Vachon, 2016; Wilkinson et al., 2017). This may lead

to compassion fatigue and decreased empathy in caregivers (Vachon, 2016). Training programs may be able to help caregivers and those who work with the older population develop new ways of coping with empathy distress and compassion fatigue (Flasbeck & Brüne, 2019; Pulsford et al., 2016; Vachon, 2016). Additionally, training and educational programs for the community could be vital to increasing the empathy that community members feel towards individuals with dementia and their caregivers.

Increasing Mental Health Awareness in the Community

Community psychology focuses on the impact of social, cultural, environmental, and other factors that have the ability to promote positive changes, health, and environment on individual and systemic levels (Society for Community Research and Action, 2019a). Community psychology utilizes varying means of increasing awareness and prompting discussions about mental health. One way this is accomplished is through the use of devoting specific months out of the year to mental health awareness (National Alliance on Mental Illness, 2019a; Society for Community Research and Action, 2019b). The month of November was dedicated to the awareness of Alzheimer's by Ronald Reagan in 1983 (Centers for Disease Control and Prevention, 2018b). During that time, there were less than 2 million people living with the disease whereas today, approximately 5.8 million people are living with Alzheimer's (Centers for Disease Control and Prevention, 2018b; Senior Living, 2018). Devoting months to promoting awareness of mental health does not directly impact the prevalence of growing diseases such as Alzheimer's, but it does function to raise community awareness through fighting the stigma associated with mental illnesses (National Alliance on Mental Illness, 2019b). This can be accomplished through talking about mental illnesses, discussing the importance of

education on mental illness and symptoms to look for, and advocating for policies that promote equality for individuals with mental illnesses (National Alliance on Mental Illness, 2019b).

Community education about different populations of people that are afflicted with mental illness is vital in order to promote understanding and differences within the community. Change has been seen to be most effective at the communal level and reaches a significantly greater amount of people when compared to individualistic frameworks (Society for Community Research and Action, 2019b; Townley et al., 2018) This may also aid in community cohesion and the well-being of those in the community who once felt less understood (Stivala, 2017). This lends credence to the importance of strengthening the sense of community while still respecting and acknowledging diversity within the community (Stivala, 2017). Few programs have combined education of dementia within the community along with interventions to promote continuous awareness and empathy for the population.

Interventions for Empathy Building and Dementia Awareness in Communities

Interventions exist in order to train specific parts of the community to think beyond treatment and some employ empathy building skills where they may be lacking. However, most existing interventions focus on increasing the skills, knowledge, and confidence of the caregivers specifically (Adefila et al., 2016). They also have the ability to decrease depression and caregiver burden. These interventions include various types such as virtual reality empathy building programs as well as psychoeducational programs to increase the knowledge and skill base for people interested in learning about dementia (Adefila et al., 2016; Hepburn et al., 2003; Teri et al., 2005). These types of studies could be expanded upon in order to extend past the caregiver and attempt to address increasing awareness, empathy, and skills for members of the community regarding dementia.

One such intervention used is a virtual reality (VR) simulation that aims to increase empathy levels regarding the experiences of persons with dementia (Adefila et al., 2016). The researchers worked alongside experts in the field of treating dementia in order to develop ways to simulate age- and dementia-related impairments through the use of VR. The goals of the study were to increase awareness, empathy, and reflection on how the participants had dealt with people with dementia in the past (Adefila et al., 2016). Most VR simulations are used as a way to increase skill base for the user; however, this study was unique in that it was used to increase empathy and evaluate the interpersonal effects of a disease. The experience consisted of wearing the VR headset that placed the user inside of an apartment (Adefila et al., 2016). Participants were told to look around and complete daily tasks they came across; however they may find that when looking in the fridge for milk to make coffee, it was not there during their initial exploration, but that it had appeared after a second look. These types of situations were presented in order to make the participant question their memory and competence (Adefila et al., 2016). The virtual reality experience simulated glaucoma, cataracts, and hearing loss to further develop the genuineness of the experience from the eyes of a person with dementia. The results of this study showed improved awareness of the experiences of persons with dementia as well as increased empathy and a reflection on the clinical care that the participants had experienced with the population in the past (Adefila et al., 2016). While this study examined the reactions of students, it could be very helpful in increasing the empathy that caregivers have for persons with dementia as well as members of the community at large. However, the long term effectiveness of interventions lacks clear evidence (Adefila et al., 2016).

The Savvy Caregiver Program (SCP) is another psychoeducational program for caregivers. The goal of the program is to provide caregivers with a training program that could

be offered by a variety of organizations (Hepburn et al., 2003). This program is a prototype of a workshop that would educate family members on the transition into the caregiving role (Hepburn et al., 2003). The SCP consists of a training manual and a caregiver's manual (Hepburn et al., 2003). The training manual aids the program facilitator in the following ways: setting the tone for training, leading different exercises, and assigning homework for participants to complete. The caregiver's manual was designed to follow the curriculum of the workshop (Hepburn et al., 2003). The initial field test of the program was conducted in conjunction with the Alzheimer's Association in which they helped to recruit volunteers to facilitate the SCP (Hepburn et al., 2003). This test served to analyze the effectiveness of the SCP and allow for revisions (Hepburn et al., 2003). The second field test was a quasi-experimental design that included three sites, and recruited volunteers to serve as participants who were affiliated with their respective site. The second field test consisted of 22 SCP programs (Hepburn et al., 2003). The main finding of this study was the ability to turn a research-based intervention into a program that can be easily adopted into a variety of settings (Hepburn et al., 2003). Overall, this program aids new caregivers in adjusting to their roles by providing them with the skill sets and attitudes needed to handle their new responsibilities.

Resources including community consultants set out to address the needs of caregivers and individuals with dementia. Teri et al. (2005) examined how community consultants could be utilized to assist caregivers in problem-solving and support them in improving communication, mood, and support. This program is otherwise known as the STAR-C program. Clinical supervisors met the caregivers, who were a part of the experimental group, in their homes for an eight week period of time. The first three weeks were devoted to psychoeducation and developing a behavior-management plan (Teri et al., 2005). The latter weeks were devoted to

improving communication and enhancing caregiver support. The control group received routine medical care that included crisis intervention (Teri et al., 2005). No behavior management training was provided, and participants received only advice from physicians and nurses. As a result of the STAR-C program, burden, depression, and reaction to caregiver recipient behavioral issues all decreased (Teri et al., 2005). This implies that the use of consultants in the community could help to implement interventions that could increase the well-being of family caregivers and their care receivers (Teri et al., 2005). These studies serve to solidify the need for communal resources, empathy, and support for people with dementia and in turn their caregivers.

Validation Theory

Validation is one such theory that has been shown to be effective when used by caregivers to foster more effective communication among caregivers and persons with dementia (Feil, 1993a). Introducing validation theory offers the general community a new perspective about dementia awareness and education. This has the potential to ensure that the community is equipped with the skills to effectively communicate with a person with dementia. Additionally, validation can assist and help the person with dementia feel that they are being understood within the social and community context, further decreasing the feeling of being discriminated against or stigmatized for the disease.

Validation is an attitude, a theory, and a method that attempts to address empathy building in caregivers (Feil, 1993a). The attitude promotes acceptance and non-judgment on the part of caregivers of persons with dementia. Feil's theory addresses the fact that all older adults have unfinished business and proposes a method of communication that allows them to express themselves and to feel heard (Feil, 1993a). In promoting communication between caregivers and persons with dementia, caregivers can establish empathy through listening. This theory is used in

order to further develop caregiver empathy with a person who has dementia through the facilitation of communication and listening (Feil, 1993b). For professional caregivers, validation can also reduce frustration and burnout while increasing joy and job satisfaction. For familial caregivers, validation can decrease frustration, increase communication, lead to an interest in the improvement of the person with dementia, and promote self-awareness (Feil, 1993a). Validation allows for the person with dementia to gain purpose and control over their lives while also being able to express their painful feelings. Individuals with dementia often experience sadness, frustration, anger, withdrawal and isolation, all of which make it of the utmost importance to improve their lives and the lives of their caregivers, giving them every opportunity to give purpose and control to persons with dementia and their caregivers (Feil, 1993b). Validation ensures the person with dementia is being heard and understood and that their needs are being met. The goal of validation is to recognize and accept the feelings of individuals with dementia and acknowledge their losses and needs. This is accomplished by restoring social roles, facilitating well-being, and stimulating interactions with others (Feil, 1993b).

Validation facilitates communication between caregivers and individuals with dementia and prompts caregivers to think beyond treatment (Adefila et al., 2016). After the implementation of validation, individuals with dementia showed signs of being confirmed and increased well-being while caregivers developed better communication skills with increased quality and quantity of the interactions (Teri et al., 2005). This can be achieved in a number of ways and can even be tailored to the type of dementia the individual is suffering from. Techniques such as centering, using non-threatening and factual words, rephrasing, utilizing direct and prolonged eye contact, and using a low, loving tone may all be employed (Feil, 1993a). All techniques involved in validation can be used as a framework for teaching members

of the community how to interact effectively with persons with dementia. This could increase meaning and purpose for the individual with dementia as well as decrease stress and burden that caregivers experience. However, most existing studies focus on implementing validation with paid caregivers.

Communication can be difficult between paid caregivers and individuals with dementia when proper training is lacking. An existing study on validation evaluated the communication between nurses and persons with dementia in a nursing home (Söderlund et al., 2016). The study encompassed a naturalistic design that evaluated the conversations between nursing staff and persons with dementia (Söderlund et al., 2016). The study was part of a one year validation method implementation program in various nursing homes in one Swedish city (Söderlund et al., 2016). The study included four persons with dementia and four nurses whose conversations were videotaped and analyzed for the use of the validation method (Söderlund et al., 2016). The analysis of the video tapes showed that when the nurses were able to support and validate the individual with dementia, the individual's well being and ability to converse increased (Söderlund et al., 2016). The reciprocity in communication led to a better established relationship between the nurse and the person with dementia (Söderlund et al., 2016). It also increased the compassion that the nurses had for their role in the patients' lives (Söderlund et al., 2016). This study highlights the need for the implementation of methods such as validation in order to promote the well being of both caregivers and persons with dementia (Söderlund et al., 2016). It is also one of very few studies that highlights the use of or need for the implementation of validation as a whole.

Increasing the effectiveness in communication between paid caregivers and care receivers through education has continued to be effective in improving the well-being of both individuals.

Morris et al. (2018) examined how a communication method similar to validation could be taught to nursing aides in a nursing home to improve the well-being of both the residents and the aides. The participants of the study included 24 nursing aides and 26 residents of a nursing home in the Netherlands specifically for individuals with dementia. The intervention lasted a total of eight weeks. The nursing staff in the experimental group were taught to use short, general instructions, biographical statements, and positive speech while interacting with the individuals with dementia (Morris et al., 2018). These are all communication skills that have been shown to be effective when communicating with individuals with dementia. Members of the nursing staff were then observed by two raters and given feedback on the quality of their communication skills (Morris et al., 2018). After the 8 week intervention, the aides were assessed for the second time on quality and quantity of instructions as well as speech and caregiver distress. Residents were assessed for agitation and psychopathology (Morris et al., 2018). The intervention decreased caregiver distress as well as the severity of the psychopathology of the residents. The intervention also resulted in an increase in the quality and quantity of communication itself which resulted in increased well-being for the aides and residents involved (Morris et al., 2018). Overall, it is clear that an intervention based in validation-type practices can be helpful for improving the lives of not only those with dementia but their caregivers as well (Morris et al., 2018; Söderlund et al., 2016).

The effectiveness of using validation with caregivers and individuals in the health professions has been seen and found to be effective on a large scale (Morris et al., 2018; Söderlund et al., 2016). It is of further interest to explore the extent that validation can influence and impact the community. Validation offers a means of education, theory, and technique that focuses on using empathy with a vulnerable and at risk population. Applying validation to

community settings and offering training in it can potentially create a more welcoming and empathetic environment for individuals diagnosed with dementia. Furthermore, by teaching the community how to effectively utilize validation techniques and communicate with individuals with dementia can increase inclusivity of communities.

Conclusion

Dementia is a neurodegenerative disorder that affects older adults physically, cognitively, and behaviorally. It is more progressive and affects older adults more severely than the normal aging process (Alzheimer's Association, 2019c). Due to these effects, persons with dementia commonly need caregivers in order to accomplish their activities of daily living and maintain quality of life (Centers for Disease Control and Prevention, 2018a). It is clear that being the caregiver of a person with dementia can be taxing on the well-being of the caregiver (Nam, 2016). Caregivers are responsible for the health and safety of the person with dementia as well as ensuring that their needs are being met ((Abdollahpour et al., 2015; Bejjani et al., 2015; Flasbeck & Brüne, 2019; Hepburn et al., 2003; Kuo et al., 2014; Lee et al., 2017)). Burnout and empathy fatigue occur when excessive strain is placed on the caregiver including lack of emotional and financial support (Wilkinson et al., 2017). Strain is further added on the relationship between the caregiver and the person with dementia in regard to how they interact and communicate with one another ((Abdollahpour et al., 2015; Bejjani et al., 2015; Flasbeck & Brüne, 2019; Hepburn et al., 2003; Kuo et al., 2014; Lee et al., 2017)). This can result in empathy fatigue on behalf of the caregiver and decrease their compassion for the person with dementia. This will in turn have a negative effect on their ability to communicate and relationship as a whole. Strain can also lead to high levels of depression, a loss of sense of self, and a decreased quality of life (Liu et al., 2015; Nam, 2016; Takai et al., 2009; Truzzi et al., 2012).

A significant amount of research exists in the field regarding different types of interventions aimed at providing the best possible types of care for individuals with dementia (Adefila et al., 2016; Feil, 1993a; Hepburn et al., 2003; Teri et al., 2005). Additionally, past research shows a clear lack of interventions that deeply involve a community understanding of dementia as well as how to interact with persons with dementia and their caregivers. Without community support, understanding, and empathy towards dementia, both caregivers and individuals with dementia feel socially isolated, unheard, and rejected (Jennings et al., 2016). Numerous studies in other countries as well as some states in the United States have aimed to create more effective care for this population; however, none thoroughly involve educating the community and giving them an opportunity for hands-on experience interacting with persons with dementia and their caregivers (A Place for Mom, 2019; Caregiving MetroWest, n.d.; Oregon Department of Human Resources, n.d.).

Although interventions are available to caregivers to promote empathy and increase quality of life, a lack of understanding from the community towards individuals with dementia is prevalent. This is due to the lack of educational resources available, and the risk factors that contribute to negative health of caregivers and individuals with dementia are numerous (Chattillion et al., 2013; Hepburn et al., 2003). There have been gaps identified in existing training interventions for caregivers. Specifically, a need exists to alleviate the feelings they have of burnout and empathy fatigue as well as a need to improve the quality of life for the person with dementia. Additionally, it is noted that basic communication skills between caregivers and the person receiving their care need to be addressed and improved in order to accomplish these goals (Chattillion et al., 2013; Hepburn et al., 2003; Morris et al., 2018; Teri et al., 2005; Vachon, 2016). A need also exists for more structured programs to provide education and

empathy building opportunities to caregivers who often have little formal education (Adefila et al., 2016; Hepburn et al., 2003; Teri et al., 2005; Vachon, 2016). Finally, the lack of community support and understanding for caregivers and persons with dementia should also be addressed.

Validation theory addresses the need for an intervention that places importance on communication (Feil, 1993a). This method seeks to improve communication between members of the community and the person with dementia while striving to fulfill the needs of both. The theory allows community members to develop more empathy and the person with dementia to feel accepted and for their needs to be met. However, few independent studies have been found on the use of validation. Even fewer studies exist which assess how validation methods influence the effectiveness of communication between community members and the person with dementia. This leads to a lack of understanding in how the method can be effective for both the person with dementia as well as the community. There appears to be a lack of research on the implementation of validation techniques in a community setting with the goal of alleviating burden on caregivers and/or increasing the quality of life for the individual with dementia (Adefila et al., 2016; Hepburn et al., 2003; Teri et al., 2005). The researchers identified numerous studies on the subject that take place in nursing homes, assisted living facilities, and hospitals with paid or family caregivers (Morris et al., 2018; Söderlund et al., 2016; Sprangers, Dijkstra, & Romijn-Luijten, 2015). However, the researchers were unable to find studies on implementing a validation intervention in the United States that would be geared towards increasing knowledge about and interactions with people who have dementia and their caregivers in a community setting. This is a gap in the literature and therapeutic practice that has been neglected, as this type of intervention can positively impact the experiences people with dementia have while interacting within the community. Additionally, this type of intervention could potentially ease

the burden caregivers experience and combat the isolation experienced by individuals with dementia.

The current study aims to fill the gap in previous research about dementia and community understanding as well as exposure and involvement with individuals who have been diagnosed with dementia. The current study also aims to teach validation, a technique for interacting and communicating with persons with dementia, to small business employees to potentially increase their social comfort towards and understanding of persons with dementia, with the hopes of ultimately increasing empathy for this population. The study seeks to provide intervention in the lives of the community, specifically with employees in the community, through the use of a virtual reality experience of dementia and education on validation. The researchers hypothesized that through intervention and education, knowledge about dementia would be increased in the community. Researchers also hypothesized that through intervention and education, social comfort towards persons with dementia would be increased within the community.

Chapter Three

Methodology

Participants

The participants in the current study were employed at a local coffee shop and served as the main subjects of the study. There were 11 total participants in the current study. Of the 11 participants, there were 8 (72.7%), 2 (18.2%) male, and 1 declined response. Ages ranged from 21 to 69 ($M=33.30$, $SD=18.63$). Years participants have been employed at the coffee shop ranged from 1 to 4 years total ($M=2.10$, $SD=1.10$). Seven employees identified that they had a member of their immediate family diagnosed with dementia, 4 identified that they did not have an immediate family member diagnosed with dementia. Two employees identified that they had a close acquaintance who has been diagnosed with dementia while 9 indicated that they did not have an acquaintance diagnosed with dementia. However, of these 11 participants, there was a drop out of 6 individuals, leaving a total of 5 employee members that completed all the required pre and post test measures.

The current sample size consisted of 4 (80%) females and 1 (20%) male. Ages ranged from 22 to 44 ($M= 26.606$, $SD= 9.737$). Years participants have been employed at the coffee shop ranged from 1 to 2 ($M= 1.60$, $SD= .548$). Two employees identified that they had a member of their immediate family diagnosed with dementia. One employee reported having an acquaintance with dementia. A group of caregivers and individuals with dementia from a local senior center were invited to receive services from the coffee shop following the implementation of the intervention. It is unclear how many caregivers and individuals with dementia were able to volunteer their time to receive services due to the COVID-19 pandemic. The manager of the

senior center reported that it is likely that at least two sets of caregivers and individuals with dementia were able to visit the coffee shop prior to the end of the study.

Measures

Dementia Attitude Scale. The Dementia Attitude Scale (DAS) is a 20-item scale with a two factor structure, each item is rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree) (O'Connor & Mcfadden, 2010). The measure assesses two separate factors: dementia knowledge and social comfort towards individuals with dementia. Questions 3,7,10,11,12,14,15,18,19, and 20 specifically assess levels of Dementia Knowledge. Dementia knowledge is assessed through these series of questions examining three levels of attitude: affective, behavioral and cognitive components towards dementia (O'Connor & Mcfadden, 2010). Questions 1,2,4,5,6,8,9,13,16, and 17 assess social comfort towards individuals with dementia. O'Connor and Mcfadden argue that the construct of social comfort can be assessed as a possible precursor to empathy towards individuals with dementia as it reflects the individual's ability to understand and share the feelings of an individual diagnosed with dementia (O'Connor & Mcfadden, 2010). The DAS helps serve to identify a connection between individuals' attitudes and feelings about people who are diagnosed with dementia and their behaviors towards them. On the DAS, scores range from a total of 20 to 140. Low scores on the DAS represent more negative attitudes towards dementia while higher scores indicate more positive attitudes towards dementia.

The authors conducted a series of studies to test the validity of the DAS. Researchers found that it correlated with several dementia-related scales (O'Connor & Mcfadden, 2010) that have been most commonly used to assess for attitudes related to dementia knowledge. These noteworthy scales include Attitudes towards Disabled Person Scale, the Interaction with

Disabled Persons Scale, Kogan Attitudes toward Old People Scale, and the Fraboni Scale of Ageism (O'Connor & Mcfadden, 2010). These measures were found to have a significant correlation with the DAS. In three separate studies testing for test validity, the authors administered the DAS and other valid measures to three different populations. In the last study, researchers used Pearson correlations to calculate the total scores on the DAS and other measures. Analyses were run with a single and two factor models, the latter being allowed to correlate. Researchers then used Chi-square difference tests to examine the relative of fit, which was found to be significant in both single and two factor models. Overall, the DAS has been found to have solid psychometric properties and has evidence for convergent validity.

The DAS has many strengths including consistently found reliability. It's item structure accurately reflected the components of attitude, however, more items addressed the cognitive domains as opposed to the affective and behavioral domains of dementia attitudes. The DAS's reliability was consistently found to be above 0.8.

Procedures

After obtaining IRB approval, researchers recruited employee participants from a local coffee shop. The researchers met with the employees one time for a one and a half hour time period. During this time the participants read and signed the informed consent. Following this, participants completed a demographics questionnaire that included questions about age, gender, educational level, marital status, and whether or not the individual knew of anyone who has or has had dementia. The coffee shop employees completed the Dementia Attitude Scale as a pre-test to assess their awareness, knowledge, and attitudes towards dementia. Immediately following this, participants were led through a virtual reality experience of dementia.

The virtual reality dementia experience was an immersive exercise that mimicked the symptoms of dementia in order to provide first-hand experience of the disorder and to build empathy for the disorder. Participants were garbed with gloves, shoe inserts, cataracts goggles, and also listened to an audio track; participants were then asked to complete a number of tasks (Beville, 2002). The employees were asked to: read the first items on the menu on the wall out loud, take two sugar packets and give them to someone, order a caramel macchiato with a double shot, take two straws and bang them on the counter like a drum, and go sit on the couch. After the participant completed, or believed they completed the tasks they were sent to a debriefing group to talk about what they experienced during the activity. The participants also discussed how this experience changed their view of dementia and individuals with dementia. The virtual dementia experience taught the employees through experimental and immersive means, about the multiple ways in which dementia can affect different domains of functioning, This revealed the many physical, mental, and emotional difficulties.

Subsequent to the virtual reality dementia experience, the researchers provided the validation information to the coffee shop employees to increase knowledge and awareness of dementia. This objective was accomplished through the introduction and use of validation theory and training. Participants received training that taught the main features of what dementia looks like, how to properly identify someone who has dementia, and ways to utilize specific techniques to interact effectively and appropriately with the individuals diagnosed with dementia.

The researchers recruited individuals from a local senior health and activity center for caregivers of individuals diagnosed with dementia. Researchers informed caregivers about the purpose of the study as well as the extent and role of the research project. After the coffee shop employees completed the virtual reality experience of dementia and validation training,

researchers invited a group of individuals with dementia and their caregivers to visit the local coffee shop during a two week period. The caregivers and individuals with dementia had the opportunity to receive services at the local coffee shop during these encounters. Researchers expected that the employees would utilize what was learned from the virtual reality experience and validation training in their interactions with the caregivers and the individual with dementia through social interaction, communication, assistance, and patience in the experience at the shop.

Altogether, the virtual reality dementia experience, training and teaching on validation theory, and the face-to-face experience with the employee members, caregivers, and individuals with dementia functioned as the intervention for this study. Following the end of the intervention, the employees were asked to complete the Dementia Attitudes Scale once more as a post-test measure. The intervention aimed to increase dementia knowledge and overall social comfort towards individuals diagnosed with dementia. This was measured through the pre and post-test Dementia Attitudes scale from the employee participants.

Chapter Four

Results

The present study evaluated community members' attitudes towards individuals with dementia through assessing dementia knowledge and level of social comfort towards individuals diagnosed with dementia both before and after the implementation of an intervention approach. The researchers hypothesized that through intervention and education, knowledge about dementia would be increased in the community. Researchers also hypothesized that through intervention and education, social comfort towards persons with dementia would be increased within the community.

Preliminary Results

The Dementia Attitude Scale was normed using a sample size of 157 individuals recruited from a participant pool web site. Overall, in the normative data the mean score was 98.64 for the DAS with a standard deviation of 12.82 ($\bar{x}=98.64$, $SD=12.82$). No cut offs exist for the DAS, as higher scores indicate more favorable attitudes towards individuals with dementia and lower scores indicate less favorable attitudes. In the present study, there were a total of 11 participants. Out of the 11 individuals, 5 individuals completed in full the pretest measure, participated fully in the intervention, and completed the posttest measure in its entirety. In the current sample, participants scored an average score of 96.40 and the standard deviation was 5.41 in the pretest DAS measure ($\bar{x}=96.40$, $SD=5.41$), falling within one standard deviation of the normative data. In the pretest administration the range was 14, with a maximum score of 103.00 and a minimum score of 89.00 ($r=14.00$, $\max = 103.00$, $\min = 89.00$). The average was 102.40 and standard deviation was 14.58 in the posttest DAS measure ($\bar{x}=102.40$, $SD=14.58$). These scores also fall within one standard deviation of the normative data. In the posttest administration the range was 31, with a maximum score of 118.00 and a minimum score of 87.00 ($r=31.00$, $\max = 118.00$, $\min = 87.00$).

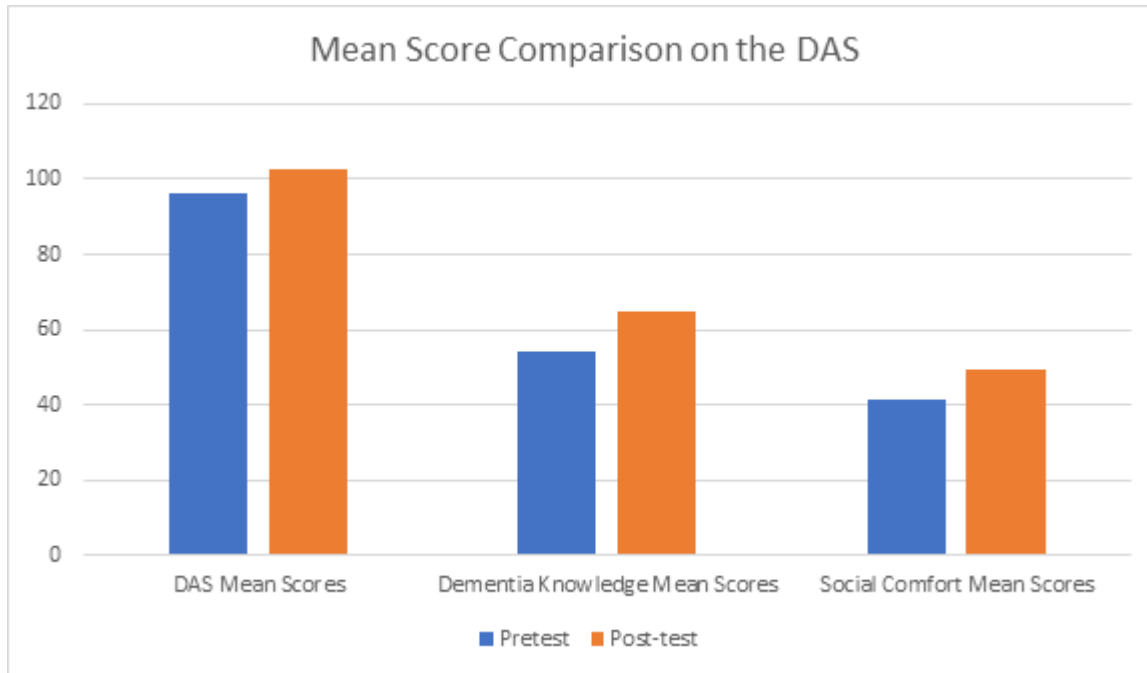
Hypothesis Tests

In order to test the hypothesis that through intervention and education, knowledge about dementia would be increased in the community a paired sample t-test analysis was run with the dependent variable being dementia knowledge and social comfort towards individuals with dementia. The p-value criterion was set at $p < .05$. Results were not significant in the scores for the pretreatment score on dementia knowledge and the posttreatment score on dementia knowledge ($t_{(4)} = - 1.917$, $p = .128$). The mean scores on the posttreatment test on the dementia

knowledge section on the Dementia Attitude Scale ($\bar{x}=64.80$) was higher than the mean pretest score ($\bar{x}=54.20$) (figure 1), but not significantly, indicating that validation training did not significantly increase dementia knowledge within the community.

In order to test the hypothesis that through intervention and education social comfort towards persons with dementia would be increased within the community a paired sample t-test analysis was run. The p-value criterion was set at $p < .05$. Results indicated that there was not a significant difference in the scores for the pretreatment score on social comfort towards individuals with dementia ($t_{(4)} = -1.244, p = .281$). The mean scores for the posttreatment test on empathy towards individuals with dementia section on the DAS ($\bar{x}=49.60$) increased, however scores were not significantly higher than the pretreatment score on social comfort towards individuals with dementia section ($\bar{x}=41.20$) (figure1).

Figure 1



Exploratory Analyses

In order to determine if there would be a relationship between age and DAS total change scores a Pearson correlation was run. Results were significant ($r=.881, p=.048$). A positive

correlation exists between age and DAS difference scores which implies that increased age is associated with an increase in the difference score. In order to determine if there would be a relationship between age and dementia knowledge change scores a Pearson correlation was run. Results were significant ($r = .881$, $p = .048$). A Pearson correlation was also run to determine if there would be a relationship between age and empathy change scores. Results were not significant ($r = -.172$, $p = .782$).

In order to determine if there would be a difference in amount of improvement (DAS total change score) between those who have an immediate family member with dementia and those who do not, an independent samples t-test was run. Results were not significant ($t_{(3)} = 2.077$, $p = .129$). Homogeneity of variance was not violated ($F = 5.288$, $p = .105$). In order to test a difference between those who have an immediate family member with dementia and dementia knowledge change scores an independent sample t-test was run. Results were not significant ($t_{(3)} = 2.077$, $p = .129$), homogeneity of variance was not violated ($F = 5.288$, $p = .105$). In order to test a difference between those who have an immediate family member with dementia and social comfort change scores an independent sample t-test was run. Results were not significant ($t_{(3)} = -1.197$, $p = .317$), homogeneity of variance was not violated ($F = 4.333$, $p = .129$).

In order to determine if participants who had an immediate family member with dementia would score higher on the pre-test dementia knowledge and empathy scores than those who do not have an immediate family member with dementia two independent t-tests were run. Results concerning dementia knowledge pre-test scores were not significant ($t_{(3)} = -1.100$, $p = .352$) and homogeneity of variance was not violated ($F = 2.799$, $p = .193$). Results concerning social comfort pre-test scores were significant ($t_{(3)} = 6.837$, $p = .006$) and homogeneity of variance was not violated ($F = .450$, $p = .550$).

In order to determine if there would be a relationship between dementia knowledge improvement and social comfort improvement a Pearson correlation was run. Results were not significant ($r = -.035$, $p = .955$).

Chapter Five

Discussion

The present study examined local community employee participants pre-test and post-test knowledge about dementia and social comfort towards individuals diagnosed with dementia. It was hypothesized that through the implementation of intervention and education, knowledge about dementia as well as social comfort would be increased in the community. Results showed that neither knowledge about dementia nor social comfort significantly increased within the sample. Although the results were not significant, the dementia knowledge on the DAS post-test scores were higher than the pre-test scores; additionally, the social comfort scores were higher at post-test than at pre-test. This indicates that dementia knowledge and social comfort increased within the treatment group; however, it did not increase enough to raise to the level of significance.

One possible explanation for this is validation training coupled with the immersive dementia experience alone may not be enough to increase dementia knowledge within the community. Validation training was provided to all participants; however, there were participants that did not consent to being part of the virtual dementia training. Validation training alone may not be enough because it does not provide as impactful of an experience when paired with the virtual dementia training. Although validation training enables the participants with awareness and insight on how to effectively communicate, the additional virtual dementia

training allows for further empathy building (Feil, 1993a). Due to the external circumstances which impacted the study, this may have impacted the ability to effectively replicate the outcomes of validation training.

Another possible explanation of the results is that the dose of training was too low to lead to substantial changes. It may be that more intense training is needed, as well as longer periods of time implementing validation training. Although the current study implemented similar validation training and techniques to previous studies, one of the differences is the length of time for the implementation. When validation techniques were utilized in a previous study, the researchers spent one year implementing training (Söderlund et al., 2016). In another study, the researchers implemented validation training over the course of eight weeks (Morris et al., 2018). Lack of evidence exists to give a specific time frame for how long it takes empathy and attitudes to change, as well as the long term effectiveness of interventions (Adefila et al., 2016).

Exploratory analyses were run to test if age would be related to the difference in scores from pre-test to post-test on dementia knowledge, social comfort for individuals with dementia, and overall DAS scores. This yielded a significant positive relationship between the two variables which implies that older employees benefited more from treatment; older employees had a greater increase in their overall DAS change scores as well as dementia knowledge change scores. A possible explanation for the relationship between increased age and increased overall DAS change scores is the increase in personal awareness due to higher probability of developing dementia sooner. It is also possible that older participants may have had more opportunity for exposure to dementia. Analyses were also run to compare participants with and without an immediate family member with dementia on DAS total change scores as well as for dementia knowledge and social comfort change scores. The results of all three analyses were not

significant. Exploratory analyses were also run to determine if there was a difference between people with and without immediate family members with dementia on dementia knowledge and social comfort pre-test scores. Results showed that social comfort was significantly higher for individuals who have an immediate family member with dementia on pre-test scores. This serves as a ceiling effect, limiting the amount that scores can increase since they started off as high scores. Last, exploratory analyses were run to determine if there was a relationship between dementia knowledge improvement and social comfort improvement; results showed there was no significant relationship. The low number of participants in the study is likely the reason that there was not a significant difference in amount of improvement across these variables. Another possible explanation for the lack of significance in results of this study could be due to the homogeneity in ethnicity and race in the sample. While formal demographics about race were not recorded, the sample appeared to be primarily caucasian. This decreases the generalizability of this study within multicultural communities.

Another possible explanation for the results is that there was not enough power in the current sample size to detect changes in attitudes and social comfort levels towards individuals with dementia. According to the power analysis that was run to determine a medium effect size, a sample of 10 participants would be needed. Other studies that have found significant differences have had a population sample size ranging from 10-157 individuals (O'Connor & Mcfadden, 2010). The lack of significance in the current findings could have been influenced due to low statistical power which reduces the overall statistical conclusion validity. The low sample size for the current study can be attributed to the COVID-19 epidemic. This pandemic impacted not only the participants of this study, but every member of the community. The group of caregivers and older adults from a local senior center who were invited to receive services

from the coffee shop had to take their own health, well-being, and safety into consideration.

They were encouraged to engage in social distancing, as older adults are at a greater risk. Thus, it is unknown how many older adults with dementia had received services. Additionally, the coffee shop had reduced open hours of operation for the safety of the employees; which impacted how many clients on whom they would be able to implement their learned validation techniques.

Overall, the experience of this study indicates that it is possible for the validation training and techniques to be taught to employees in various local establishments and implemented with the target population of older adults and their caregivers. A safe, comfortable, and enjoyable experience in different restaurants and coffee shops can indeed be provided to these individuals while dementia awareness and empathy skills can be provided to employees.

The results of the study were not as the researchers expected. This is because the sample size was limited as only one coffee shop was utilized with a limited number of employees. It was also taken into consideration that there would be participants in the study who would not want to partake in the validation training and virtual reality dementia experience. The hypotheses of the study were not supported by the results; however, it did allow for further insight about how employees within a community demonstrate their ability to understand, empathize, and interact with individuals diagnosed with dementia. Taken as a whole, the hypothesis that the implementation of intervention and education, knowledge about dementia as well as social comfort level would increase in the community was not supported by the results.

Limitations

There were threats to internal and external validity within this study. The nature of the research design makes it difficult to determine if validation education, the virtual dementia experience, or a one-one one interaction with a caregiver and individual with dementia is

responsible for the results. This is a threat to internal validity. The participants completed the same measure twice which makes testing a threat as well. All of the participants also worked in the same place and were a part of the treatment group making selection of subjects a threat. Last, history, or the events that happened between pre-test and post-tests served as a threat to internal validity due to the COVID-19 pandemic.

The low sample size is a threat to external validity and statistical conclusion validity. While it is possible to attempt to generalize these results to other communities and for other populations, it is difficult to do so based on the results of five community members. Reactive effect of testing is also a threat to external validity since participants took the same pre-test measure as a post-test. Multiple treatment interference is also a threat to external validity since it is difficult to determine if validation education, the virtual dementia experience, or a one-one one interaction with a caregiver and individual with dementia is responsible for the results.

Statistical conclusion validity is threatened by the low power of the study. It is also threatened by poor reliability of treatment implementation since the researchers were unable to follow a pre-standardized protocol for the implementation of the treatment. Researchers attempted to avoid issues with construct validity due to inexact definitions of constructs, and appear to have successfully done so with the operationalizing of dementia knowledge. Monopoperation bias is also present, as only one measure is used to assess dementia knowledge and social comfort. Treatment-sensitive factorial structure is a threat to construct validity as well due to the possible sensitization of the participants after the treatment implementation. These various threats have implications for this study in that it is very difficult to generalize; however, this is a pilot study that lays a foundation to create more valid and powerful study.

The current study sought to have a diverse and representative sample group that represents the community, but was limited in regard to sample size as a result of participant involvement. Eleven employees of a local coffee shop volunteered to participate in the current study and completed the pre-test measure of the Dementia Attitude Scale. However, only six employees completed the post-test measure and of that six only a total of five employees participated in the entirety of the study: pre-test, intervention, and post-test. This could be attributed to participant drop out rate. Participant drop out rate could be attributed to the COVID-19 outbreak, as many businesses were forced to operate with limited staff during the post-test administration of the study. Additionally during this time, any individuals who were considered to be high risk for COVID-19 were encouraged to self-quarantine as a means of avoiding catching the virus. If any of the participants of the current study fell into this high risk category, their ability to participate in the study would have been impacted.

As the result of limited participant involvement, only one group was observed and used for the treatment group for the study. This group underwent the education and validation intervention of the study, and there was no other group or a means of control. Knowledge about dementia and empathy towards dementia could have also been influenced by other factors that were not accounted for by the researchers. As a result, future research would benefit from having a total of four separate groups: a control group, a group that receives education, another group that receives intervention, and one group that receives both education and intervention to assess any significant differences or results among the groups.

Regarding the purpose of the study and the findings, it is possible that people with positive attitudes, as measured by high levels and scores of knowledge and empathy towards dementia, developed more positive attitudes upon being informed of the purpose of the study, as

deceit was not used. Many participants of the current study identified that they knew someone who had been diagnosed with dementia. These participants did score significantly higher on the pre-test measure than those who did not have an immediate family member with dementia. This serves as a ceiling effect, limiting the amount that their scores can increase as a result of the intervention.

Strengths

Although validation has historically been used in medical settings, the strengths of the study lie in the intervention's applicability to other populations. Validation can be utilized in numerous settings, such as libraries and small businesses, and is not just limited to being used in a restaurant setting. Although the current study recruited participants from a local coffee shop, the study could be generalized to other businesses as well in order to reach a larger population. Education programs could also expand community knowledge about and empathy for individuals with various diseases and disorders. This could in turn help the community and affected individuals learn to foster a symbiotic relationship with one another.

Although the results of this study were not significant and the hypotheses were not supported, the findings contributed to the existing body of literature to increase understanding, awareness, and advocacy of dementia and Alzheimer's related diseases. The study began to fill these gaps as expected; however, more research is needed to provide further clarity and definitive insight about implementing validation techniques and increasing community involvement. Additionally, the study and the validation training provided education to members of a community on how to interact and communicate with greater empathy. The study and the virtual reality dementia experience provided advocacy and awareness of the difficulties and

challenges older adults with dementia may experience, and how these may hinder their ability to navigate day to day experiences.

The findings of this study resemble prior studies as it further emphasizes the need for community involvement, support, empathy, and outreach to older adults diagnosed with dementia. However, no other study found in the literature had a global pandemic listed as a limitation to their study nor as an alternative explanation for their results. The pandemic highlights the importance of a community coming together to provide compassion to those who are limited in their ability to care and advocate for themselves. The study did provide a voice for those who may not always be able to articulate their struggles and difficulties. Further, the study was an initial step in providing action as well as advocacy to create a necessary change in community focused outreach for older adults and their caregivers.

Implications

Although the results of this pilot study were not significant, this study still provided valuable insight to the field of psychology. It contributed to the existing body of literature regarding community psychology, gerontology, empathy for dementia and Alzheimer's disease, empathy for their caregivers, and validation theory. This study will provide other therapists and researchers a foundation and a starting point for future research regarding the importance of caring for often neglected populations and marginalized groups. This should inform practice in the field that knowledge and awareness of marginalized groups and their needs should become a norm. Due to these results people should take it upon themselves to seek out information to make them more knowledgeable and accommodating to diverse populations. Additionally, this must be put into use on a larger scale such as company-wide or community-wide training about people

with dementia and other marginalized groups pertaining to their needs while interacting in the community. It is understood that these are very large implications that reach for radical change in the way that communities and businesses cater to their customers. However, the researchers believe that living in a community that is knowledgeable and comfortable in social proximity towards a wide variety of individuals with a wide variety of abilities that provides a high quality of life and business should not be as rare as it currently is. All people should be able to engage in their community and receive empathy and understanding back from those they engage with. This study helps to shed light on the impact that education and empathy building can have on members in the community and their attitudes towards and knowledge about a marginalized population.

Future studies

It would be beneficial for future studies if larger sample sizes were utilized to continue this research. Different assessment measures also exist which can be used to gain additional insight and data about empathy and dementia knowledge. Future studies might also benefit from utilizing caregivers and individuals with dementia as participants, as well as the employees of different establishments. This has the potential to explore the relationships between caregivers and care receivers, as well as their quality of life. Incorporating different forms of caregivers such as facility provided or familial caregivers could also add variability to different participants of the study. Utilizing multiple restaurants, coffee shops, and local establishments such as public libraries may increase generalizability of this study. Additionally, expanding participant demographics may also increase generalizability. As previously indicated, future research would benefit from having control and experimental groups to explore any significant differences or results among them.

Recommendations

It is recommended that this concept be applied to other populations in order to provide advocacy and awareness of other marginalized groups. Alternative ideas for the research design may be taken into consideration for future studies. It is also recommended that future researchers explore other available measures and instruments which can be applied to this study. The research and studies which will follow this study have the potential to enable employees with knowledge, awareness, and empathy to implement more optimal experiences not only for older adults diagnosed with dementia and their caregivers, but other variations of clientele.

Conclusion

As a result of the increased need to create dementia friendly communities, further research is needed to compare and differentiate existing attitudes about dementia in order to better understand how to implement dementia friendly communities more effectively. The global variations of dementia friendly communities which already exist have similar objectives of expanding and maintaining environments for older adults, their families, and their caregivers in which they can live among others in comfort, ease, and safety. These communities aspire to create a way of existing with necessary accommodations for this population and without judgement, isolation, or disconnect from others. Research is urgently needed to establish the usefulness of efforts to increase dementia awareness and ultimately create a more accepting, supportive, empathetic, and safe community in which individuals diagnosed with dementia feel they belong.

References

A Place for Mom. (2019). *Massachusetts dementia care resources and facilities*.

Alzheimers.Net. <https://www.alzheimers.net/resources/massachusetts/>

Abdollahpour, I., Nedjat, S., Salimi, Y., Noroozian, M., & Majdzadeh, R. (2015). Which variable is the strongest adjusted predictor of quality of life in caregivers of patients with dementia? *Psychogeriatrics*, 15(1), 51–57. <https://doi.org/10.1111/psyg.12094>

Adefila, A., Graham, S., Clouder, L., Bluteau, P., & Ball, S. (2016). MyShoes: The future of experiential dementia training? *The Journal of Mental Health Training, Education, and Practice; Brighton*, 11(2), 91–101. <https://dx.doi.org/10.1108/JMHTEP-10-2015-0048>

Administration for Community Living. (2019). *National Family Caregiver Support Program*. <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

Aging and Disability Resource Connection of Oregon. (2014). *ADRC: Aging and disability resource connection of Oregon*. <https://adrcforegon.org/consite/explore-caregiver-supports.php>

Almeida, D. M., Wethington, E., & Kessler, R. C. (2002). The daily inventory of stressful events: An interview-based approach for measuring daily stressors. *Assessment*, 9(1), 41–55. <https://doi.org/10.1177/1073191102091006>

Alzheimer's Association. (2019a). *Community environments*. Alzheimer's Disease and Dementia. <https://alz.org/professionals/public-health/core-areas/community-environments>

Alzheimer's Association. (2019b). *What is a dementia-friendly community?* Alzheimer's Society. <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/what-dementia-friendly-community>

Alzheimer's Association. (2019c). *What is dementia?* Alzheimer's Disease and Dementia.

<https://alz.org/alzheimers-dementia/what-is-dementia>

Alzheimer's Disease International. (2019). *Principles of a dementia friendly community.*

<https://www.alz.co.uk/dementia-friendly-communities/principles>

Alzheimer's Disease International (ADI). (2016). *Dementia friendly communities: Key principles.* 16.

Bartolo, M., De Luca, D., Serrao, M., Sinforiani, E., Zucchella, C., & Sandrini, G. (2010).

Caregivers burden and needs in community neurorehabilitation. *Journal of Rehabilitation Medicine*, 42(9), 818-822(5). <https://doi.org/10.2340/16501977-0612>

Batsch, N. S., Mittelman, M. S., & Alzheimer's Disease International. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia.* <https://www.alz.co.uk/research/world-report-2012>

Bejjani, C., Snow, A. L., Judge, K. S., Bass, D. M., Morgan, R. O., Wilson, N., Walder, A.,

Looman, W. J., McCarthy, C., & Kunik, M. E. (2015). Characteristics of depressed caregivers of veterans with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 30(7), 672–678. <https://doi.org/10.1177/1533317512461555>

Bekhet, A. K., & Avery, J. S. (2018). Resilience from the perspectives of caregivers of persons with dementia. *Archives of Psychiatric Nursing*, 32(1), 19–23.

<https://doi.org/10.1016/j.apnu.2017.09.008>

Beville, P. K. (2002). The Virtual Dementia Tour: A call to action for sensitivity training.

American Journal of Alzheimer's Disease & Other Dementias, 17(5), 261–262.

<https://doi.org/10.1177/153331750201700502>

Brooks, A., Farquharson, L., Burnell, K., & Charlesworth, G. (2014). A narrative enquiry of

- experienced family carers of people with dementia volunteering in a carer supporter programme: Impact of volunteering on peer supporters. *Journal of Community & Applied Social Psychology*, 24(6), 491–502. <https://doi.org/10.1002/casp.2188>
- Cacioppo, J. T., & Hawkley, L. C. (2009). Perceived social isolation and cognition. *Trends in Cognitive Sciences*, 13(10), 447–454. <https://doi.org/10.1016/j.tics.2009.06.005>
- Caregiving MetroWest. (n.d.). *Dementia friendly communities*. Retrieved October 27, 2019, from <http://www.caregivingmetrowest.org/Caregiver-Toolkit/Dementia-Friendly-Communities>
- Case, A. D., Todd, N. R., & Kral, M. J. (2014). Ethnography in community psychology: Promises and tensions. *American Journal of Community Psychology*, 54(1–2), 60–71. <https://doi.org/10.1007/s10464-014-9648-0>
- Centers for Disease Control and Prevention. (2018a, February 13). *Caregiving for person with Alzheimer's disease or a related dementia*. <https://www.cdc.gov/aging/caregiving/alzheimer.htm>
- Centers for Disease Control and Prevention. (2018b, September). *U.S. burden of Alzheimer's disease, related dementias to double by 2060*. <https://www.cdc.gov/media/releases/2018/p0920-alzheimers-burden-double-2060.html>
- Centers for Disease Control and Prevention. (2019, February 15). *Caregiving index*. <https://www.cdc.gov/aging/caregiving/index.htm>
- Chalk, A., & Page, S. (2016). Dementia RED (Respect Empathy Dignity): Collaborating to build dementia supportive communities in North Wales. *Dementia*, 15(2), 257–262. <https://doi.org/10.1177/1471301214563203>
- Chattillion, E. A., Ceglowski, J., Roepke, S. K., von Känel, R., Losada, A., Mills, P. J., Romero-Moreno, R., Grant, I., Patterson, T. L., & Mausbach, B. T. (2013). Pleasant events,

- activity restriction, and blood pressure in dementia caregivers. *Health Psychology, 32*(7), 793–801. <https://doi.org/10.1037/a0029412>
- Cheng, S.-T., Mak, E. P. M., Fung, H. H., Kwok, T., Lee, D. T. F., & Lam, L. C. W. (2017). Benefit-finding and effect on caregiver depression: A double-blind randomized controlled trial. *Journal of Consulting and Clinical Psychology, 85*(5), 521–529. <https://doi.org/10.1037/ccp0000176>
- Clark, C. N., Nicholas, J. M., Agustus, J. L., Hardy, C. J. D., Russell, L. L., Brotherhood, E. V., Dick, K. M., Marshall, C. R., Mummery, C. J., Rohrer, J. D., & Warren, J. D. (2017). Auditory conflict and congruence in frontotemporal dementia. *Neuropsychologia, 104*, 144–156. <https://doi.org/10.1016/j.neuropsychologia.2017.08.009>
- Cohen-Mansfield, J., Golander, H., & Heinik, J. (2013). Delusions and hallucinations in persons with dementia. *Journal of Geriatric Psychiatry and Neurology, 26*(4), 251–258. <https://doi.org/10.1177/0891988713509136>
- Collins, S. E., Clifasefi, S. L., Stanton, J., The LEAP Advisory Board, Straits, K. J. E., Gil-Kashiwabara, E., Rodriguez Espinosa, P., Nicasio, A. V., Andrasik, M. P., Hawes, S. M., Miller, K. A., Nelson, L. A., Orfaly, V. E., Duran, B. M., & Wallerstein, N. (2018). Community-based participatory research (CBPR): Towards equitable involvement of community in psychology research. *American Psychologist, 73*(7), 884–898. <https://doi.org/10.1037/amp0000167>
- Colorado Department of Human Services. (2017, February 17). *Caregiver support*. Department of Human Services. <https://www.colorado.gov/pacific/cdhs/caregiver-support>
- Dauphinot, V., Delphin-Combe, F., Mouchoux, C., Dorey, A., Bathsavanis, A., Makaroff, Z., Rouch, I., & Krolak-Salmon, P. (2015). Risk factors of caregiving burden among patients

- with Alzheimer's disease or related disorders: A cross-sectional study. *Journal of Alzheimer's Disease*, 44(3), 907–916. <https://doi.org/10.3233/JAD-142337>
- Dementia Friendly America. (2015). *What is DFA*. Dementia Friendly America. <https://www.dfamerica.org/what-is-dfa>
- Dementia Society of America. (n.d.). *Definitions*. 11815. Retrieved December 6, 2019, from <https://www.dementiasociety.org/definitions>
- Department of Human Services. (n.d.). *Data on dementia*. <https://aging.georgia.gov/data-dementia>
- Ducharme, F., Lachance, L., Kergoat, M.-J., Coulombe, R., Antoine, P., & Pasquier, F. (2016). A comparative descriptive study of characteristics of early- and late-onset dementia family caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 31(1), 48–56. <https://doi.org/10.1177/1533317515578255>
- Elnasseh, A. G., Trujillo, M. A., Peralta, S. V., Stolfi, M. E., Morelli, E., Perrin, P. B., & Arango-Lasprilla, J. C. (2016). Family dynamics and personal strengths among dementia caregivers in Argentina. *International Journal of Alzheimer's Disease*, 2016. <https://doi.org/10.1155/2016/2386728>
- Feil, N. (1993a). *The Validation Breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia."* US: Health Professions Press.
- Feil, N. (1993b). *The Validation breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia."* US: Health Professions Press.
- Flasbeck, V., & Brüne, M. (2019). Neural correlates of empathy for physical and psychological pain. *Journal of Psychophysiology*, 33(1), 54–63. <https://doi.org/10.1027/0269-8803/a000205>

- Forester, B. P., & Oxman, T. E. (2003). Measures to assess the neurocognitive symptoms of dementia in the primary care setting. *Primary Care Companion to The Journal of Clinical Psychiatry*, 5(4), 158–163. <https://doi.org/10.4088/pcc.v05n0403>
- Foster-Fishman, P., Cantillon, D., Pierce, S., & Van Egeren, L. (2007). *Building an active citizenry: He role of neighborhood problems, readiness, and capacity for change*.
- Fryer, D. (2008). Some questions about “The history of community psychology.” *Journal of Community Psychology*, 36(5), 16. <https://doi.org/10.1002/jcop.20240>
- Gagnon, M. M., Gelinas, B. L., & Friesen, L. N. (2017). Mental health literacy in emerging adults in a university setting: Distinctions between symptom awareness and appraisal. *Journal of Adolescent Research*, 32(5), 642–664. <https://doi.org/10.1177/0743558415605383>
- Garrett, W. (2019, April 1). *Marginalized populations*.
- Graham, T. M., & Ismail, T. (2011). Content and method trends in the Journal of Community Psychology between 2003 and 2007. *Journal of Community Psychology*, 39(2), 121–135. <https://doi.org/10.1002/jcop.20420>
- Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*, 43(6), 908–915. <https://doi.org/10.1093/geront/43.6.908>
- Heponiemi, T., Elovainio, M., Pekkarinen, L., Noro, A., Finne-Soveri, H., & Sinervo, T. (2006). The moderating effect of employee hostility on the association of long-term elderly care unit’s negative resident characteristics to employee stress and well-being. *Journal of Occupational Health Psychology*, 11(2), 157–168. <https://doi.org/10.1037/1076-8998.11.2.157>

History.com Editors. (2019). *Gay Rights*. HISTORY. <https://www.history.com/topics/gay-rights/history-of-gay-rights>

Holland, C., Boukouvalas, A., Wallis, S., Clarkesmith, D., Cooke, R., Liddell, L., & Kay, A. (2017). Transition from community dwelling to retirement village in older adults: Cognitive functioning and psychological health outcomes. *Ageing and Society*, 37(7), 1499–1526. <https://doi.org/10.1017/S0144686X16000477>

Howrey, M. M. (2018). Health sciences library outreach to family caregivers: A call to service. *Journal of the Medical Library Association*, 106(2), 251–258. <https://doi.org/10.5195/jmla.2018.390>

Jansen, A. P. D., van Hout, H. P. J., Nijpels, G., Rijmen, F., Dröes, R.-M., Pot, A.-M., Schellevis, F. G., Stalman, W. A. B., & van Marwijk, H. W. J. (2011). Effectiveness of case management among older adults with early symptoms of dementia and their primary informal caregivers: A randomized clinical trial. *International Journal of Nursing Studies*, 48(8), 933–943. <https://doi.org/10.1016/j.ijnurstu.2011.02.004>

Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., Hays, R. D., Wenger, N. S., & Reuben, D. B. (2016, December 20). *Patient and caregiver goals for dementia care*.

Jutten, R. J., Dicks, E., Vermaat, L., Barkhof, F., Scheltens, P., Tijms, B. M., & Sikkes, S. A. M. (2019). Impairment in complex activities of daily living is related to neurodegeneration in Alzheimer's disease-specific regions. *Neurobiology of Aging*, 75, 109–116. <https://doi.org/10.1016/j.neurobiolaging.2018.11.018>

Kerr-Tar Regional Council of Governments. (n.d.). *Family caregiver support program*. Retrieved September 26, 2019, from

- <https://www.kerrtarcog.org/departments/aging/family-caregiver-support-program/>
- King, R. A., & Shelley, C. A. (2008). Community feeling and social interest: Adlerian parallels, synergy and differences with the field of community psychology. *Journal of Community & Applied Social Psychology, 18*(2), 96–107. <https://doi.org/10.1002/casp.962>
- Kolanowski, A. M., Hill, N. L., Kurum, E., Fick, D. M., Yevchak, A. M., Mulhall, P., Clare, L., & Valenzuela, M. (2014). Gender differences in factors associated with delirium severity in older adults with dementia. *Archives of Psychiatric Nursing, 28*(3), 187–192. <https://doi.org/10.1016/j.apnu.2014.01.004>
- Kuo, L.-M., Huang, H.-L., Hsu, W.-C., & Shyu, Y.-I. L. (2014). Health-related quality of life and self-efficacy of managing behavior problems for family caregivers of vascular dementia and Alzheimer's disease patients. *Dementia and Geriatric Cognitive Disorders, 38*(5–6), 310–320. <https://doi.org/10.1159/000360414>
- Land of Sky Regional Council. (2012). *Project C.A.R.E.* Land of Sky. <http://www.landofsky.org/projectcare>
- Lang, S. F., & Fowers, B. J. (2019). An expanded theory of Alzheimer's caregiving. *American Psychologist, 74*(2), 194–206. <https://doi.org/10.1037/amp0000323>
- Lee, J., Sohn, B. K., Lee, H., Seong, S., Park, S., & Lee, J.-Y. (2017). Impact of behavioral symptoms in dementia patients on depression in daughter and daughter-in-law caregivers. *Journal of Women's Health, 26*(1), 36–43. <https://doi.org/10.1089/jwh.2016.5831>
- Lieberman, M. A., & Fisher, L. (1999). The effects of family conflict resolution and decision making on the provision of help for an elder with Alzheimer's disease. *The Gerontologist, 39*(2), 159–166. <https://doi.org/10.1093/geront/39.2.159>
- Liu, Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Re-examining the relationships

- among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*, 23(3), 283–299.
<https://doi.org/10.1007/s10823-008-9075-5>
- Liu, Y., Kim, K., Almeida, D. M., & Zarit, S. H. (2015). Daily fluctuation in negative affect for family caregivers of individuals with dementia. *Health Psychology*, 34(7), 729–740.
<https://doi.org/10.1037/hea0000175>
- Lytle, A., & Levy, S. (2017). Reducing ageism: Education about aging and extended contact with older adults. *The Gerontologist*, 59. <https://doi.org/10.1093/geront/gnx177>
- Maidment, I. D., Fox, C. G., Boustani, M., Rodriguez, J., Brown, R. C., & Katona, C. L. (2008). Efficacy of memantine on behavioral and psychological symptoms related to dementia: A systemic meta-analysis. *Annals of Pharmacotherapy*, 42(1), 32–38.
<https://doi.org/10.1345/aph.1K372>
- Mankowski, E. S., Galvez, G., & Glass, N. (2011). Interdisciplinary linkage of community psychology and cross-cultural psychology: History, values, and an illustrative research and action project on intimate partner violence. *American Journal of Community Psychology*, 47(1–2), 127–143. <https://doi.org/10.1007/s10464-010-9377-y>
- Mark, R. E. (2016). Promote the health of dementia caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 31(2), 181–183. <https://doi.org/10.1177/1533317515588182>
- McFarland, S. (2018). *How psychology has helped society accept homosexuality*.
<https://www.apa.org/ed/precollege/ptn/2018/05/society-accept-homosexuality>
- Mental Health America. (2019). *Quick facts and statistics about mental health*.
<https://www.mhanational.org/mentalhealthfacts>
- Mihelicova, M., Brown, M., & Shuman, V. (2018). Trauma-informed care for individuals with

- serious mental illness: An avenue for community psychology's involvement in community mental health. *American Journal of Community Psychology*, 61(2), 141–152.
<https://doi.org/10.1002/ajcp.12217>
- Mitrani, V. B., Lewis, J. E., Feaster, D. J., Czaja, S. J., Eisdorfer, C., Schulz, R., & Szapocznik, J. (2006). The role of family functioning in the stress process of dementia caregivers: A structural family framework. *The Gerontologist*, 46(1), 97–105.
<https://doi.org/10.1093/geront/46.1.97>
- Mittelman, M. S., & Bartels, S. J. (2014). Translating research into practice: Case study of a community-based dementia caregiver intervention. *Health Affairs*, 33(4), 587–595.
<https://doi.org/10.1377/hlthaff.2013.1334>.
- Morris, L., Horne, M., McEvoy, P., & Williamson, T. (2018). Communication training interventions for family and professional carers of people living with dementia: A systematic review of effectiveness, acceptability and conceptual basis. *Aging & Mental Health*, 22(7), 863–880. <https://doi.org/10.1080/13607863.2017.1399343>
- Nam, I. (2016). Financial difficulty effects on depressive symptoms among dementia patient caregivers. *Community Mental Health Journal*, 52(8), 1093–1097.
<https://doi.org/10.1007/s10597-016-0033-3>
- National Alliance on Mental Illness. (2017). *Work is recovery*.
<https://www.nami.org/Blogs/NAMI-Blog/August-2017/Work-is-Recovery>
- National Alliance on Mental Illness. (2019a). *Mental health month*.
<https://www.nami.org/mentalhealthmonth>
- National Alliance on Mental Illness. (2019b). *NAMIWalks Georgia*. NAMI.
<https://www.namiwalks.org/index.cfm?fuseaction=donorDrive.event&eventID=824>

National Alliance on Mental Illness. (2019c). *What is NAMIWalks?* NAMI.

<https://www.namiwalks.org/?fuseaction=cms.page&id=1006>

National Association of Councils on Developmental Disabilities. (n.d.). *Civic engagement*.

Retrieved September 12, 2019, from <https://nacdd.org/civicengagement/>

National Institute of Mental Health. (2019). *Mental illness*.

<https://www.nimh.nih.gov/health/statistics/mental-illness.shtml>

North Carolina Department of Health and Human Services. (n.d.). *Project CARE*. Retrieved

October 27, 2019, from <https://www.ncdhhs.gov/assistance/adult-services/project-care>

O'Connor, M. L., & Mcfadden, S. H. (2010). *Development and psychometric validation of the*

Dementia Attitudes Scale. <https://doi.org/10.4061/2010/454218>

Omoto, A. (2005). *Processes of community change and social action* (1st ed.). Psychology Press.

Oregon Department of Human Resources. (n.d.). *Family caregiver program*. Retrieved

September 26, 2019, from <https://www.oregon.gov/DHS/SENIORS->

[DISABILITIES/SUA/Pages/Family-Caregiver-Program.aspx](https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SUA/Pages/Family-Caregiver-Program.aspx)

Perkins, D. D. (2009a). International community psychology: Development and challenges.

American Journal of Community Psychology, 44(1–2), 76–79.

<https://doi.org/10.1007/s10464-009-9256-6>

Perkins, D. D. (2009b). International community psychology: Development and challenges.

American Journal of Community Psychology, 44(1–2), 76–79.

<https://doi.org/10.1007/s10464-009-9256-6>

Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost,

D., & Hasan, H. (2019). Involvement of people with dementia in raising awareness and

changing attitudes in a dementia friendly community pilot project. *Dementia*, 18(7–8),

2679–2694. <https://doi.org/10.1177/1471301218754455>

Pulsford, D., Duxbury, J., & Carter, B. (2016). Personal qualities necessary to care for people with dementia. *Nursing Standard*, *30*(37), 38. <https://dx.doi.org/10.7748/ns.30.37.38.s40>

Purple Tables. (2017). *Purple Table reservations*. Purple Table Reservations.

<https://www.purpletables.com>

Qualls, S. H. (2016). Caregiving families within the long-term services and support system for older adults. *American Psychologist*, *71*(4), 283–293. <https://doi.org/10.1037/a0040252>

Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities. *Dementia*, *17*(2), 131–137. <https://doi.org/10.1177/1471301217751533>

Reddy, P. H., Blackmon, J., Molinar-Lopez, V., Ament, C., Manczak, M., Kandimalla, R., Yin, X., Pandey, A., Kuruva, C. S., Wang, R., Fry, D., Osborn, C., Stonum, K., Quesada, K., Gonzales, R., & Boles, A. (2015). Garrison Institute on Aging: A new hope for elderly individuals and patients with Alzheimer's disease. *Journal of Alzheimer's Disease : JAD*, *48*(2), 547–555. <https://doi.org/10.3233/JAD-150490>

Reyes Cruz, M., & Sonn, C. C. (2011). (De)colonizing culture in community psychology: Reflections from critical social science. *American Journal of Community Psychology*, *47*(2), 203–214. <https://doi.org/10.1007/s10464-010-9378-x>

Roy, A. L., Godfrey, E. B., & Rarick, J. R. D. (2016). Many forms of culture. *American Journal of Community Psychology*, *57*, 448–458.

Scharlach, A., Li, W., & Dalvi, T. B. (2006). Family conflict as a mediator of caregiver strain. *Family Relations*, *55*(5), 625–635. <https://doi.org/10.1111/j.1741-3729.2006.00431.x>

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*,

12(3), 240–249. <https://doi.org/10.1097/00019442-200405000-00002>

Semple, S. J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *The Gerontologist*, 32(5), 648–655.

<https://doi.org/10.1093/geront/32.5.648>

Senior Living. (2018, June 8). *Alzheimer's awareness month 2019*. SeniorLiving.Org.

<https://www.seniorliving.org/memory-care/alzheimers/awareness/>

Senior Living Residences. (2019). *Caregiver support groups in Massachusetts*.

<https://www.seniorlivingresidences.com/giving-back/support-groups/>

Shanley, C., Quirke, S., Shaw, L., & Sammut, A. (2004). Working with organization to implement dementia awareness training for public contact staff. *American Journal of Alzheimer's Disease & Other Dementias*, 19(3), 166–171.

<https://doi.org/10.1177/153331750401900312>

Sherman, C. W., Webster, N. J., & Antonucci, T. C. (2013). Dementia caregiving in the context of late-life remarriage: Support networks, relationship quality, and well-being. *Journal of Marriage and Family*, 75(5), 1149–1163. <https://doi.org/10.1111/jomf.12059>

Society for Community Research and Action. (2019a). *What is community psychology?*

<https://www.scra27.org/what-we-do/what-community-psychology/>

Society for Community Research and Action. (2019b). *Who we are*. <http://www.scra27.org/who-we-are/>

Söderlund, M., Cronqvist, A., Norberg, A., Ternstedt, B., & Hansebo, G. (2016). Conversations between persons with dementia disease living in nursing homes and nurses: Qualitative evaluation of an intervention with the validation method. *Scandinavian Journal of Caring Sciences*, 30(1), 37–47. <https://doi.org/10.1111/scs.12219>

- Song, J.-A., Park, M., Park, J., Cheon, H. J., & Lee, M. (2018). Patient and caregiver interplay in behavioral and psychological symptoms of dementia: Family caregiver's experience. *Clinical Nursing Research*, 27(1), 12–34. <https://doi.org/10.1177/1054773816678979>
- Sörensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: Mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology*, 5(11), 961–973. [https://doi.org/10.1016/S1474-4422\(06\)70599-3](https://doi.org/10.1016/S1474-4422(06)70599-3)
- Sprangers, S., Dijkstra, K., & Romijn-Luijten, A. (2015). Communication skills training in a nursing home: Effects of a brief intervention on residents and nursing aides. *Clinical Interventions in Aging*, 10, 311–319. <https://doi.org/10.2147/CIA.S73053>
- Stivala, A. (2017). Diversity and community: The role of agent-based modeling. *American Journal of Community Psychology*, 59(3–4), 261–264. <https://doi.org/10.1002/ajcp.12131>
- Strawbridge, W. J., & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist*, 31(6), 770–777. <https://doi.org/10.1093/geront/31.6.770>
- Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13(6), 709–716. <https://doi.org/10.1177/1471301214548143>
- Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., Oishi, S., & Miyaoka, H. (2009). The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Archives of Gerontology and Geriatrics*, 49(1), e1–e5. <https://doi.org/10.1016/j.archger.2008.07.002>
- Tanaka, H., Hashimoto, M., Fukuhara, R., Ishikawa, T., Yatabe, Y., Kaneda, K., Yuuki, S., Honda, K., Matsuzaki, S., Tsuyuguchi, A., Hatada, Y., & Ikeda, M. (2015). Relationship between dementia severity and behavioural and psychological symptoms in early-onset Alzheimer's disease. *Psychogeriatrics*, 15(4), 242–247.

<https://doi.org/10.1111/psyg.12108>

Tay, K. C. P., Seow, C. C. D., Xiao, C., Lee, H. M. J., Chiu, H. F. K., & Chan, S. W.-C. (2016).

Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in Singapore. *The International Journal of Social Research and Practice*, 15(2), 204–220.

<https://doi.org/10.1177/1471301214522047>

Tebes, J. K. (2010). Community psychology, diversity, and the many forms of culture. *American Psychologist*, 65(1), 58–59. <https://doi.org/10.1037/a0017456>

Teri, L., McCurry, S. M., Logsdon, R., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45(6), 802–811. <https://doi.org/10.1093/geront/45.6.802>

Terracciano, A., Stephan, Y., Luchetti, M., & Sutin, A. R. (2018). Cognitive impairment, dementia, and personality stability among older adults. *Assessment*, 25(3), 336–347. <https://doi.org/10.1177/1073191117691844>

Townley, G., Brown, M., & Sylvestre, J. (2018). Community psychology and community mental health: A call for reengagement. *American Journal of Community Psychology*, 61(1–2), 3–9. <https://doi.org/10.1002/ajcp.12225>

Tremont, G., Davis, J. D., & Bishop, D. S. (2006). Unique contribution of family functioning in caregivers of patients with mild to moderate dementia. *Dementia and Geriatric Cognitive Disorders*, 21(3), 170–174. <https://doi.org/10.1159/000090699>

Trujillo, M. A., Perrin, P. B., Panyavin, I., Peralta, S. V., Stolfi, M. E., Morelli, E., & Arango-Lasprilla, J. C. (2016). Mediation of family dynamics, personal strengths, and mental health in dementia caregivers. *Journal of Latina/o Psychology*, 4(1), 1–17.

<https://doi.org/10.1037/lat0000046>

Truzzi, A., Valente, L., Ulstein, I., Engelhardt, E., Laks, J., & Engedal, K. (2012). Burnout in familial caregivers of patients with dementia. *Brazilian Journal of Psychiatry, 34*(4), 405–412. <https://doi.org/10.1016/j.rbp.2012.02.006>

Vachon, M. L. (2016). Targeted intervention for family and professional caregivers: Attachment, empathy, and compassion. *Palliative Medicine, 30*(2), 101–103. <https://doi.org/10.1177/0269216315624279>

Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. *Frontiers in Psychology, 8*. <https://doi.org/10.3389/fpsyg.2017.00585>

Wang, R., Tanjasiri, S. P., Palmer, P., & Valente, T. W. (2016). Network structure, multiplexity, and evolution as influences on community-based participatory interventions. *Journal of Community Psychology, 44*(6), 781–798. <https://doi.org/10.1002/jcop.21801>

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M.-J., & Antoine, P. (2016). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics, 17*(5). <https://doi.org/10.1111/psyg.12234>

Weisman de Mamani, A., Weintraub, M. J., Maura, J., Martinez de Andino, A., & Brown, C. A. (2018). The interplay among mindfulness, caregiver burden, and mental health in family members of individuals with dementia. *Professional Psychology: Research and Practice, 49*(2), 116–123. <https://doi.org/10.1037/pro0000181>

Wilkinson, H., Whittington, R., Perry, L., & Eames, C. (2017). Examining the relationship between burnout and empathy in healthcare professionals: A systematic review. *Burnout Research, 6*, 18–29. <https://doi.org/10.1016/j.burn.2017.06.003>

World Health Organization. (2014). *Measuring quality of life*. WHO.

<https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/index3.html>

World Health Organization, & Alzheimer's Disease International (Eds.). (2012). *Dementia: A public health priority*.

Wright, D. K., Brajtman, S., Cragg, B., & Macdonald, M. E. (2015). Delirium as letting go: An ethnographic analysis of hospice care and family moral experience. *Palliative Medicine*, 29(10), 959–966. <https://doi.org/10.1177/0269216315580742>

Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26. <https://doi.org/10.1016/j.ijnurstu.2017.10.008>

Zeisel, J., Reisberg, B., Whitehouse, P., Woods, R., & Verheul, A. (2016a). Ecopsychosocial interventions in cognitive decline and dementia: A new terminology and a new paradigm. *American Journal of Alzheimer's Disease and Other Dementias*, 31(6), 502–507. <https://doi.org/10.1177/1533317516650806>

Zeisel, J., Reisberg, B., Whitehouse, P., Woods, R., & Verheul, A. (2016b). 3(6), 502–507. <https://doi.org/10.1177/1533317516650806>