

CONSEQUENCES OF SOCIAL ISOLATION ON ELDERS WITH ALZHEIMER'S
DISEASE IN CARE FACILITIES: A COMPARATIVE LITERATURE REVIEW

By

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PART 1—PAPER

Abstract:

Alzheimer's Disease is a widespread and devastating diagnosis for which there is no cure. Utilization of care facilities is an option for patients with advanced stages, yet isolation due to contagious diseases within these facilities can be devastating for their psychological, cognitive, social, and physical health. Performing a comparative literature review, this paper looks at the psychological effects of COVID-19 isolation on young adults, older adults in care facilities, and on patients with Alzheimer's Disease in care facilities. Preliminary results for younger and older adults indicate a significant array of negative effects caused by isolation. There is very sparse literature regarding the effects of social isolation on elders with Alzheimer's Disease in care facilities, however. This thesis goes on to perform interviews with staff of care facilities to gain inside opinion into what can be done to minimize the negative psychological effects. Finally, an informational brochure is created with suggestions for isolation improvement from both the literature and from the staff of care facilities. There is a tremendous amount of research to be done in long-term care for individuals who have Alzheimer's Disease.

Introduction:

As of 2020, there were about 6 million people with Alzheimer's disease in the United States—a number that is expected to double by 2050 (Alzheimer's Disease Facts and Figures, 2022).

Although there are cures being tested, only medications to slow the progression are commonly used. So, what happens after diagnosis? As the 6th leading cause of death in the United States, there is not much that can be done. Many opt to be part of the 47.8% of nursing home residents

who live with the disease (FastStats - Alzheimers Disease). Nursing homes are a great way to have loved ones cared for later in life, but their responses to the unexpected must be carefully considered. What if there is an outbreak of a communicable disease within the nursing home or—more recently— throughout the entire world with COVID-19? Given the large number of individuals who live in nursing homes with Alzheimer’s, the current incurable status of the disease, and the tragic change in life plans that it causes, there needs to be investigation into the psychological effects of social isolation within nursing homes and ways to minimize the negative effects of the disease progression.

In order to gain perspective on the experiences of individuals with Alzheimer’s, this literature review will be analyzing the effect of social isolation on young adults and older adults with no Alzheimer’s diagnosis during the COVID-19 worldwide lockdowns.

The physiological aspect of this project will pertain to COVID-19 as well as Alzheimer’s Disease and its physical and neural progression. Mainly, this project will look at the physiological and psychological intersection of social isolation in the long-term health outcomes of patients who have been diagnosed with the disease while keeping in mind the goal of “prevent[ing] social distancing from becoming social isolation” (Cerami et al., 2021).

Background:

What is Alzheimer's?

Alzheimer's Disease (AD) is a pathology which falls under the umbrella of dementia and is categorized by distinct biological markers and neurodegeneration. Dementia is a broad category of memory loss that can be caused by a variety of pathologies or trauma (Knopman et al., 2021). AD is characterized by two biological changes: beta-amyloid-containing-plaques among neurons and tau tangles within neurons.

Within the axon of a neuron are microtubules that run from the soma to the synaptic terminal.

These are used to transport vesicles containing essential proteins and neurotransmitters.

Microtubules are held together in large part by tau proteins which act as biological twist ties.

With AD, tau proteins come apart therefore disassembling the microtubule. The tau proteins are attracted and form clumps which are called "tau tangles". With no microtubule, the essential transport along the microtubule cannot take place and communication is terminated from that neuron. Tau tangles present primarily in the medial temporal lobe and isocortical regions of the temporal, parietal and frontal lobes, respectively.

AD also causes the formation of amyloid plaques between the neurons in the brain. As a normal byproduct of synaptic activity, these are found throughout the cerebral cortex. Without AD, these are quickly processed and kept in small concentrations. This breakdown does not happen in AD, which causes a dangerous buildup on amyloid plaques. The buildup eventually affects the dendrites of the neurons as well as the synaptic efficiency.

The progression of AD is highly variable which may be accounted for by the nature of the disease or comorbidities. Unique symptoms can present themselves depending on the areas within the brain which have been affected. If the Hippocampus has been affected then short-term memory loss will likely be present. The inability to make decisions or organize events would be caused by altering the frontal lobes. These are both early signs of AD. Later in the progression of the disease, areas such as the cortex, temporal lobe, amygdala, right parietal, and left hemisphere in general may be altered by AD which can cause deficits in long term memory, inability to recognize faces and objects, difficulty portraying emotions, impaired 3D perception, and impaired language, respectively.

AD Diagnosis:

Previously, the only definitive diagnosis for AD was through an autopsy, but there are now new methods which can achieve high accuracy for the diagnosis of AD. For individuals with symptoms of cognitive impairment, a complete diagnosis of AD would include a thorough cognitive exam in conjunction with biomarker tests that test for AD specifically.

Three main types of biomarker tests are used in clinical practice today. The most popular way is through a cerebrospinal fluid (CSF) test (Knopman et al., 2021). CSF is found in the subarachnoid space which covers the brain and spinal cord down to the sacrum (Telano & Baker, 2022). A spinal tap is done by puncturing the subarachnoid space in the lumbar region of the spine and extracting CSF (Lumbar puncture (spinal tap), 2020). The lack of specific isoforms of beta-amyloid containing plaques as well as increases in phosphorylated tau proteins indicate the presence of AD pathology (Knopman et al., 2021)

Imaging biomarker tests can include computerized tomography (CT), magnetic resonance imaging (MRI), fluorodeoxyglucose-positron emission tomography (FDG-PET), tau-positron emission tomography (tau-PET), and beta-amyloid-containing plaque positron emission tomography (beta-amyloid PET) (Alzheimer's disease, 2022; Knopman et al., 2021). MRI and FDG-PET can also map the extent of neurodegeneration and, when used in conjunction with beta-amyloid PET and tau-PET, aid with staging of AD in a particular individual as well as locations within the brain that AD has reached (Knopman et al., 2021).

Finally, blood tests can be done to establish biomarkers for AD. Although convenient and popular, they lack specificity for AD which makes it better for screening rather than diagnosis (Alzheimer's disease, 2022).

AD Treatment & Care:

Although there are no approved methods of prevention for AD, it is thought that lifestyle modifications (e.g., control of blood pressure, exercise) may delay the onset of symptoms. For example, cognitive stimulation has been thought to delay the progression of AD by 6-9 months (Fisher Center for Alzheimer's Research Foundation Receives Coveted 4-Star Rating from Charity Navigator, for the 7th time, 2012). There are currently no cures for AD to date-- only methods in which individuals can slow the progression.

Medications that do this include cholinesterase inhibitors (donepezil, rivastigmine and galantamine) and the NMDA receptor antagonist memantine (How Is Alzheimer's Disease Treated?, 2021; Knopman et al., 2021). These medications are thought to slow the progression

by about 6 months with a few minor side effects possible such as nausea, loose stools, or loss of appetite (How Is Alzheimer's Disease Treated?, 2021). Despite their effectiveness, none of the medications work by changing the underlying cause of AD.

Due to the incurable nature of AD as well as its debilitating effects in later stages, the patient and their families are often faced with difficult choices regarding sources of care. One choice is for the family to care for the patient at home, however this can be extremely taxing.

If no family members are willing or able to take care of the patient, at-home care services can also be provided by third party vendors. These services can range from companionship to skilled care (medical care delivery) (In-home Care, 2022).

If a person is unable to remain at home due to the nature of their illness or due to other external factors, care facilities (CF) are available. There are three types of CF that are referenced in this review and which range in many factors such as type of care provided, security levels, and end prognosis.

Assisted living (AL) is generally used for older populations who are in need of minimal help with activities of daily living (ADL) which include activities such as personal hygiene, getting dressed, using the restroom, ambulating, and eating (Edemekong et al., 2022). AL also simulate home-like environments as opposed to a clinical or hospital setting. Residents of these facilities may also be free to come and go as they please.

Nursing homes (NH) provide full support of ADL and full-service clinical care (Finding Long-Term Care for a Person with Alzheimer's, 2017). This is a primarily clinical setting. NH are “facilities purposefully built for the residential and/or nursing care of older people living with advanced physical and/or cognitive disabilities.” (Giri et al., 2021) Individuals with AD may find themselves in this category of care as these facilities are also generally more secure to prevent patient wandering.

Long term memory care facilities (LTMCF) provide full support of ADL and full-service clinical care very similar to NH. However, this is a highly secured locked down clinical setting. LTMCF are generally designed for advanced stages of AD or other patients who have other severe cognitive impairments.

This paper is interested in the effects of isolation specifically in NH and LTMCF since these are already more secluded by nature and also have a higher incidence of AD patients as well as unique lockdown protocols for contagious disease outbreaks within the facility.

What is Social Isolation?:

Social isolation is defined as involving “loneliness, little (or markedly reduced) face-to-face contact, little (or markedly reduced) physical contact, and little (or markedly reduced) possibilities of physical activities, as well as uncertainty about the duration of the isolation” (Allé & Berntsen, 2021). Loneliness is not the same as social isolation but rather simply one part of it. Loneliness is “the unpleasant experience that occurs when a person’s network of social relations is deficient in some important way, either quantitatively or qualitatively” (Bao et al., 2021). AD,

as a result of the decrease in memory and day to day functioning, will naturally decrease these interactions for an individual throughout the progression of the disease. This review will look to investigate the effects that the cognitive isolation, inherent to the disease, paired with the physical isolation due to contagious disease containment protocols has on a patient with AD. This is especially important in foreign environments such as NH or LTMCF that may be a source of stress for these already frail and impaired individuals.

What is COVID-19?:

Coronavirus Disease 2019 (COVID-19) is a highly contagious condition caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). After being first reported in late December 2019 in China, the disease has spread to the entire world and is considered a pandemic by the World Health Organization (WHO).

Both Yesudas et al. and Shang et al. describe the method of viral infection well by saying that SARS-CoV-2 has a basic viral structure which includes spike proteins on the surface of the virus and the viral single stranded RNA (ssRNA) inside of it (Shang et al., 2020; Yesudhas et al., 2021). On the host, there are receptors called angiotensin-converting enzyme 2 (ACE2) which are found in large quantities on the respiratory epithelium within the alveolar of the lungs. ACE2 receptors are able to bind to the spike proteins on the surface of the virus via the virus's receptor binding domain (RBD) (Shang et al., 2020; Yesudhas et al., 2021). When this happens, host proteases will activate fusion sequences which allow the two membranes to bind and their inner contents become one (Shang et al., 2020; Yesudhas et al., 2021).

The ssRNA will then be transcribed and translated by the host's own machinery. This results in rapid amplification of the viral genome. The host then packages the products in vesicles and transports it to different areas within the body resulting in wide-ranging effects and symptoms of the virus (Shang et al., 2020).

How is COVID-19 Diagnosed?:

COVID-19 is diagnosed in many ways. With concern of current infection, a swab using a real-time PCR assay would be preferred due to its high sensitivity (La Marca et al., 2020). A PCR assay can also be done by collecting samples from a throat swab, nose swab, bronchoalveolar lavage (BAL) (a washing of the lungs and collection of resulting fluids), and via a saliva sample (La Marca et al., 2020). This test detects the nucleic acids from SARS-CoV-2. SARS-CoV-2 antigen tests are also available. These tests are quick and look for specific proteins that are present on the surface of the virus (La Marca et al., 2020). However, antigen tests are less sensitive and are therefore less preferred than the PCR tests (La Marca et al., 2020).

If there is no current concern for COVID-19 infection and if a patient would like to know if they have the antibodies for COVID-19, an antibody test can be performed (Interim Guidelines for COVID-19 Antibody Testing, 2022; La Marca et al., 2020). Antibodies, proteins made by a host after there has been an infection, are memory proteins that are ready to fight off another infection of the same sort if it returns (Interim Guidelines for COVID-19 Antibody Testing, 2022).

Contracting COVID-19 & Symptoms:

Everyone is susceptible to contracting COVID-19, however individuals who are over the age of 50 years old, who have underlying health issues, or who have recently been pregnant are more susceptible of contracting it and are at an increased risk of having more severe symptoms (COVID-19 Information for Specific Groups of People, 2022). Underlying health issues and comorbidities can include but are not limited to obesity, cardiovascular disease, chronic kidney disease, diabetes, chronic lung disease, smoking, cancer, solid organ or hematopoietic stem cell transplant patients (COVID-19 Information for Specific Groups of People, 2022).

Symptoms of a COVID-19 infection can range from asymptomatic to critically ill which would include clinical manifestations such as acute respiratory illness, septic shock, and/or multiple organ failure (Management of Patients with Confirmed 2019-nCoV, 2021). The majority of individuals who contract the disease have symptoms such as fever, cough, sore throat, malaise, headache, muscle pain, nausea, vomiting, diarrhea, anosmia, or dysgeusia but without shortness of breath or abnormal chest imaging (Management of Patients with Confirmed 2019-nCoV, 2021). Oxygen saturation levels within the blood may also slowly start to decline with the worsening of symptoms due to the buildup of inflammation caused by the virus' effect in the lungs (Management of Patients with Confirmed 2019-nCoV, 2021).

Preventing COVID-19:

To combat the initial infection with COVID-19, several vaccines have been created. Two companies, Pfizer and Moderna, have created mRNA vaccines which are somewhat

nontraditional in nature and work by introducing mRNA which will be translated by the host to create spike proteins (Understanding mRNA COVID-19 Vaccines, 2022). These are recognized by immune cells and a small immune response is made. Antibodies will now be present in the host so that in the event of a COVID-19 infection, the immune system will be prepared (Understanding mRNA COVID-19 Vaccines, 2022).

Due to the high transmissibility, it was recommended for a time by the Center for Disease Control (CDC) that all persons should maintain 6 feet in distance, avoid large groups, and wear facial masks over the mouth and nose (How to Protect Yourself & Others, 2022). Several states and countries implemented mandatory quarantine periods during the height of the pandemic.

Methods:

With the disease state of individuals with AD, it is difficult to obtain reliable information regarding their experiences while under isolation. During COVID-19, a large percentage of the world was mandated to undergo quarantine or similar forms of isolation so as to prevent the spreading of the virus. Although not exact, this experience is comparable to the isolation that AD patients in CF face. The effects of social isolation due to COVID-19 on young health individuals will be reviewed in Search 1. The effects of being in CF during this isolation is another factor that is of interest to the authors of this paper. The effect of isolation due to COVID-19 on healthy individuals who live in CF will be considered in Search 2. It is also of interest to investigate previous literature regarding individuals with AD in CF who have undergone isolation of some

sort. In order to maintain relative consistency over the three search conditions, Search 3 was also conducted with regards to COVID-19 isolation.

Searches were done using the PubMed database. In order to have the broadest inclusion of articles, three separate searches were performed with the following keywords:

Search 1 (Young Adults):

- Social isolation
- Effect
- Young adults
- Mental health/ health

Search 2 (Older Adults):

- Nursing home
- Social isolation
- Quality of life/ quality of care/ quality improvement/ loneliness
- Mortality/ death/ neglect/ family involvement/ family contribution/ family burden/ family

Search 3 (Isolation of Older Adults in Nursing Homes):

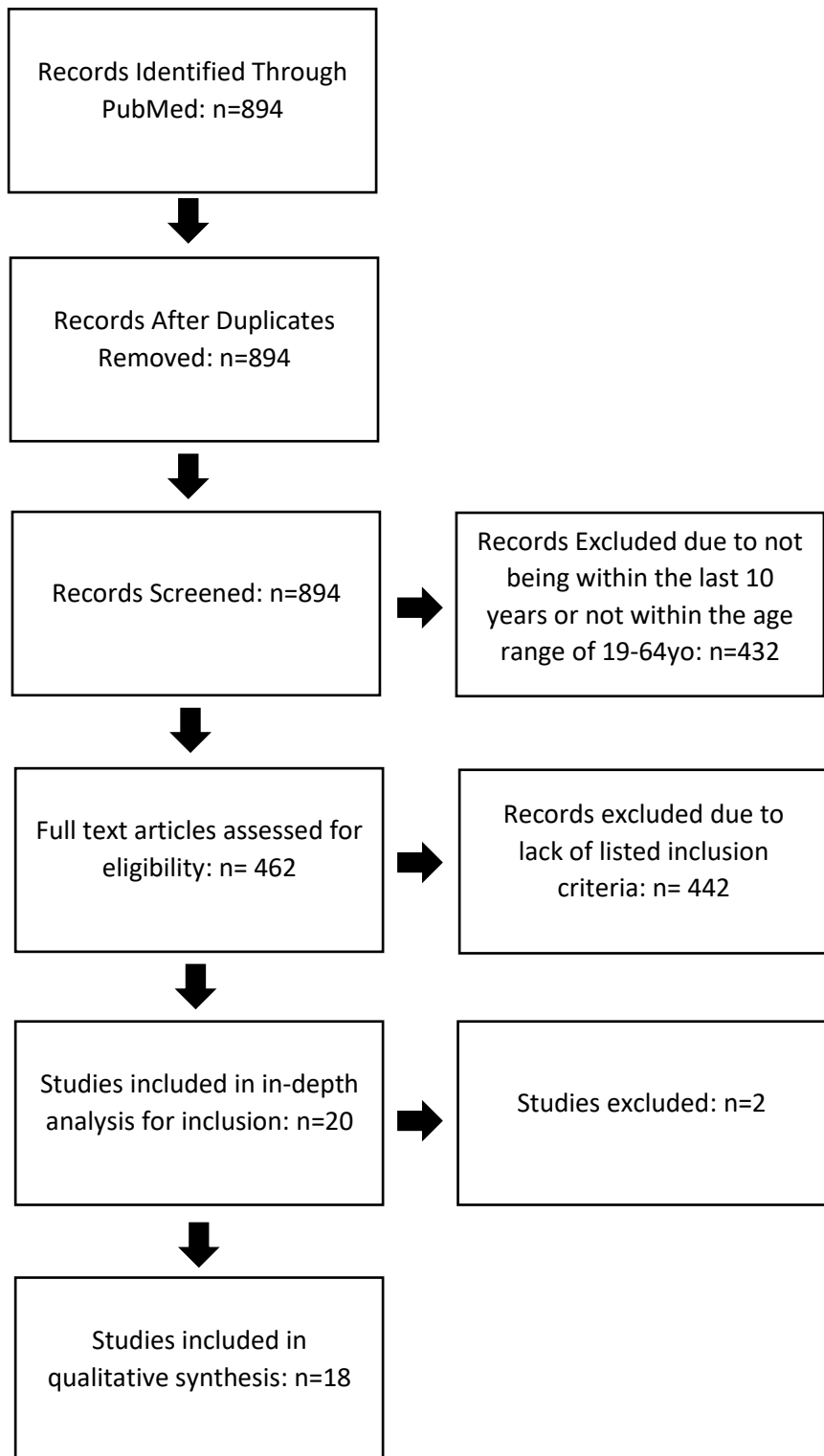
- Nursing home
- Social isolation
- Quality of life/ quality of care/ quality improvement/ loneliness
- Mortality/ death/ neglect/ family involvement/ family contribution/ family burden/ family
- Alzheimer's/ dementia

Exclusion criteria for all three searches included being a protocol, not having access to the entire article, or omission of COVID-19 isolation/ lockdown. Specifically, Search 1 must have been some sort of a survey during the COVID-19 lockdown period. Searches 1 and 2 must not be focusing on any population with a specific disability as that could possibly skew results. Any articles that discussed both younger and older adults were not used so as to keep a clear distinction between the two age groups.

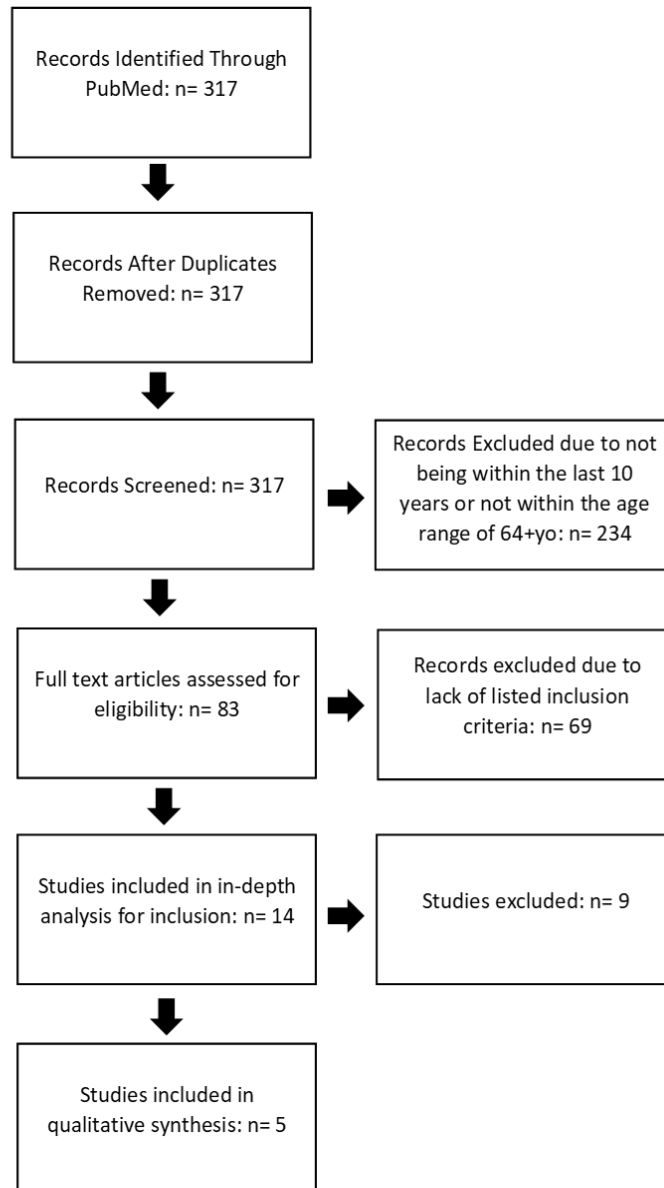
Finally, Search 1 must include only patients ages 18-65 while Search 2 must only include patients ages 65+. Search 3 did not have an age cutoff.

Search 1 resulted in 894 articles and, after criteria were implemented, 19 resulted for further review. Search 2 resulted in 317 articles and, after criteria were implemented, 5 resulted for further review. Search 3 resulted in 49 articles and, after criteria were implemented, 2 resulted for further review.

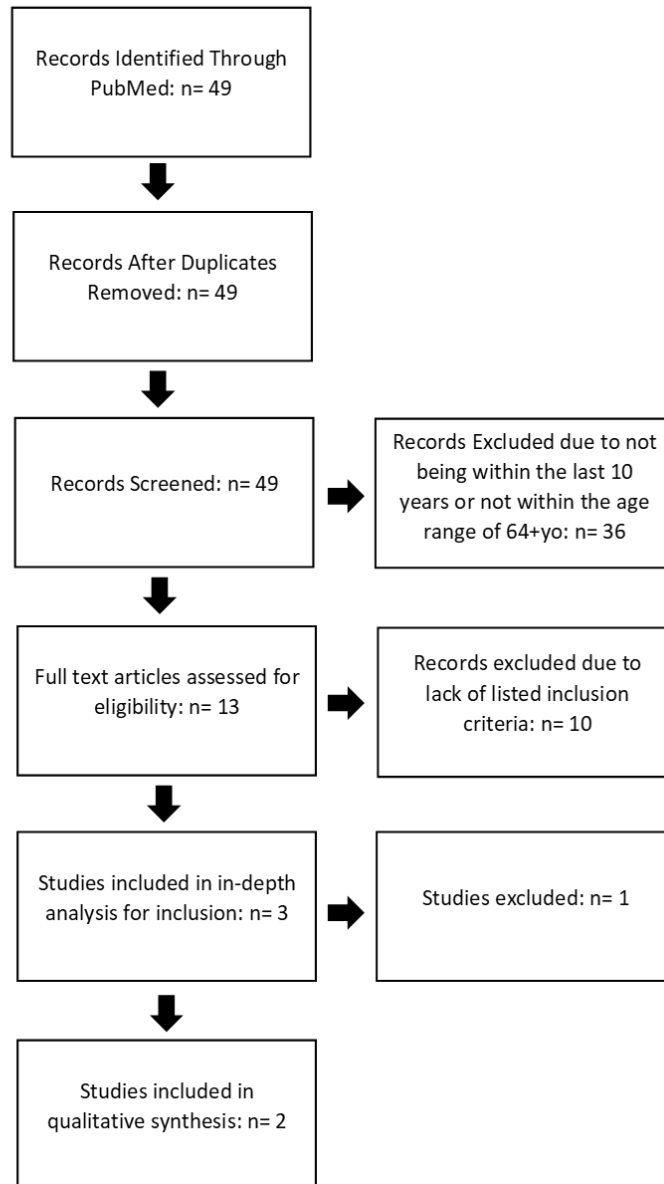
Search 1: PRISMA Diagram



Search 2: PRISMA Diagram



Search 3: PRISMA Diagram:



Results:

Although some physiological effects were listed in the reviewed articles, psychological effects were given priority since this is lacking in the literature for individuals with AD.

Search 1:

The periods of isolation that took place during COVID-19 had numerous psychological effects on young adults. Given the age and cognition level of the patients, it is assumed that accurate data was collected from these individuals.

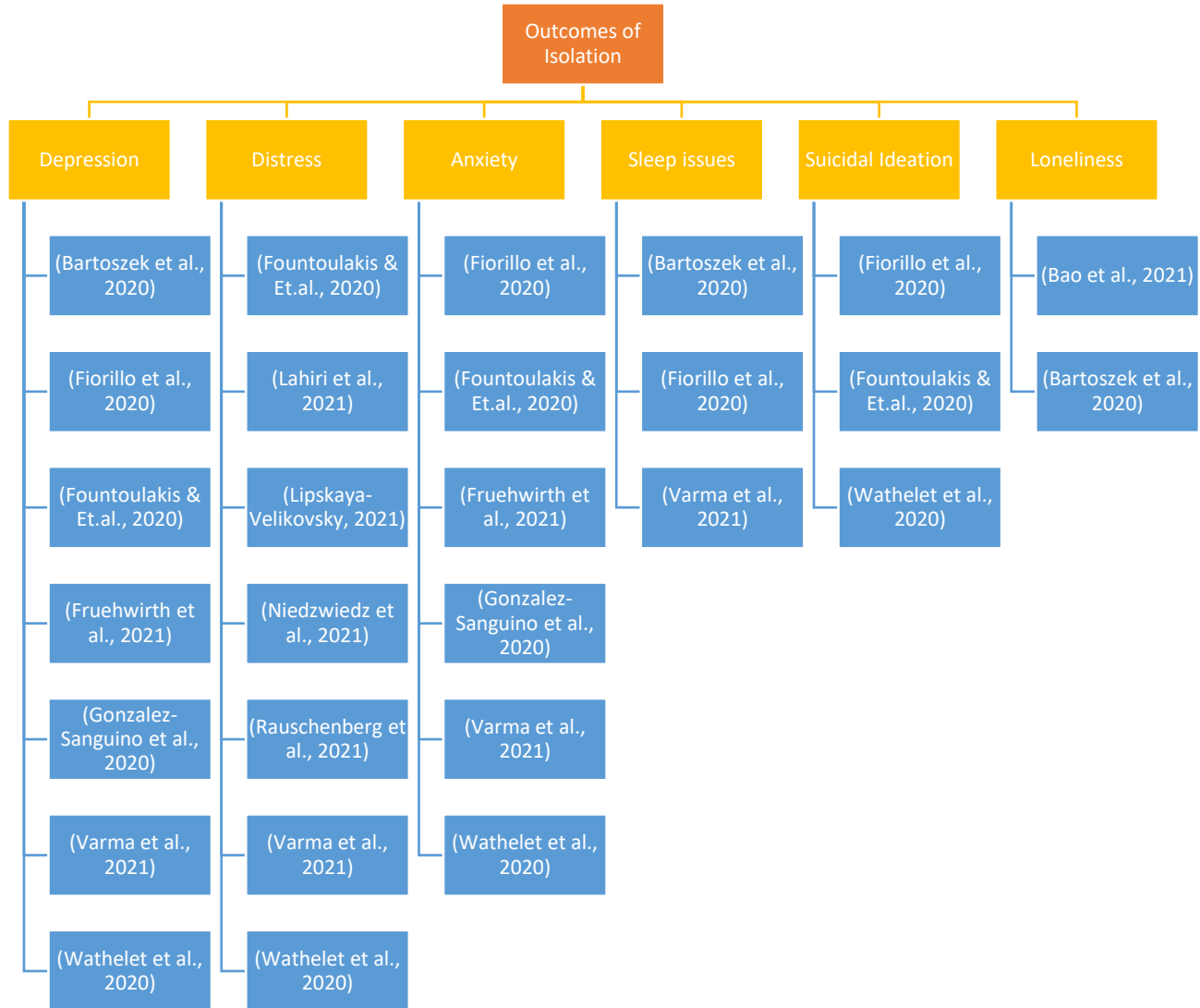
| Paper | Number of Participants | Mean Age/ Age Range | Date Collection Date Range | Data Collection Tool | Significant Findings |
|--------------------------|------------------------|---------------------|-----------------------------|----------------------|--|
| (Allé & Berntsen, 2021) | 211 | 38 | April 27-May 20, 2020 | Qualtrics Survey | A connection between isolation and psychotic symptoms/ cognitive issues during the COVID-19 lockdown that should be further investigated. |
| (Bao et al., 2021) | 7741 | 33.1 | January 27-February 2, 2020 | Online Questionnaire | Suggests that mental health treatments to mitigate these effects if isolation is necessary. Found a higher percentage of loneliness than prepandemic measures and increased loneliness associated with younger age. |
| (Bartoszek et al., 2020) | 471 | 25.5 | April 3-17, 2020 | Online Questionnaire | Found a higher incidence of depression, insomnia, loneliness, and everyday fatigue with isolation. |
| (Cerami et al., 2021) | 1258 | 43 | March 14-March 31, 2020 | Online Questionnaire | Found increased frailty with age, increased frailty and vulnerability with increased isolation, and increased vulnerability in really old and really young populations. |
| (Fiorillo et al., 2020) | 20720 | 40 | March 30- May 4, 2020 | Online Questionnaire | Found increased depression and anxiety with increased isolation, worsened outcomes for females in isolation, pre-existing psychological issues led to worsened anxiety and depression outcomes with isolation, increased use of the internet |

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|----------------------------------|------|-----------|---|----------------------|---|
| | | | | | during isolation led to increased depression and anxiety, high rates of suicidal ideation with isolation, increased sleep disturbances with increased isolation, and good perceived social support during isolation. |
| (Fountoulakis & Et.al., 2020) | 3399 | 35 | April 11- May1, 2021 | Online Questionnaire | Found increases in anxiety, depression, distress, and suicidality with isolation. 95% of individuals surveyed felt that they had a good idea of why they were isolated. |
| (Fruehwirth et al., 2021) | 419 | 18.9 | Before Oct. 2019- Feb. 2020 and after June- July 2020 | Qualtrics Survey | Correlation between social isolation during COVID and significantly increased symptoms of depression and anxiety. Suggest that colleges be ready to provide additional counseling and support as well as find ways to give this support virtually in the event of future isolation. |
| (Fumagalli et al., 2021) | 334 | 21.5 | April- May 2020 | Online Questionnaire | Found that, during isolation, messaging apps can improve feelings of loneliness while social networking apps may worsen feelings of loneliness. Suggest public policy changes to help young adults adopt ways of managing their perceived isolation in order to maintain better long-term mental health. |
| (Gonzalez-Sanguino et al., 2020) | 3480 | 18-60yo | March 21- June 4, 2020 | Online Questionnaire | Found increased levels of depression and anxiety from survey 1 (beginning of lockdown) to survey 3 (post lockdown). Suggest looking at perceived loneliness (strong predictor of psychological wellbeing) and spiritual well-being (strong predictor of resilience). Suggest paying special attention to more vulnerable groups like young people and women. |
| (Lahiri et al., 2021) | 1249 | 18-65yo | April 17-May 16, 2020 | Online Questionnaire | Found an increase in psychological distress during isolation. The two main factors of this increase are poor coping strategies and perceptions of social distancing. Suggest proper knowledge of the magnitude of the pandemic, mitigating rumors, and addressing the psychosocial concerns. Suggest improved mass counselling and increased digital social connectivity. |
| (Lipskaya-Velikovs) | 571 | median=29 | spring 2020 | Online Questionnaire | Results indicate high rates distress and decreased quality of life with isolation. Found routines to be helpful in mitigating |

| | | | | | |
|------------------------------|------|------------|--------------------------|-----------------------------------|--|
| ky, 2021) | | | | | the negative effects of isolation and that demographics had an effect on the level of negative effects. Suggest psychoeducation regarding pandemics and lockdown, actions to encourage participation in daily life activities, occupational therapists' intervention to help mitigate negative effects, further development of public health strategies, and continuation of a routine. |
| (Liu et al., 2021) | 3973 | media n=22 | five time points in 2020 | Qualtrics Survey | Found social isolation to have a negative effect on overall wellbeing. Suggest isolation be a large focus of future interventions, that interventions be delivered in an m-Health/ tele-Health format, and that future efforts be aimed at identifying the most at-risk populations during isolation. |
| (Lopez-Carral et al., 2020) | 112 | 32.38 | April 9-20, 2020 | Online Study | Found quarantine to have a negative impact on the mood of an individual. Found that people who missed their life pre-quarantine or people who lived alone were more susceptible to worsened mood. Noted that the results are highly dependent on the intensity of an individual's isolation. Suggest implementing the emotional well-being program into an app and regular clinical service as well as investigating the long-term effects of isolation on mood. |
| (Niedzwi edz et al., 2021) | 9748 | 49.5 | 2015-2020 | tele/ face to face/ online survey | Found an increase in distress during the lockdown time period, however loneliness remained relatively stable. Found correlation between demographics and distress. Suggest more widely available psychological support to minimize these effects. |
| (Rausche nberg et al., 2021) | 666 | 21.3 | May 5-16, 2020 | Online Question naire | Found an increase in distress during the COVID-19 lockdowns. Found that this distress was associated with social isolation, lack of company, COVID-19 related cognitive preoccupation, worries, and anxiety. In addition, found correlation between demographics and increased distress levels. Found use of mHealth apps was more likely in those with severe distress, frequent social isolation, and lack of company. Suggest investigation into |

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|-------------------------|-------|------------|---------------------|----------------------|---|
| | | | | | mHealth app that can help with mental health during isolation times. |
| (Sahi et al., 2021) | 486 | 20 | 2020-2021 | Qualtrics Survey | Found an increase in the number of virtual interactions was associated with better mental health during isolation. Suggest people continue to have more virtual interactions despite the technology burnout that may happen. |
| (Varma et al., 2021) | 1653 | 42.09 | April 9-May25, 2020 | Qualtrics Survey | Found an increase in distress, anxiety, depression, and poorer sleep with isolation. Aggravating factors included younger age and previous diagnosis of mental health issues. Suggest the implementation of mHealth interventions to minimize distress. In addition, suggest that public health programs focus on the importance of sleep, which is a significant correlate to the amount of distress the individual is in. |
| (Wathelet et al., 2020) | 69054 | media n=20 | April 17-May4, 2020 | Online Questionnaire | Found higher rates of severe self-reported mental health symptoms after quarantine. Found an association between gender and worse mental health outcomes as well as higher rates of suicidal thoughts, severe self-reported distress, depression, anxiety, and stress with isolation. Suggest interventions should pay special attention to more at-risk populations. |

Most commonly mentioned outcomes of isolation. Only outcomes that were mentioned more than once were noted in this figure:



As seen in the figure, there were significant increases in depression, distress, anxiety, sleep issues, suicidality, and loneliness. Sources noted that an increase in distress during the COVID-19 lockdowns was associated specifically with social isolation, lack of company, covid related cognitive preoccupation, worries, anxiety, poor coping strategies, and perceptions of social distancing (Lahiri et al., 2021; Rauschenberg et al., 2021). Despite the majority of papers stating

that loneliness increased over time, one paper did state that loneliness remained constant instead (Niedzwiedz et al., 2021).

There was also evidence that the depression and anxiety was worsened by technology use (Fiorillo et al., 2020). This was especially true to social media due to its non-interactive nature and may be attributed to the fear of missing out (FOMO) or to the further realization of the state of isolation (Fiorillo et al., 2020).

Of special interest to the authors of this paper, there was found to be evidence of cognitive decline over the period of isolation (Allé & Berntsen, 2021). In addition, about 95% of the lockdown participants knew the purpose of the lockdown– something that may not be true for patients with AD (Fountoulakis & Et.al., 2020). This could have a tremendous influence on the overall outcome of lockdowns for patients with AD and may prevent a closer association between COVID-19 lockdown individuals and patients with AD in CF.

The severity of these negative effects may be influenced by gender, age, minority populations, introduction of novel prescriptions, and previous diagnosis of mental health problems (Bao et al., 2021; Cerami et al., 2021; Fiorillo et al., 2020; Varma et al., 2021; Wathelet et al., 2020).

Although the majority of the papers agree that age is a factor, one did not come to this conclusion and stated that age was not a factor in the severity of the effects (Lahiri et al., 2021).

One article by Rauschenberg et. al., stated that there are some positive factors that resulted from the isolation such as more participation in the use of mHealth apps for patients who were

exhibiting higher levels of distress, isolation, and loneliness. It seems as though the more troubled an individual is during the isolation, the more willing they are to perform self-help activities (Rauschenberg et al., 2021).

There are a plethora of suggestions that the reviewed articles mention which are noted here to serve as a possible guideline for creating interventions for individuals with AD.

An education program was suggested for those experiencing the lockdowns and isolation so that they are aware of the extent of the situation as well as the proper techniques for getting through it with minimal psychological effects (Lahiri et al., 2021; Lipskaya-Velikovsky, 2021). It was also suggested that widely available mental health treatments specifically aimed at loneliness should be in place and ready to be delivered in case isolation is necessary (Bao et al., 2021; Fruehwirth et al., 2021). The treatment should be available virtually despite the possibility of technology burnout and could be offered to either individuals or groups (Fruehwirth et al., 2021; Lahiri et al., 2021; Liu et al., 2021; Niedzwiedz et al., 2021; Sahi et al., 2021; Varma et al., 2021). Virtual treatments could also help to track emotional and mood changes over time, act as an educational platform to inform participants of important factors to their mental health such as sleep, and be used as a social connectivity platform (Lahiri et al., 2021; Lopez-Carral et al., 2020; Varma et al., 2021). To aid in this endeavor, changes to public policy should be made so as to support young adults in adopting better long-term mental health coping strategies (Lipskaya-Velikovsky, 2021; Varma et al., 2021).

Continuing in a routine throughout the isolation period is suggested to aid in the mitigation of negative psychological effects and so should be a priority for anyone in that situation (Lipskaya-Velikovsky, 2021).

One of the most important and supported suggestions is to ensure that the treatment interventions are tailored to all demographics— especially more at-risk individuals such as women, young people, and minority populations (Fiorillo et al., 2020; Fruehwirth et al., 2021; Gonzalez-Sanguino et al., 2020; Liu et al., 2021; Niedzwiedz et al., 2021; Rauschenberg et al., 2021; Wathélet et al., 2020). However, more research should be done to further identify at risk groups (Liu et al., 2021). One study suggested doing this by looking at perceived loneliness, which is a strong predictor of psychological well-being, and spiritual well-being, which is a strong predictor of resilience (Gonzalez-Sanguino et al., 2020).

Search 2:

For older adults, the isolation caused by COVID-19 lockdowns created a variety of changes which included physical and mental deconditioning (Giri et al., 2021; Kotwal et al., 2021). However, Kotwal et. al. noted that this age group demonstrated remarkable adaptability and resilience during the COVID-19 lockdowns since their levels of loneliness increased initially, but then evened out after a certain period of time. Although this was true for the majority of participants, that article also noted that a select few individuals refused to adapt and experienced worsened symptoms of loneliness (Kotwal et al., 2021).

It was noted that there were many characteristics of CF that exacerbated the negative mental health outcomes of residents as well as the efficiency of contagious disease outbreak containment efforts. A higher number of beds and patients, the high traffic nature of nursing homes, for profit status of the facility, and reduced staffing levels were characteristics noted by Giri et.al. It was also found that "During the pandemic, reduced staff-resident contact time, lower levels of physical activity, decreased mealtime conversation and reduced social interactions may all have contributed to physical decline and/or weight loss in some residents, new instances of pressure ulcers and/or falls, and a general decline in psychological well-being and cognition, necessitating new supports for residents that were not previously mandated by quality standards" (Giri et al., 2021)

Despite the few sources that look at loneliness and the effects of isolation for these specific subgroups, there are some experimental interventions that have been implemented (Kotwal et al., 2021). For example, there were some apps that could help with the feelings of loneliness/isolation including apps such as facetime and skype (Banskota et al., 2020). However, it was found that participants preferred more unsolicited interactions rather than pre-planned or a self-initiated conversation (Kotwal et al., 2021).

Contradicting themes arose regarding the use of technology to avoid loneliness. Several sources highlighted the importance of developing interventions that do not rely on in-person interactions; however, several more discounted the potential for technological substitutes—some going so far as to state that technology does not have the capacity to replace human interaction for any amount of time (Banskota et al., 2020; Fingerman et al., 2021; Giri et al., 2021; Kotwal et al.,

2021). Even with the various forms of technological interventions, many patients were not comfortable with technology nor did they have adequate access to it leading some to make the conclusion that technology should be used with caution and sparingly (Kotwal et al., 2021). To further this point, there was found to be a positive effect of in-person interactions during the isolation period which draws away from the allure of solely technological solutions to loneliness and isolation (Fingerman et al., 2021). Giri et.al., Fingerman et.al. found continued evidence when patients did not respond as positively as anticipated when talking on the phone during isolation. This is thought to be because it appears to make the patient increasingly aware of their solitary state (Fingerman et al., 2021). But, given that technological interventions continue to be researched despite the criticism, it is essential to assess technological proficiencies and accessibility for certain populations and subgroups (Kotwal et al., 2021). By recognizing these boundaries, especially for individuals with AD, interventions can cater to the needs and abilities of the patient— especially those who may struggle more with the effects of isolation.

There were multiple suggestions made by these articles regarding CF. Among these were the need for CF to address understaffing and workforce crises so that the caregivers can be more attentive to the emotions of the residents (Bethell et al., 2021). Bethwell et. al. also noted that this is especially important in times when the staff and residents are in “crisis mode” due to external factors such as pandemics. In addition, trained staff should provide more information , reorientation, reassurance, and cognitive stimulation to the patients to decrease the negative effects of isolation (Giri et al., 2021).

The knowledge that an individual has regarding the reasoning for isolation is a recurring theme in both Search 1 and 2 and so should be considered important for interactions with individuals with AD. For future interventions, the characteristics of the facility should be taken into account so as to account for the method of intervention delivery, content that should be focused on, and practicality of an intervention (Giri et al., 2021).

Regardless of the facility or the technology that is used, novel ways of maintaining social connections during isolation should be researched for the general population as well as with special focus on individuals who have dementia (including different severities within the diagnosis) (Bethell et al., 2021; Kotwal et al., 2021).

It is important to note that although individuals may experience isolation when entering a CF under normal conditions, families play a large role in this transition. From the patient's care, representing the patient's perspective, and maintaining familial connections, they are a crucial part to keeping the patient in as positive of spirits as possible (Bethell et al., 2021). However, when there is a lockdown due to a contagious disease outbreak, this family interaction is lost which causes more strain on the patient as well as the CF who now must provide both medical and emotional care (Bethell et al., 2021).

Although this section was focused on individuals with no AD diagnosis, there were also mentions of how these findings would apply to individuals with AD. The consensus is that patients with AD may not grasp the complexity of the situation and therefore are unable to participate in many technological interventions to help with the feelings of loneliness during

isolation (Giri et al., 2021). As stated before, this can be exceptionally dangerous since loneliness has the potential to lead to a host of other physical and mental health problems. New methods of social connectivity should be engineered specifically for individuals with dementia (and different severities as well) (Bethell et al., 2021).

Search 3:

Similar to the first two searches, social isolation was found to have several negative effects, but even more so on an individual who is already cognitively fragile.

These negative effects due to social isolation (and the resulting reduced sensory stimulation) include compromising social contacts, sedentary behavior, lowering engagement with other residents, increasing fall risks, increased hospitalizations, reducing physical exercise, lowering meaningful or joint activities in the facilities, and increased risk of death (Bolt et al., 2021; Edelman et al., 2020). These go on to cause anxiety, apathy, boredom, agitation, loneliness, distress, confusion, and depression specifically for residents who have dementia (Bolt et al., 2021; Edelman et al., 2020). The loneliness that is caused also lead to undesirable effects including poorer mental/ physical health outcomes and higher mortality risk (Bolt et al., 2021). At the time that this review was being done, there were no officially documented effects of COVID-19 isolation in this population, but short-term effects were given anecdotally by nursing staff in Bolt et.al. These included rapid decline in function and health (e.g., nutrition issues and renal dysfunction), hopelessness, severe depression, and increased suicidal ideation (Bolt et al., 2021).

Both Bolt et.al. and Edelman et.al. provided care suggestions for patients who may be in an isolation period either by themselves or if the facility itself is isolated from the outside world.

Bolt et.al. provided a wealth of suggestions for nursing staff in particular which were split into psychological and social aspects and have been summarized in the chart below (Bolt et al., 2021):

| Psychological aspects of care | Social aspects of care |
|--|---|
| <ul style="list-style-type: none"> • Decreased social interaction and unfamiliar PPE may cause feelings of anxiety, depression, grief and trauma in residents • Reduce anxiety regarding COVID-19 by reducing media exposure, provide simple explanations, and listen to the patient’s concerns. • Encourage participation in activities and routines. • Entertain residents by using old photographs, objects, or songs from their past. • Stimulate movement. • Isolation may worsen symptoms of dementia, so patience is essential. • Use technology to promote interaction among residents and their families. • Collaboration with mental health professionals so as to maintain mental health as much as possible. | <ul style="list-style-type: none"> • Although it is recommended that patients with COVID-19 should be isolated, careful weighing of a visit against infection risk should be done especially when a patient is nearing the end of life. • Families and friends should be encouraged to drop off letters, drawings or other packages. • Arrange regular family or friend check-ins using technology or distanced visitation. • Continue small group activities within the facility when possible. • Creative uses of technology for visitation such as virtual reality. • In certain circumstances, offering a family caregiver the chance to move in with the resident so as to provide social support. |

Edelman et.al. supported the use of technology to provide increase social support especially in the form of videoconferencing, however voiced concern that it would be minimal due to limitations in wireless access in the majority of facilities as well as financial caps on device access (Edelman et al., 2020).

Discussion:

By looking at searches 1 and 2, it is likely that individuals with Alzheimer's Disease in nursing homes face a more of psychological, cognitive, social, and physical challenges when forced into isolation due to contagious diseases during their time in a CF than we were previously aware of. It is possible that these effects are even more profound due to their already fragile state and so should be addressed with more urgency than is currently demonstrated.

With the small number of sources that met the inclusion and exclusion criteria outlined for the Search 3, more efforts should be made to understand this area of long-term AD care. Given the interventions that have been tested in Searches 1 and 2, as well as the persistent negative effects that isolation can have on individuals with and without Alzheimer's Disease, it is also worth the time and effort for future researchers to more closely investigate the intersection of technology and human contact as well as a safer way of human interaction with patients even through a highly contagious disease state.

The author of this paper recognizes that it is difficult to obtain very detailed feedback from individuals with AD regarding their care experiences and emotions that may arise, however more of an effort needs to be made. As represented by the disease progression outline provided by Johns Hopkins Medicine, these individuals effectively become invisible once they receive an AD diagnosis even though there is evidence that they are aware of events surrounding them well into the disease progression (*Stages of Alzheimer's Disease*, n.d.). Cerami et.al. summarizes the point exceptionally well: " We must prevent social distancing from becoming social isolation".

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PART 2: Care proposal

In addition to the literature review, interviews with staff of care facilities will also be conducted. Their personal and professional thoughts and suggestions regarding the effects of social isolation were documented. A combination of the suggestions found in the literature review and the anecdotal input from the local care facilities will be used to form a care proposal pamphlet.

Two care facilities participated in this section and one decided to remain anonymous. The answers to various questions can be found in the table below:

| Question | Jose Cruz with Hacienda at the River | Anonymous Care Facility |
|---|--|--|
| What kind of facility would you consider yourself? | “Assisted community living and memory care” | “Assisted living and memory care” |
| Prior to COVID-19 how does your facility make the transition from independent living to assisted living easier on the patient so as to avoid loneliness or feelings of isolation? | “Many outings in the community with some third-party help” | <ul style="list-style-type: none"> • “Community activities where residents were encouraged to participate • 5-1 patient to caregiver ratio so that the caregiver can spend more time with the patient and figure out what they liked (especially when it came to activities so that they could better cater that to the patients)” |
| Prior to COVID-19 how did your facility handle the outbreak of contagious diseases such as shingles or the flu so as to avoid loneliness or feelings of social isolation? | <p>“Would put up isolation doorways which were plastic doorways that were the most effective for containing the disease (this is especially in memory care since it kept the patient from wandering as well)</p> <ul style="list-style-type: none"> • Would also use PPE • Effective since they are mainly private | <ul style="list-style-type: none"> • “Isolation by 24-hour increments (especially for the flu) <ul style="list-style-type: none"> ○ Only gowned caregivers are allowed in the room” |

| | | |
|--|--|---|
| | rooms so there was no relocation of roommates” | |
| How has this changed or been modified during COVID-19? | <p>“Added items such as:</p> <ul style="list-style-type: none"> • More community activities within the facility rather than going out into public • I-pad/tablet used now for Zoom calls with patient family and friends • Once there were not positive cases within the facility, but they were still shut down, there were window visits using a phone system to communicate • Once there were vaccines available, in person visits were allowed in outdoor spaces or vaccinated guests were allowed only in the patient room • Kiosk symptom checker at check in for case tracking and for an extra safety measure effort” | <ul style="list-style-type: none"> • “Only isolation that took place at this facility was the entire facility isolation which was mandated by the United States government • The majority of internal community activities were continued since there were no major outbreaks in this facility” |
| What aspects of this seemed to work? | <ul style="list-style-type: none"> • “All of these seemed to work really well • The I-pad/tablet zoom calls will be continued since it was very effective and convenient especially for family that may be out of town • The kiosk symptom checker will continue to be used for the time | <ul style="list-style-type: none"> • “Nearly always open to families (even throughout most of the more difficult lockdowns) <ul style="list-style-type: none"> ○ Just added many precautions for these visitors • Zoom calls were regularly used” |

| | | |
|---|---|---|
| | being since COVID-19 is still going around” | |
| In what ways do you think this could have been improved? | <ul style="list-style-type: none"> • “Convey the idea of COVID-19 more clearly to the patients • Hire rotating psychologists to come do regular checks on the patients so that they can get more tailored care from a professional in that field rather than getting that from the care staff <ul style="list-style-type: none"> ○ Care staff had to play a dual role in psych/emotional support and in regular care” | <ul style="list-style-type: none"> • “Overall, avoiding lockdowns in all communities would be optimal since this facility saw a decrease in the COVID-19 symptom severity when there was still regular interaction with the patient <ul style="list-style-type: none"> ○ These lockdowns were mandated by the government” |
| Do you have any personal ideas for how these negative feelings could be better avoided? | <ul style="list-style-type: none"> • “Just preventing the cases from rising again so that they can get back to normal and fully open operations <ul style="list-style-type: none"> ○ Continue with kiosks ○ Make sure that 3rd party vendors are all aware of the protocol changes ○ Continue zoom visits ○ Increase pet therapy sessions” | <ul style="list-style-type: none"> • “Residents seemed to have more symptoms of depression and anxiety because it seems the patients were able to watch the news and had an idea of what was happening • Noted that patients should have autonomy in deciding if they would like to put themselves at risk to participate in social activities or if they would like to stay distanced” |

These, in addition to the suggestions made throughout the literature review were compiled and made into a comprehensive pamphlet which would be beneficial for both the care facilities as well as any family or friends who are involved in the care of the individual with AD.

Part 3: Brochure

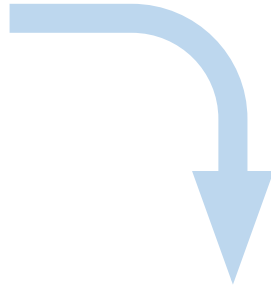
See next page.

What is this?

Individuals with Alzheimer's are likely aware of their surrounding until very late in the disease progression



Due to physical constraints, care facilities are excellent targets for contagious disease outbreaks



Alzheimer's Disease

Social Isolation Care Protocol

This pamphlet is a part of a thesis completed as a requirement for graduation with Honors in Physiology (B.S.).

All of the sources for these statistics can be found in the following paper: *Consequences of social isolation on elders with Alzheimer's Disease in care facilities: A comparative literature review* by Camille DeMarcus

Any questions regarding this information can be directed to Camille DeMarcus at camilledemarcus@hotmail.com

Isolation

Often, the response to a disease outbreak (such as shingles or the flu) is physical isolation.

Isolation—for even a small amount of time in young healthy people—can cause a plethora of issues such as:

Depression
Sleep Issues
Anxiety
Suicidal Ideation
Loneliness
Distress

From studies on young healthy adults during COVID-19 isolation as well as feedback from various care homes, a list of things that can be used to minimize the negative effects of isolation can be found below.

Now what?

1. Implement virtual interactions (Zoom, FaceTime)
2. Increase patient education regarding the cause and purpose of the isolation
3. Encourage maintenance of routines throughout isolation
4. Pay careful attention to at-risk populations such as women or those who are significantly older
5. Higher caregiver to resident ratios
6. More careful monitoring of symptoms so as to not keep individuals in isolation for longer than needed
7. With more strict precautions, continue to allow family/ friends to visit
8. Increase pet therapy visits if possible
9. Provide more individualized activities for those in isolation so as to keep their morale up
10. Increase psychological counselling as much as possible

It is always important to ask yourself: “How would I feel if I were in this situation?”

Making care protocol/policy changes is essential to improving care for these residents.

Having a plan in place will allow for better allocation of limited staff and for better recovery.

Remember to have patience with these residents and their families. As part of the care staff, you can minimize these negative psychosocial effects!

Future of Care