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An Overview of Individualized Management of Neuropsychiatric Symptoms in Dementia

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An Overview of Individualized Management of Neuropsychiatric Symptoms in Dementia

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III. Abstract

Background: It is estimated that about 11% of adults 65 and older have dementia in the United States. Neuropsychiatric symptoms are common in the presentation of dementia. These symptoms often result in increased morbidity and mortality, negative patient outcomes, caregiver burden, institutionalized care, and diminished quality of life. The focus of this paper is to analyze the therapeutic effectiveness of nonpharmacologic interventions in the management of neuropsychiatric symptoms of dementia.

Methods: A literature review was conducted to critique current evidence on the use of nonpharmacologic interventions in managing neuropsychiatric symptoms in older adults with dementia. Searches were performed using PubMed, UpToDate, and Google Scholar.

Results: Pharmacotherapy should be cautiously considered in treating neuropsychiatric symptoms of dementia due to adverse effects and black box warnings. Although further studies are needed, music therapy, tailored bathing routines, bright light therapy, multisensory stimulation, and eliminating the use of elderspeak language are nonpharmacologic interventions that contain some evidence in improving quality of life in dementia. The validation technique is still an ethically controversial approach to communication. As a result of the COVID-19 pandemic, social isolation has worsened in people with dementia.

Conclusion: Dementia is a disease that requires multifactorial care in approaching management. Nonpharmacologic interventions are the first-line plan of treatment in managing neuropsychiatric symptoms of dementia and present with fewer side effects and are person-centered in implementing. Future research in developing measures for quality of life is needed to study effectiveness of nonpharmacologic therapy.

IV. Introduction

Dementia is an umbrella term for the collection of symptoms caused by brain disease or injury causing a decline in cognition.¹ Various brain pathologies can contribute to dementia: Alzheimer's disease, vascular dementia, Lewy body disease, frontotemporal dementia, Parkinson disease dementia, and other pathologies.^{2,3} Alzheimer's disease makes up about 60% of all dementias.² The estimate for 2021 in the United States is that about 11% of adults 65 and older have dementia.⁴ This number is only predicted to increase with the aging and growing population. Dementia affects memory, learning, language, cognitive abilities, sense of self, relationships, attention, and ability to perform activities of daily living (ADLs).³ Location of residence, age of onset, pathology, stage, and comorbidities are among the confounding variables that make the experience and needs unique to every individual with dementia. Since no cure exist for dementia as of now, the goal is management.

Neuropsychiatric symptoms (NPS) are distressing in dementia and increase as the disease progresses. Some of the symptoms can include agitation, aggression, apathy, wandering, irritability, hallucinations, delusions, anxiety, depression, appetite disorders, psychosis, rejection of care, repetitive verbalizations, hoarding, rummaging, screaming, spitting, sexual behaviors, and sleep changes.^{2,5-7} Although it is not always easy or even possible to identify triggers of specific symptoms within NPS, many triggers are in relation to portraying unmet needs, environmental stressors, or internal cues.

NPS are often what prevent individuals from living at home due to the higher level of care required for managing these episodes and the associated family member provider burnout.²⁸ These symptoms often contribute to care giver burden, worsened outcomes, diminished quality of life, increased hospitalizations, and accelerated morbidity and mortality.² People with

dementia are at an increased risk of neglect and abuse from caretakers due to these symptoms. Many caretakers experience burnout due to short staffing and lack of understanding in communicating with people with dementia. People with dementia can have difficulty in communicating needs and may express themselves using distressed behaviors.⁹ Caretakers often feel emotionally exhausted interpreting and extinguishing these behavioral outbursts.⁹

It has become common practice to manage NPS of dementia with *pro re nata* (PRN) medications that contain insufficient evidence and severe warnings in use with the elderly population. These medications can increase the risk of adverse effects and mortality. In comparing standard pharmacologic treatment in people with dementia residing in care facilities, hospitals, or in the community, the research question is: do nonpharmacologic interventions improve the quality of life and diminish neuropsychiatric symptoms in people with dementia? Due to the variation in presentation of NPS in dementia and confounding variables, likely the plan of management will vary per individual.

This paper will explore the nonpharmacologic options in managing NPS in dementia by outlining the therapeutic effectiveness of pharmacotherapy, music therapy, bathing rituals, validation technique, bright light therapy, and sensory stimulation used in the management of caring for people with dementia. The aftermath effects of the COVID-19 pandemic on people with dementia will also be considered in exploration of this paper. With no cure for dementia, the goal of this analysis is to provide evidence-based recommendations as to whether these interventions can offer an individualized approach and be utilized in improving the quality of life in people with dementia.

V. Background: Literature Review

Pharmacologic Treatment

Polypharmacy is common in the elderly population and especially in people with dementia due to comorbidities present. Taking multiple medications increases the risk of drug-drug interactions, adverse drug reactions, falls, malnutrition, pneumonia, and death.² When it comes to the pharmacologic management of dementia, there is not a cure. No drugs have been proven to slow or stop the damage and destruction that is inevitably the progression that comes with dementia.⁴ According to the FDA, no drugs are specifically approved and recommended to treat NPS unless the patient is causing harm to self or others.² Medications with insufficient evidence and contain Black Box warnings are commonly prescribed to this population. These factors of pharmacologic therapy can potentially increase the risk of mortality and diminish quality of life.

The American Geriatrics Society Beers Criteria[®] for Potentially Inappropriate Medication Use in Older Adults is an updated list of medications that should be avoided in adults sixty-five years and older.¹⁰ In managing dementia, this list recommends avoiding the use of anticholinergics, antipsychotics, and benzodiazepines in the elderly.¹⁰ Just recently, combination dextromethorphan/quinidine was added to the list in patients with dementia without symptomatic pseudobulbar affect due to limited efficacy in managing NPS, numerous drug-drug interactions, and potentially increased fall rates.^{10,11}

It is estimated that about 82% of patients with dementia are on some form of psychotropic medication.² The use of antipsychotics is thought to be appropriate in relieving caregiver stress and create a calmer environment for people with dementia.² Yet the use for antipsychotics in dementia management is controversial and presents with many warnings against use. Antipsychotic medications propose an increased risk of abnormal gait, falls, excessive sedation, metabolic syndrome, weight gain, akathisia, drug-induced parkinsonism, and

risk of stroke.^{6,8,10,12} There is a Black Box warning on first- and second-generation antipsychotics for increased risk of mortality in the elderly due to the increased risk of cardiovascular events and infections.²¹⁰ Antipsychotics have also been shown to increase the rate of cognitive decline which is counter-productive in managing dementia.¹⁰ The exception for supported antipsychotic use is when a patient with dementia is at risk of harm.⁵

Nonpharmacologic interventions must first be attempted, but if those options have failed or are not able to be administered, antipsychotics may be considered in the case that the individual is threatening harm to self or others.^{5,10}

Benzodiazepines are widely used as PRN sedative agents in dementia.⁸ Common side effects include excessive sedation, worsening gait, agitation, tolerance, and physical dependence.¹¹ Benzodiazepines have an increased risk of cognitive deficits, falls, and fractures in the elderly.¹⁰ The exception of their use is for managing extreme agitation or aggression when safer interventions fail and during predicted stressful episodes.^{8,11} A predictable stressful episode would be a necessary medical procedure such as drawing blood or getting dental work done that is previously known to agitate an individual. Even in these scenarios, risks and benefits must be weighed in administering benzodiazepines.

Some drugs in the management of NPS in dementia have been shown in some studies to be beneficial and present with fewer side effects. Cholinesterase inhibitors are typically well tolerated in patients with mild to moderate dementia and can have additional benefits on cognition.¹¹ A trial of selective serotonin reuptake inhibitors (SSRIs), specifically citalopram, can be useful in the management of agitation and paranoia in patients with Alzheimer's disease.¹¹ Citalopram, however, can cause QTc prolongation and should be avoided in patients at increased risk for arrhythmias.^{8,11} Also, trazadone is well tolerated and often used for initiating

sleep in patients with dementia experiencing difficulty in falling asleep after a trial of nonpharmacologic intervention.¹¹ The reason trazadone is well tolerated is because it does not have a high affinity for cholinergic receptors, therefore has less cholinergic side effects in the elderly.^{2,8} It is typically a PRN option for insomnia, irritability, and agitation.²⁸ Even these drugs mentioned need further investigation on effectiveness due to limited evidence.

Prior to determining a medication approach in managing agitation and aggressive symptoms, it is important to rule out pain as the triggering factor of these symptoms.⁸ Pain is not always easily expressed or stated in severe stages of depression and will be a trigger for NPS in many cases.¹¹ This can make determining severity of pain difficult. Patients have the right for pain management. The Pain Assessment in Advanced Dementia (PAINAD) shown in Table 1 is a tool commonly used in assessing severity of pain in more advanced dementia.¹¹ It is important to create a care plan of scheduled and PRN analgesics to provide adequate pain control.¹¹ PAINAD uses observations of breathing, vocalization, facial expression, body language, and ability to be consoled to score pain severity.¹¹ NPS can be clues for indicating that pain is being experienced.

It should be noted that no medication algorithm for managing dementia can be applicable to every patient with dementia.⁸ Every individual with dementia presents uniquely and progresses at an unpredictable rate through the stages of decline. If a new medication is initiated it is important to check and consider drug-drug interactions, the evidence for the medication, and the side effect and tolerability profiles.^{2,8} Start with a low dose and slowly titrate to a therapeutic level with continuous monitoring for adverse effects.²⁸ Patients and family members should be made aware and included in the discussion of the risks versus benefits, potential adverse effects, given information on black box warnings, and must provide consent prior to initiation.²

Nonpharmacologic interventions are recommended as the first-line treatment of NPS, but medications are often supported in emergency situations or persisting NPS.^{2,10,12} Medication lists need to be continually assessed for discontinuation.¹² A low threshold is warranted in discontinuing medications for the safety and preservation of quality of life.

Music Therapy

Across generations and cultures, music plays a role in everyday lives. Many people of all ages use music for recreation, distraction, or relaxation daily. Music therapy involves the patient and either a caretaker or music therapist. Some of the exercises a patient could participate in are singing, listening to music, composing music, dancing, or playing instruments alone or in group settings.^{13,14} Music therapists design group and individual sessions to meet the needs of each participant. They are skilled in facilitating singing, movement, and tonal therapeutic sessions to promote positive self-esteem and allow for a safe, creative outlet.¹⁵ They are also trained in selecting compositions that elicit certain emotions and meet individual preferences.¹⁵ Music is a relatively safe and cost-effective intervention to implement.

The effects of music on the mind can be powerful. It has a way of energizing, focusing, soothing, distracting, and uniting people.¹⁶ Music can trigger pleasure and emotional reward.¹⁴ As shown in functional magnetic resonance imaging studies, music does this by enhancing dopamine activity, the reward pathway, in the mesolimbic striatal system, creating a desirable experience for the listener.¹⁴ Dopamine influences pleasure perception.

Music can also trigger memory even in advanced dementia. When listening to music from one's past, memories may elicit: "Autobiographical information associated with musical melodies is evoked when we hear relevant music or when we are engaged in conversation about music or episodes and events in our life in which music has been important. Hearing music

associated with our past often evokes a strong 'feeling of knowing'."¹⁷ By listening to recognized music, memory and a recognizable stimulus may be elicited therefore overriding the overwhelming and confusing trigger of agitation.^{18,19} Is individualized music an effective approach in providing music therapy to people with dementia? According to neuroscience research, people with later stages of dementia can still recognize titles, melodies, pitches, and lyrics of familiar songs.¹⁹ Studies have demonstrated an improved recall of phrases presented in song versus spoken context.¹⁶ Some studies propose that receptive music therapy using individualized playlists is more effective in decreasing agitation than participatory music activities.^{7,20}

The Music & Memory Program is a program that recently began in the United States as a therapy for people with cognitive difficulties. As of July 2021, about 4,316 care facilities in the United States are certified to offer this program.²¹ State funding is offered in some states for its implementation and research in managing NPS in dementia. Studies in the United States on the Music & Memory Program have resulted in findings of a decrease in PRN antipsychotic medication use, a reduction of behavioral problems, and a decrease in pain from use of this intervention.^{20,22}

In this program, residents in facilities are assigned a portable music player with headphones. If headphones are not preferred to an individual, the music can be played over speaker. Participants are encouraged to listen to music for 30 minutes per day in the late morning or during a time of day when increased agitation occurs.¹⁸ Caregivers provide the intervention as needed with increased episodes of irritability and when the patient requests the music. Patients have individualized playlists grouped according to decade using music a patient previously enjoyed listening to in the past.

Participants are encouraged to help in the process of selecting songs. It can be difficult at more advanced stages of dementia for participants to list their favorite songs and genres of music, so it is important to include close family members in selecting songs that include meaning and memories of the past for creating individualized playlists.²² In some cases it can be difficult to obtain information on an individual's favorite songs, so it can be helpful to make playlists of popular songs from the individual's young adulthood as a start to the process in individualizing music therapy.²²

Administrators of nursing facilities in Wisconsin, using the Music & Memory Program, reported common barriers of this program being difficulty managing culture change, limited resources and staffing, lack of implementation policy, lack of training, and hesitancy of effectiveness.¹⁹ Developing better implementation strategies could lead to a more successful program in future studies. It is also important to get the input from family members, direct care staff, and participants in surveys about this program for future advancement.

Some participants reported that their music was upsetting or that they were frustrated that the technology was not user-friendly.¹⁹ Special designed music boxes have also made the technology even simpler to use music as intervention if portable music players are not preferred. Songs can be directly uploaded to the music player box and a lever on top of the box is lifted to play the music. The box contains a single button that can be pressed to skip a song in the playlist.

Music can also play a role in treating acute and chronic pain. Although evidence does not yet support replacing the use of analgesics in pain management care plans, music activates positive reward pathways in the brain and can improve affect and mood.¹⁴ Another way in which music has been shown to reduce the perception of pain and suffering is by altering cognition and

sensory processes.¹³ It can have a calming and relaxing effect on the mind and body by enhancing dopamine pathways.¹³

Group music therapy uses music intervention for social interaction. Through music, participants are sharing the experience through singing with others and conversing about the music.¹⁸ One of the many reasons people attend concerts, musicals, music festivals, orchestras, and operas is that music has a way of bringing out a shared connection and emotional social experience. A study in Switzerland using the Music & Memory Program in sessions with a caregiver and participant found that emotional connection can develop between patients with dementia and their caregivers using a shared experience of music.²² Using the Observed Emotion Rating Scale on recorded playback, positive emotions occurred more often than negative during sessions.²² Other group therapy studies have shown a decrease in depressive mood and agitation during sessions.¹⁵ This is likely due to the mind and body stimulating activities and social benefits of the group interaction.¹⁵

Music presents with limitless potential as a nonpharmacologic intervention. During bathing, playing individualized music in the bathroom has been shown to significantly decrease episodes of agitated behavior.²³ In later stages of dementia, it can be very frustrating to an individual to lose the ability to verbally communicate, but music can act as a form of self-expression.¹⁸ Individuals with dementia may often still retain their ability to play the piano through memory and sight reading long past their lost ability to remember the names and faces of loved ones. Music intervention positively impacts quality of life in people with dementia.

Bathing

People with dementia require higher levels of assistance in personal cares as the disease progresses. Bathing is the most frequent NPS triggering personal care task to perform in certain

dementia, especially in more advanced stages of dementia.²³ Even people with dementia residing in their own homes can find bathing a frustrating ADL. Bathing is often resisted and refused. One reason for refusal to bathe is that the individual with dementia may no longer be able to perceive need for hygiene or remember last time bathed. This is also a very vulnerable care task and loss of independence and control may be felt in requiring assistance, especially if the caretaker is not a familiar person to the individual.

Elderspeak is another common reason for refusals of personal care tasks in caring for people with dementia.^{23,24} In this form of communication, younger adults are speaking a portrayed message of incompetency to dependent elderly people.²⁴ Elderspeak can be described as using “baby talk”, terms of endearment, repetition, speaking louder and slowly, and using simple vocabulary when speaking to the elderly population.²³ This form of talk may be used with good intentions from a caretaker to appear warm and friendly to a dependent patient, but ultimately comes across as demeaning and patronizing.²⁴ Table 2 shows types of communication in elderspeak as well as examples of the effects it can have on people with dementia.²⁴ Emotional tone and language used during care tasks are very important in cooperation and diminishing behavioral outbursts.²⁴ Appropriate communication that uses person-centered language reduces refusals and enhances self-esteem.²⁴ People with dementia need to feel respected in all personal cares being performed. This respect starts with choice of communication.

20% to 40% of nursing home residents with dementia display distressed behaviors during bathing, making it an uncomfortable experience for both the resident and caretakers.²⁵ Outbursts of agitation and aggression during the bathing process can put caretakers at risk of physical injury. The risk of neglect is increased due to refusals of care and increased aggressive behaviors. A lack of bathing can cause skin infection, skin breakdown, urine burns, and poor

hygiene.²³ Residents in nursing homes have the right to refuse cares, so bathing cannot be forced. Instead, methods need to be considered in providing a better experience in the bathing process to prevent NPS and refusals.

Although it is unreasonable to believe that refusals and distressed behaviors towards bathing can be avoided altogether, nonpharmacologic interventions can be helpful in reducing refusals of care in bathing. Teaching caretakers about these interventions can make bathing a better experience for people with dementia. Bathing Without a Battle is a training program used to teach nursing home staff to utilize patient-centered care with the goal of reducing behaviors of agitation in patients with dementia during the bathing process.²⁵ Current staff and new staff are trained in a course to learn how to best predict triggers, provide a comfortable bathing environment, and respect resident preferences.²⁵ Overall, studies have shown that this program significantly reduces verbal behaviors, bath duration, and after bathing antipsychotic use.²⁵ More research is needed for this patient-centered care approach to become a standard training and practice in all facilities.

It is important to realize that it can be distressing to an individual with dementia to lose the sense of independence as well as feel vulnerable and exposed when being bathed, especially in the case of not remembering the individual providing the care. Body language should be observed for signs of discomfort, pain, hunger, and fear to address these needs prior to bathing.²³ A focus on providing privacy, reassurance, options, and allow for independent tasks in bathing are helpful tips for caretakers.²³

The Alzheimer's Association, a resource for caregivers with tips for caring for people with dementia, suggests preparing the bathroom prior.²⁶ Surfaces, water, and air temperature that feel too cold or hot to the person with dementia can create aggravating symptoms.²⁶ Additional

tips for a positive bathing experience are: developing a routine, covering exposed areas as much as possible to conserve dignity, and allowing the individual to perform tasks in bathing.²⁶ Playing music during bathing and promoting independence by offering options throughout the bathing process has been shown to reduce behaviors associated with refusals and agitation.^{23,26}

If financial resources, bathroom amenities, and safety measures allow, it would be beneficial to discover preference of a bath or shower.^{11,26} Choices allow for bathing to be based on individual comfort and preference, supporting person-centered care.²⁶ Another option that is often overlooked is a packaged bed bath. In this type of bath, a package of wipes is warmed in the microwave to provide a cleansing gentle massage as the person receiving the bath lays in bed. Packaged shampoo caps can also be heated and used for hair hygiene. This form of bath allows for the individual to remain covered throughout the process.²⁶ Studies have shown a decline in agitation, aggression, and discomfort using this form of bathing in comparison to control groups.¹¹

To ensure a positive bathing experience for a person with dementia, it may require a great deal of trial-and-error to develop a patient-centered routine that results in increased comfort and less refusals. Structured protocols and training on person-centered communication show positive results in reducing agitation, aggression, anxiety, and discomfort, but more studies are needed in developing these protocols.⁷

Validation Technique

In treating and managing care in people with dementia, communication is a complex tool. Communication not only builds relationship, but orientates, instills trust, preserves dignity, and guides behaviors through verbal language and body language. As dementia progresses, communication becomes increasingly more difficult causing frustrations in both the individual

and in the caretakers.²⁷ Validation therapy, is designed to validate an individual's perception on reality and emotions.⁷ The controversy in communication still stands as to whether it is more ethical to validate an individual with dementia's current reality and risk lying versus reorientate the individual to reality and potentially cause distress.

The UK uses an approach for caretaker communication in people with dementia called SPECAL[®] (Specialized Early Care for Alzheimer's). This method is made up of "Three Golden Rules" that guide caretaker interactions: "avoid posing questions to the person with dementia; listen to the person with dementia and learn from them; and do not contradict the person with dementia."⁹ SPECAL[®] aims to discover the components that will best meet patient-centered care by care planning and keeping record of experiences, perspectives, and thought patterns.⁹ The focus in communication is to validate rather than contradict emotions and perceptions.⁹ Listening closely and developing a close relationship to detect patterns of thoughts and past experiences works best in this method. Listening allows the care-taker to gain a patient-led vocabulary that uses phrases the person with dementia being cared for connects best with when hearing.⁹ Using the techniques of SPECAL[®] has been shown to diminish anxious behavior and redirect the person with dementia to a calmer interaction state when used correctly.⁹ It can be argued that this method can make some caretakers uncomfortable because it validates the patient's reality versus actual reality to maintain well-being.⁹ By avoiding contradiction, critics argue that caretakers are lying by omitting the truth to patients.⁹

How often do caretakers use lies in caring for people with dementia? Although controversial, it is common practice to present some form of lie to people with dementia in cares.²⁷ A survey study in Italy revealed that in one group, focused on behavior, when nurses of various facilities were asked if they had ever used lies in caring for dementia only 3.8% were

against using lies in the situation of diminishing aggressive behaviors.²⁷ In this same group, 51.0% were against using lies in the situation of avoiding wasting time.²⁷ The debate falls on distinguishing if therapeutic lies exist.²⁷ Those in favor against this notion believe that lying to this population opens the doors to avoiding difficult situations and disabling the foundation of trust.²⁷ Authors in favor of therapeutic lies believe that lies can enhance patient self-esteem by avoiding the embarrassment and NPS that often arise from contradicting patients.^{9,27} Ultimately it would be beneficial to have guidelines on the correct use of a lie in caring for people with dementia.²⁷ Communicating and interacting effectively and meaningfully to gain trust in a person with dementia is a delicate and complex matter. More research is needed to further identify the risks versus benefits in lying for caretakers to practice ethical principles to avoid harm and enhance care in people with dementia.²⁷

In communicating with patients with dementia it is important to assess each encounter of NPS outbursts. Always be conscientious of body language and assess for triggering factors. Figure 1 shows examples of nonpharmacologic interventions in these situations.¹¹ Evidence suggests that these interventions can be effective in managing episodes of anxiousness or agitation.¹¹ Care takers must remain calm and provide reassuring responses.¹¹ More research is needed on person-centered communication to develop a better approach and understanding in communicating with people with dementia.

Light Therapy

Bright light therapy is the act of administering artificial or natural sources of lighting at a therapeutic level. The light can be administered by a window, using ambience lighting, through a light box at eye level, or time outdoors.⁷ Bright light therapy is thought to be an intervention for

reducing agitation and improving sleep in people with dementia. The theory behind the benefits of light therapy is based on light being the cue of the circadian rhythm.²⁸

Bright light therapy is thought to improve sleep disturbances, seasonal affective disorder, mood, and cognition in people with dementia. No definitive conclusions can be made regarding the therapeutic effectiveness of bright light therapy though due to mixed results. More studies must be conducted, but many have presented with beneficial effects of use in winter months of regions with diminished light cues.²⁹ Most light therapy studies with positive results had a repeated pattern use of white bright light administered in mornings from a range of thirty minutes to two hours for the duration of two-to-four-week trial periods.⁵ In order to tailor this therapy to an individual's circadian rhythm, it is also important is use daily and use in the mornings around a consistent time.^{6,11}

Many of the studies on bright light therapy directly investigate the effects it has on sleep patterns. It is estimated that about 44% of patients with dementia face disorders of sleep.²⁹ Sleep disturbances may consist of multiple night awakenings, difficulty initiating sleep, and increased daytime sleep.⁷ Sleep deprivation can decrease attention, slow processing speed, diminish cognitive function, and enhance emotional lability.²⁸ Disordered sleep therefore can be an underlying trigger of NPS in dementia and is important to address. Sleep disturbances also contribute to caregiver distress.⁵

Along with light therapy, it is beneficial to focus on sleep hygiene. Practicing good sleep hygiene involves limiting day-time napping, reducing caffeine-containing substances, and providing an adequate environment for sleep.¹² White noise, optimized temperature, and a darkened room should be offered based on preference for the sleep environment.²⁸ Sleep hygiene in combination with light therapy have been shown to improve sleep quality.²⁸

Light panels and ambience lighting are relatively affordable, easy to implement, and safe to use. No significant adverse effects present with bright light therapy.²⁹ Care takers do need to take caution by using skin and eye protection with natural light therapy though. Bright light therapy may cause agitated behaviors in some individuals, so it is not a fit for all people with dementia.

Future research should include comparison of intensity, frequency, and duration of light therapy as well as comparison of geographic locations and seasons to determine optimal therapeutic effectiveness.⁵ Community dwelling people with dementia versus those dwelling in residential care facilities should be compared. People in the community may have more outside exposure and natural window lighting than those in nursing homes with more fluorescent lighting and limited time outdoors.²⁹ More research on natural lighting is needed to accommodate more mobile individuals.⁷ Another limitation in the effectiveness of bright light therapy within studies is that adherence is difficult.²⁸

Snoezelen Rooms

Dementia contributes to developing sensory deficits, reducing the capacity to interpret the environment.⁷ This confusion interacting with external stimuli can be distressing. Through sensory stimulation, sensory imbalances may be corrected with consideration of ensuring individuals have proper prescription glasses and hearing aids at a basic level of care.⁷ Snoezelen environments are multisensory rooms that provide sensory stimulation to increase engagement and decrease NPS.³⁰ The rooms are designed for the individual to explore independently to promote autonomy in care.⁷

These environments stimulate sight, sound, touch, smell, and taste. Visual stimulation equipment used can include bubble tubes, optic fiber ropes, projectors, glitter balls, fish

aquariums, UV lamps, hand-held lights, light panels, picture books, LED nets, and star machines.^{30,31} Tactile stimulation equipment examples are optic fiber ropes, tactile balls, fabrics, soft toys, massage, vibrating tubes, vibrating cushions, and fidget lap blankets.³⁰ Olfactory stimulation can be through aroma diffusers, food, air fresheners, or aroma therapy sessions.^{30,31} In several small randomized trials, lemon balm or lavender oil were frequently used for agitation, although the mechanism of effectiveness is still not clear.¹¹ Auditory stimulation involves music relaxation, nature sounds, classical music, bells, musical instruments, or wind chimes.³⁰ Gustatory stimulation is also offered through food and drink. The tools of these rooms are to be implemented in sessions using a person-centered approach in the proper therapeutic amount to avoid sensory overload.³¹

 Snoezelen rooms were first implemented in the Netherlands to engage people with severe learning disabilities.³⁰ This approach of sensory room stimulation contains evidence in the potential to reduce agitation, improve engagement, manage pain perception, and provide social interaction to enhance quality of life in people with dementia.³⁰ In recent studies, nursing home residents in later stages of dementia appeared to gain the most benefits from these sensory sessions.³⁰ A trend of a decrease in agitation, apathy, anxiety, and depression was detected, although larger sample studies are required for future research.^{7, 31}

 The set-ups of these rooms are entirely variable and dependent on the funds and layouts of the facilities of implementation making comparative study difficult. Each facility Snoezelen room is different in design. Staff with access to Snoezelen rooms are often hesitant to use these rooms because the staff lack appropriate training with equipment and implementation of sessions.³⁰ Another limitation of the effectiveness of Snoezelen rooms is that research is made difficult due to the variety of set-up in facility layouts. Some facilities may have a lack of space

and are not willing to invest in renovation without sufficient evidence of effectiveness. Another consideration of these rooms is ensuring person-centered care by incorporating age-appropriate and familiar items for resident interaction.³⁰ Through further research of Snoezelen rooms, it would be beneficial to explore extending sensory components to more than just one room in a facility such as in bathrooms, bedrooms, and dining rooms. Sensory gardens are also another option to explore in providing multisensory stimulation.⁷

Effects of the Pandemic

In late 2019, the emergence of COVID-19 (SARS-CoV-2) led to a global pandemic. The world faced many public health measures that changed life as people knew it. This was the start of restrictions on public gatherings, self-isolation, restricted health resources, increase in virtual health appointments, and restriction of visitors at health facilities.³² People with dementia fell within the higher risk category due to comorbidities, vulnerability, and communal living spread if residing in nursing facilities.³³ Staff and residents residing in long-term care settings devastatingly make up 40% of the COVID-19 deaths in the United States.⁴ Prior to this pandemic, people living with dementia had already been facing social isolation. After the pandemic hit, people with dementia residing in nursing facilities faced a further loss of in-person contact with family support, decrease in daily social activities, isolation to room, virtual health appointments, and caretakers with increased fear and levels of stress.

The effects of social isolation have led to an increase in depression, anxiety, and distress in people with dementia.³⁴ The interaction of family support is a vital need for this population.³⁴ During the initial shock of the pandemic it was impossible to replicate human touch because of the precedence to protect the most vulnerable population. Touch is an important factor in dementia care, promoting well-being and alleviating NPS.³⁴

In a recent survey, family members of residents with dementia residing in nursing homes report that they notice a progression in memory decline, worsened physical abilities, increased anxiety, and escalated NPS in residents since the start of the isolation measures. This population now more than ever needs intervention to fight the effects of the aftermath of social isolation as well as continue to combat spread of infection through public health measures of protection. Research and policies are needed to allow for social contact to bring a physical presence of the community and family support back to this population. More research will need to be done for rapid intervention. Loneliness is detrimental to quality of life and increases the risk of morbidity and mortality.^{4,35}

VI. Methods

Dementia Background information

To gain an understanding of dementia and multifactorial approach involved in treating dementia for the framework of this paper, an initial PubMed search was performed using the following terms: “Types of Dementia,” “Nonpharmacologic Therapy AND Dementia,” “Quality of Life AND Dementia,” “Neuropsychiatric Symptoms AND Dementia,” “Treatment AND Dementia,” “Interventions AND Dementia,” and “Prevalence of Dementia.” A search filter was applied for articles published in the last 10 years. Articles were selected with updated definitions of terms used in describing and assessing dementia and articles calling attention to creating an individualized approach to care.

Pharmacologic Treatment

To gain an understanding of the current recommendations regarding the harms and benefits of pharmacotherapy management for treating NPS of dementia, a PubMed search was performed using the following terms: “Pharmacologic treatment AND Dementia,” “Psychosis

AND Dementia AND Black Box,” and “Beers Criteria AND Antipsychotics.” A search filter was applied for articles published in the last five years. Articles chosen discussed pain assessment, polypharmacy, black box warnings, adverse effects, and evidence of commonly used but not FDA supported medications in the management of dementia. Additionally, a search utilizing UpToDate using the phrase “Pharmacologic Treatment of Dementia” was used. This led to the articles named “Neuropsychiatric Symptoms of Dementia” and “Evaluation of Cognitive Impairment and Dementia.”

Music Therapy

To compile information on the effectiveness of music therapy as an intervention for people with dementia, a PubMed search was performed using the following terms and search filter applied for articles published in the last five years: “Music and Memory Program,” “Music AND Dementia,” “Music AND Neuropsychiatric Symptoms,” “Music AND Therapy AND Dementia,” “Music AND Dementia AND Quality of Life,” “Music AND Group Therapy AND Dementia,” “Everyday Listening AND Music,” and “Music Therapy AND Pain.” Articles selected discussed the effect of music on the brain, Music & Memory program, studies regarding music as therapy, and the role music plays in the memories of people with dementia.

Bathing

To compile background information regarding bathing as an aggravating ADL in dementia, a PubMed search was performed using the following terms and a search filter applied for articles published in the last ten years: “Bathing AND Dementia AND Refusal,” “Dementia AND Bathing,” and “Bathing AND BWAB.” Articles selected discussed refusals in care, tips in the bathing process, elderspeak, and studies on programs for training caretakers. Additionally, a search utilizing UpToDate using the phrase “Bathing AND Dementia” was used. This again led

to the article named “Neuropsychiatric Symptoms of Dementia” as well as a link to information about Alzheimer’s Association for care giver tips in bathing.

Validation Technique

To compile further information on the controversy regarding validation technique in communicating with people with dementia, a PubMed search was performed using the following terms and search filter applied for articles published in the last five years: “Validation Technique AND Dementia,” “Lying AND Dementia,” and “SPECAL AND Dementia.” Articles selected discussed issues of communication, SPECAL[®] approach, the lying controversy, and tips in verbal and body language to be aware of in managing NPS of dementia.

Light Therapy

To gain an understanding of the use of bright light therapy as a nonpharmacologic intervention for dementia, a PubMed and Google Scholar search was performed using the following terms and a search filter applied for articles published in the last five years: “Light therapy AND Dementia,” “Dementia AND Nonpharm,” “Bright light therapy AND Sleep,” and “Dementia AND Circadian rhythm.” Articles chosen discussed the affect light therapy has on the brain and on treating sleep disorders as well as the limitations of the therapy.

Snnozelen Rooms

To compile background information on the using multisensory rooms in managing NPS of dementia, a Google Scholar search was performed using the terms: “Snnozelen Rooms AND Dementia” and “Sensory Rooms AND Dementia”. A search filter was applied for articles published in the last five years. Articles selected explained components of Snnozelen rooms and undergoing studies regarding evidence of effectiveness and limitations in use for people with dementia.

Effects of the Pandemic

To find further information on the recent COVID-19 pandemic effects on people with dementia, a PubMed search was performed using the following terms and search filter applied for articles published in the last two years: “Pandemic AND Dementia” and “Touch AND dementia.” Articles chosen discussed the fears as a vulnerable population, effects of self-isolation, and aftermath effects of loneliness in people with dementia during this pandemic.

VII. Discussion

The aim of this research is to explore the evidence for using nonpharmacologic interventions as a first-line course of treatment in managing NPS of dementia. It would be helpful for providers and caretakers to have an algorithm for not only managing dementia but also to evaluate the cause of NPS at onset to select a targeted approach. Dementia is experienced uniquely in every person with it, so it is crucial to base interventions using person-centered care to meet the individual’s needs.⁹

When selecting an approach to managing NPS, it is important to evaluate the situation and the individual. NPS of dementia are “heterogenous”, so rather than being viewed as a whole collection of symptoms, NPS should be broken down symptom by symptom for deciding course of treatment.¹² Is the symptom due to environmental, medical, or psychosocial factors? To determine this, a thorough history and physical exam needs to be conducted.

When eliciting a history for a patient with dementia, it is important to obtain family members, care takers, and the patients input. Chief complaints of NPS should be prioritized. First and foremost the severity of the symptoms should be characterized to determine if the individual is a threat to self or others.^{1,11} Safety concerns take precedence and may require a different course of treatment. As with a standard approach to history taking, caretakers and patients should

be asked about onset, timing, frequency, severity, aggravating and alleviating factors, and associated symptoms in relation to the onset of new or changing symptoms. Refusals of care in previous plan of management should also be noted to assess adherence.

When working-up NPS, it is also important rule out iatrogenic and pathologic causes of symptoms through the history and physical exam. Make sure to review medications for recent changes, potential adverse effects, drug-drug interactions, adherence, and signs of withdrawal. In using antipsychotics for managing NPS in dementia, it is important to look for signs or excessive sedation or extrapyramidal side effects due to the increased risk of morbidity and mortality with use. Look for signs of pain, hypoxia, abdominal tenderness, fluid overload, inflammation, and skin ulceration on the physical exam.¹ Underlying pathologies are not easily expressed in this population, so it is important to run a working differential to avoid missing life threatening conditions unrelated to the pathology of dementia.

Through a review of systems and physical exam, it is important to address overall comfort and level of pain. Pain is a common trigger of NPS. Various scales are used to detect level of comfort and pain. As mentioned previously, PAINAD (Table 1) is a tool commonly used in assessing the severity of pain in people with dementia not able to verbally express the presence of pain. Caregivers can also be trained to use a pain scale in managing pain in the in-home setting.¹ It is important to create a plan for pain management in managing dementia. Figure 2 presents a summary approach of the work-up of underlying conditions related to NPS of dementia.¹¹

To detect changes in state of health and onset of new NPS in dementia, a baseline should be created.¹ This baseline will be used as a comparative measure of not only deterioration of the disease, but also a guide in assessing the effectiveness of an intervention in care planning.

Standard tools used to measure a baseline are Neuropsychiatric Inventory (NPI), Behavioral Pathology in Alzheimer's Disease rating scale (BEHAVE-AD), and Cohen-Mansfield Agitation Inventory (CMAI).¹ The NPI is a questionnaire that rates the presence, severity, and distress caused by "delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/emotional lability, aberrant motor behavior, sleep disturbances, and disorders of appetite/eating."¹ BEHAVE-AD is used to identify the most troublesome symptoms.¹ CMAI only evaluates behaviors of agitation.¹ These tools are the standard evaluation of quantifying a baseline for NPS in dementia but can be very time-consuming for the caretaker to complete.¹ Detailed logging of a symptom before and after an intervention can also be used in documentation.¹

The goal of this research is also to enhance a person with dementia's overall quality of life. One's perspective of well-being comes from a notion of experiencing positive affect, decreased negative affect, and a high level of satisfaction with one's life.⁹ When a patient is not able to communicate this perspective of satisfaction, it can take a great deal of observation and awareness from the caretaker to assess and act on behalf of the patient's well-being. Distressed behaviors can indicate unmet needs such as boredom, hunger, bathroom urgency, discomfort, or loneliness to name a few examples. Well-being is made up of more components than just being "happy".³²

One individual's definition of quality of life will not be the same as another's definition. This fact alone makes measuring quality of life a difficult assessment. How can quality of life be measured then? Tools in measuring quality of life are available but subjective self-reporting is made difficult in later stages of dementia.³² In the case that an individual is not able to self-

report, caretakers and family members can use direct observations or questionnaires in assessment.³² This poses the risk of neglecting the true perspective of people with dementia.³⁶

An overwhelming number of assessments exist in measuring quality of life in people with dementia. The overall best evidence and preference of use is in Dementia Quality of Life (DQOL), Quality of Life in Alzheimer's Disease (QOL-AD), Quality of Life in Late-Stage Dementia (QUALID), and QUALIDEM.³⁶ All of these measures pose with limitations and unique benefits though. For example, DQOL contains a large amount of quality of details, but respondents find it to be too repetitive.³⁶ QOL-AD has a version for the caretaker and a version for the person with dementia.³⁶ Overall an agreement on measuring quality of life in people of dementia has not been reached, so further investigation on a tool of measurement is necessary.³⁶ Inconsistent measures pose a challenge on analyzing evidence of intervention effectiveness.

Care planning must occur on a scheduled basis to create person-centered goals, assess effectiveness of current plan, and detect changes in status. This process ensures communications among all members of the care team and a platform for discussing ideas and for advocating improvement in quality of life. In educating the care team, it is important to offer a list of nonpharmacologic approaches and training in using these interventions to achieve best results. All caretakers are encouraged to be involved in tracking symptoms and logging medications to provide documentation on patterns of symptoms and new concerns.¹ Better patient outcomes are achieved with collaboration and communication among all members of the care team.¹

The approach to individualized medicine requires a great deal of trial and error to meet a patient with dementia's needs. These needs can change at any given time, so continuous assessment of effective management must be performed. Unfortunately, this means that a standard algorithm to treat all people with dementia does not exist due to the unique nature and

presentations that make up this disease. Because the mission is person-centered care, it is recommended to treat the person not just the disease.

VIII. Conclusion

Although further studies are needed, music therapy, tailored bathing routines, bright light therapy, multisensory stimulation, and eliminating the use of elderspeak language are nonpharmacologic interventions that contain varying levels of evidence in decreasing NPS in dementia. Pharmacotherapy should be cautiously considered in treating neuropsychiatric symptoms of dementia due to adverse effects and black box warnings. As for the validation technique, although it shows some evidence in decreasing agitation and enhancing self-esteem, it is an ethically controversial approach to communication. The debate of whether therapeutic lies exist must be further studied for consideration. This paper also brings attention to the call for a plan of action in the aftermath effects of the COVID-19 pandemic. As a result of the COVID-19 pandemic, social isolation has worsened in people with dementia, especially for those residing in nursing facilities.

The limitations of this research indicate that more research on quantifying quality of life measures to prove effectiveness of nonpharmacologic interventions is warranted. The lack of tools to measure quality of life has been a common limitation many studies face regarding nonpharmacologic therapy, especially in a population that cannot always reliably self-report. Developing a measurement with standard acceptance of use in this population would make monitoring quality of life an easier process in care planning.

Another common limitation is that caretakers and primary care providers often lack knowledge of these nonpharmacologic interventions, resulting in poor adherence. Continued education opportunities on the recent advances and research of these interventions for primary

care providers could allow for better patient education and patient-centered options to be offered during clinic visits and nursing facility rounding. It would be helpful for future studies to provide structured protocols and trainings on the use of nonpharmacologic interventions being requested in managing and preventing NPS within the care plan. Caretakers also require more support in the care they provide to this population.

A recommendation for future practice is to develop an individualized approach to identifying environmental triggers. This approach could not only be used by primary care providers, but also by direct care takers to rule out and monitor for iatrogenic and pathologic causes of NPS. In managing NPS, the approach should be aligned with being proactive and reactive to the onset of symptoms to set a realistic plan of managing NPS. Based on the literature review conducted for this paper it can be concluded that dementia is a disease that requires multifactorial care. Nonpharmacologic interventions present with fewer side effects than most pharmacotherapeutics and have the capacity to address physical, emotional, psychosocial, and spiritual needs of people with dementia contributing to overall quality of life.

IX. References

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X. Appendices

Table 1: Pain Assessment in Advanced Dementia (PAINAD) Scale¹¹

Pain Assessment in Advanced Dementia (PAINAD) scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract, or reassure.	
Total[¶]:				

This pain assessment score can be used to assess pain in patients with dementia. Patients should be observed for 5 minutes prior to performing the assessment. Total scores range from 0 to 10, with 10 representing severe pain.

* 5-item observational tool.

¶ Total scores range from 0 to 10 (based on a scale of 0 to 2 for 5 items), with a higher score indicating more severe pain (0 = "no pain" to 10 = "severe pain").

Original figure modified for this publication. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. J Am Med Dir Assoc 2003; 4:9. Illustration used with the permission of Elsevier Inc. All rights reserved.

Table 2: Elderspeak and Its Effect on Dementia Patients²⁴

Elderspeak and Its Negative Effect on Dementia Patients.

Type of communication	Negative influence on dementia patients
<ul style="list-style-type: none"> • Use of very short sentences • Slow speech, but elevated pitch • Simple vocabulary and grammar • Use of collective/plural pronouns such as <i>we</i> and <i>our</i> • Use of intimate words • Good boy/girl • Sweetie • Honey 	<ul style="list-style-type: none"> • Decrease in self-esteem • Resistiveness to care • Agitation • Emotional outbursts • Verbal and physical aggression, depression • Communication block

Figure 1: Psychological interventions for management of behavioral and psychotic symptoms in patients with dementia¹¹

Psychosocial interventions for management of behavioral and psychotic symptoms in patients with dementia

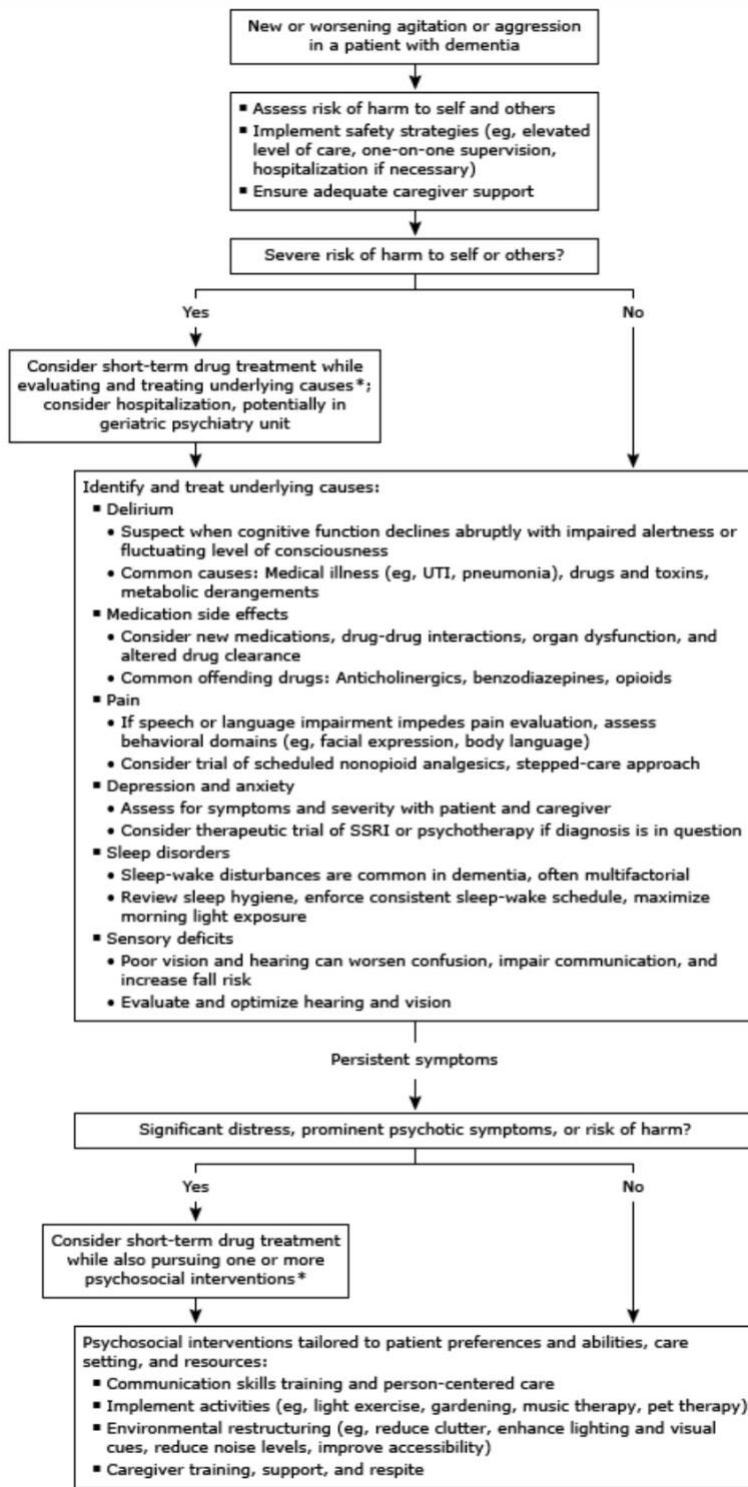
<ul style="list-style-type: none"> ▪ Routine activity. ▪ Separate the person from what seems to be upsetting him or her. ▪ Assess for the presence of pain, constipation, or other physical problem. ▪ Review medications, especially new medications. ▪ Travel with them to where they are in time. ▪ Don't disagree; respect the person's thoughts even if incorrect. ▪ Physical interaction: Maintain eye contact, get to their height level, and allow space. ▪ Speak slowly and calmly in a normal tone of voice. The person may not understand the words spoken, but he or she may pick up the tone of the voice behind the words and respond to that. ▪ Avoid finger-pointing, scolding, or threatening. ▪ Redirect the person to participate in an enjoyable activity or offer comfort food he or she may recognize and like. ▪ If you appear to be the cause of the problem, leave the room for a while. ▪ Validate that the person seems to be upset over something. Reassure the person that you want to help and that you love him or her. ▪ Avoid asking the person to do what appears to trigger an agitated or aggressive response.

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Figure 2: Approach to Agitation in Patients with Dementia¹¹

Approach to agitation in patients with dementia



UTI: urinary tract infection; SSRI: selective serotonin reuptake inhibitor.



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