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*School of Occupational Therapy*

**Social Participation Interventions for Quality of Life Among Individuals with Dementia**

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A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

Under the direction of the faculty capstone advisor:

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### **Abstract**

Dementia is an irreversible disease that impacts individuals in all areas of life and decreases quality of life (QOL) (Hsiao et al., 2018). I have identified that there is limited research stating specific ways to increase QOL and improve social participation among individuals with more progressed dementia. Utilizing the Functional Behavior Profile (FBP), I identified five individuals who required assistance and had more progressed dementia. I participated in activities such as exercise classes, crafts, and baking, alongside specific residents and utilized visual, verbal, and tactile cues as well as minor activity modifications when needed to create a just-right challenge. This promoted increased activity satisfaction and overall mood. I monitored individuals' activity enjoyment via perceived satisfaction and their reports. This research provided evidence that continued participation in social activities with adaptations improves QOL. I recommend further research at a larger scale to expand on the effects of social activity interventions on QOL among older adults with progressed dementia.

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### **Social Participation Interventions for Quality of Life Among Individuals with Dementia**

Alzheimer's disease (AD) and dementia are irreversible illnesses (Hsiao et al., 2018). Although reversing memory illness is not an option, there are numerous non-pharmacological ways to slow the progression or potentially delay onset (Hsiao et al., 2018; Letts et al., 2011; Quail et al., 2020). Non-pharmacological activities can include physical, kit-based, leisure, activities of daily living (ADLs), instrumental activities of daily living (iADLs), music-stimulated family visits, and dance (Charras et al., 2020; Huang et al., 2020; Jones et al., 2020; Letts et al., 2011; Shigihara et al., 2020; Smit et al., 2016). Activity participation typically involves physically and mentally participating in an activity, but Beerens et al. (2018) discuss that engagement via observation of activity performance feels like participation for many. Meanwhile, for some residents, structuring activities to meet their abilities will provide greater success and promote more active than passive participation (Kolanowski & Buettner, 2009). Considering both active and passive activity participation is important to identify because as adults age, they may not find themselves able to or interested in participating; rather, observing loved ones and other residents engage together is providing them with mood satisfaction and activity enjoyment (Beerens et al., 2018).

### **Benefits of Activity Participation**

Activity participation provides numerous benefits for older adults, especially those with dementia. In some instances, skilled nursing facilities and assisted living facilities focus on medical care, but there are rising concerns regarding psychological care. Participating in meaningful activities can contribute to increased psychological well-being, quality of life (QOL), and better sleep performance (Beerens et al., 2018; Huang et al., 2020; Jones et al., 2020; Letts et al., 2011; Smit et al., 2016). In research by Charrass et al. (2020), their original hypothesis

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focused on dance interventions promoting physical well-being. Their research ultimately did not support this hypothesis, but it supported increased positive self-perception in older adults.

Specifically, dance as an activity intervention helped older adults with dementia improve their behavior, cognition, QOL, social participation, and self-perceived balance (Charrass et al., 2020).

Beerens et al. (2018) discussed the importance of activity engagement and social interaction. Researchers identified a positive correlation between participation and older adults' mood with increased engagement (Beerens et al., 2018). Participating in meaningful activities is important and stimulating for both the individual with the disease as well as their caregivers. By modifying occupations and leisure activities to promote participation from the older adult with dementia, caregivers felt a greater sense of satisfaction for their loved ones (Letts et al., 2011).

### **Benefits of Social Participation**

Beerens et al. (2018) identified that the type of activity that older adults with dementia participate in is as essential as social engagement. Social participation can be beneficial to slow the loss of verbal expression and reduce cognitive decline, both being common symptoms of AD (Duong et al., 2017; Letts et al., 2011; Quail et al., 2020). Activity engagement with a social-based approach can include any activities that an older adult finds interesting and involve communication. Quail et al. (2020) specifically discussed “validation therapy, music therapy, art therapy, reminiscence therapy, talking therapy, reality orientation, cognitive training, smell therapy, food therapy, sensory stimulation, garden therapy, and physiotherapy” (p. 2). Meaningful occupations that promote physical activity can also contribute to strengthening meaningful relationships and promote more social participation, as well as reduce depression and increase ADL performance (Huang et al., 2020).

### ***Challenges with Activity and Social Participation***

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Activity engagement and social participation are significant factors in psychological well-being and QOL if they are activities or topics that are interesting and provide the appropriate cognitive stimulation for the older adult participating (Smit et al., 2016). Creating client-centered activities of interest is important, but for them to be entirely meaningful and reach the overall goal of engagement, the activities must meet the just-right challenge for one's cognitive status (Beerens et al., 2018; Cole & Tufano, 2008). While numerous researchers have collectively confirmed that activity and social participation are positively correlated with increased QOL and satisfaction (Huang et al., 2020; Letts et al., 2011; Smit et al., 2016), Beerens et al. (2018) also identified that an increased negative mood often occurs when older adults with dementia attempt to socially participate and receive no response. Identifying the challenge that social participation can present is essential to understanding that a balance between engagement and disengagement is necessary for QOL (Beerens et al., 2018). Respecting an older adult's need for mental relaxation is person-dependent and crucial to promoting activity engagement (Beerens et al., 2018).

### **Overview of Site**

Clarendale St. Peters is an independent and assisted living facility with a wing devoted to memory care located in St. Peters, Missouri. Clarendale has approximately 40 beds for memory care, with 20 occupied at the time of research (M. Bruner, personal communication, March 3, 2021; R. Muzzey, personal communication, January 27, 2022 ). Facility leaders divided the memory care side into two neighborhoods to provide a smaller, more intimate experience. Uniquely, if spouses both have dementia, they can reside in a larger room together in memory care. Muzzey discussed that he encourages this in many situations because it is a level of familiarity that will help with transitioning (R. Muzzey, personal communication, February 15,

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2022). Clarendale employees encourage activity participation among all residents in memory care, regardless of cognitive level. Activities in the memory care neighborhood are planned monthly and posted on calendars throughout the neighborhoods so residents and families can look ahead if interested, but are often not discussed until the day prior and that morning to avoid confusion.

When meeting with Muzzey, Director of Memory Care, he identified a need for small group activity adaptations and additional supports that promote social participation among individuals in memory care neighborhoods who require more visual, verbal, and tactile cues as well as more time to process these cues. These activities are essential contributions to Clarendale because social connections tend to decline as dementia progresses, leading to quicker cognitive regression (Dyer et al., 2021; Hsiao et al., 2018). Muzzey reports an interest in ways to maintain inclusivity by integrating these residents more successfully into group activities.

### ***Theory and Application***

The Person-Environment-Occupation (PEO) Model and Allen's Cognitive Levels (ACL) Frame of Reference are essential to guide the construction of activity adaptations and supportive cueing for individuals with dementia. The PEO model focuses on an individual's occupational performance formed from interactions between the person, environment, and occupation. At the center of the PEO model is participation with the goal being to guide occupational therapists in helping individuals create and maintain a level of involvement (Degenholtz et al., 2006). ACL Frame is a beneficial frame of reference to utilize for older adults with memory illnesses because it focuses on one's cognition, routines, physical context, social context, and activity demand (Cole & Tufano, 2008). Using ACL Frame to evaluate one's cognitive ability serves as a guide to promoting meaningful participation in activities at a just-right challenge level. Encouraging

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participation in activities that meet one's level of capacity motivates individuals to utilize their cognitive abilities (Cole & Tufano, 2008).

Utilizing the PEO model and ACL Frame to guide the Doctoral Capstone Experience will ensure client-centeredness and the ability to screen and evaluate which individuals qualify for the interventions. This client-centeredness will lead to the outcome goal of providing appropriate visual, verbal, and tactile cues for older adults with more progressed dementia to improve social activity participation, thus increasing their QOL.

### ***Expanding Research***

There is an abundance of research on the importance of activity engagement amongst older adults with dementia. However, there is limited research regarding benefits of small group social activities and levels of assist for older adults who benefit specifically from more support and cueing. This Doctoral Capstone Experience is intended to expand on current research to identify the benefits of social participation on QOL among a specific group of individuals with dementia.

### **Project Design**

Clarendale St. Peters Memory Care is devoted to providing activities for residents to participate in, both individually and in the group setting. I created this project because there was an identifiable need for support and activities that meet the just-right challenge of older adults with more progressed dementia. Prior to this research experience, some residents participated passively due to needing more cueing to be successful and there was not an employee who was designated to offer these supports. In some instances, some residents chose to participate passively or observe because the activity may not meet their interests or needs.

### **Outcome Assessments**

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First, to identify residents who meet the qualifications of the research, I utilized the FBP to gain information about ADLs, cognition, functional mobility, life participation, patient satisfaction, problem-solving, and social relationship (“Functional Behavior Profile”, n.d.). These are all areas of an individual’s life that can affect one’s QOL. Nursing staff and activities coordinators collaborated to complete the FBP because they are ultimately the day-to-day caregivers and know each resident deeply and personally.

Residents who scored at or below 50% (22/24) in Task Performance or Social Interaction qualified for my program development, which was working side by side with individuals to provide more assistance and cueing to promote more social engagement and activity participation. I utilized the FBP to identifying individuals who would benefit from additional cues and modifications during small group activities to promote satisfaction and improved QOL in events related to weaker areas of performance. This may include cognition, activity participation, following commands, socializing when others initiate the conversation, and time spent attending tasks (Baum et al., 1993).

### **Project Implementation**

Employees at Claredale in the memory care neighborhoods work closely with the residents every day and build strong relationships with them and their families. Thus, were excellent resources for information regarding each resident’s personality, challenges, and preferences. Every day is incredibly structured for the activities coordinators because they are the only ones leading activities every day except when they take a lunch break. The nursing staff is also incredibly busy throughout the day. The activities coordinators answered most questions, allowing me to ask the nursing staff fewer questions since I do not see them as often so it would



SOCIAL PARTICIPATION INTERVENTIONS, QUALITY OF LIFE, AND DEMENTIA have been more challenging to find time to discuss more details. It took approximately two weeks to finalize and score all FBP assessments.

Utilizing the FBP helped me to identify the common weaker areas among residents, specifically Task Performance and Social Interaction. Often, residents who scored lower were able to complete tasks asked of them with much assistance and additional time. It became apparent that many of the residents who qualified for additional support from me had the physical capabilities to participate. This provided evidence that individuals were capable of some level of participation but would be most successful with additional cueing to support their cognitive level of functioning.

### **Project Outcomes**

The FBP served as an excellent resource to identify residents who would benefit from additional cues to promote an increased QOL. This gives me a foundation that assists in better understanding residents' current abilities at baseline and how to create the just-right challenge that meets each individual's needs.

When observing nursing staff and resident interaction, much of the communication was regarding medication, helping with ADLs, and participating in activities led by activities coordinators. Often, nursing staff provided much encouragement for every resident to participate in all activities but were not considering if each activity would meet the needs of each resident. Activities coordinators reported that some activities are not interesting to each resident and were sometimes not all appropriate for everyone's cognitive level of functioning. However, I worked alongside activities coordinators to join in on activities of interest with qualifying residents to potentially improve the QOL among residents through social engagement, activity participation, and minor activity adaptations.

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Residents who scored below 50% (22/44) in Task Performance or Social Interaction on the FBP qualified for me to work alongside. It is essential to identify that an individual with dementia will not improve in any areas of the FBP independently due to dementia being a progressive disease. However, in the moment and with assistance, residents can increase their level of participation, thus, improving their QOL through meaningful activities. There are fourteen residents residing at Clarendale St. Peters Memory Care, with five who scored below 50% in Task Performance or Social Interaction on the FBP. Other residents who did not qualify scored between 52% and 79.5% (23/44 and 35/44). The individuals who scored below 50% often appeared isolated. I spoke with activities coordinators and nursing staff, who reported that it is difficult to spend enough time helping individuals with more progressed dementia engage in activities, so they often do not receive the level of assistance needed for engagement. This can contribute to their overall dementia progression (Freak-Poli et al., 2022).

I sat next to residents to provide additional cues, serve as a visual aid, and modify activities as needed. This proved to be successful based on residents' responses after each activity. I communicated with Muzzey, Director of Memory Care, and Cribb, Activities Coordinator for Memory Care, to discuss ways to gain feedback regarding the success of activity engagement. Immediately at the end of each activity, I asked residents, "Did you enjoy this activity?". This allowed residents at different cognitive levels to respond either verbally or nonverbally. While I participated in activities alongside qualifying residents, I also observed how residents acted during each activity. I looked for facial expressions, eye contact with other residents, and some level of maintained engagement.

For individuals with dementia, working with them to create an increased QOL is dependent on that specific moment in time because that is what they know and are aware of (L.

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Cribb, personal communication, January 27, 2022; R. Muzzey, personal communication, February 8, 2022). Muzzey explained that individuals with progressed dementia often cannot look beyond the current moment but happiness in a specific moment can increase their mood for some time after the activity, even if the resident cannot express or recall why they are happy (R. Muzzey, personal communication, February 8, 2022). Therefore, evaluating a resident's perceived satisfaction and QOL must occur during and immediately after each activity.

While working alongside activities coordinators and nursing staff, I helped identify ways to adapt current activities for all residents to participate in. This includes visual aids for the entire group, sitting next to the individuals who need more auditory cues, visual cues, hand-over-hand tactics, explaining directions simply, and frequently prompt one-on-one conversations. Employees of Clarendale and myself identified a need for an additional activities coordinator with a background in dementia to promote greater activity engagement and improved QOL.

Muzzey and Cribb complete paperwork with families that identify residents' backgrounds, careers, and areas of interest. They utilize these to create daily activities. This may be a contributing factor to why my research was successful. Many of the residents enjoy all the activities and the level of socializing they offer. During 10 weeks of research implementation, I successfully incorporated the qualifying residents into the activities and assisted with providing additional cueing, leading them to actively participate more. When reviewing the data, I identified that 85% of the times I participated in activities alongside residents to provide support, the residents reported satisfaction and displayed enjoyment throughout the activity. One resident reported being bored throughout craft activities. When I asked her if she would be interested in participating, she often said yes and attended but then quickly lost interest. Through discussions with the family, I learned crafts have never been a strong interest. I continued to be mindful by

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still inviting her to join but also asking if she would like to sit and watch others participate. It was very common for all residents, not just those who I was working with, to observe an activity that they did not want to participate in. Muzzey often encourages this because it still provides more opportunities for conversation and social interaction.

### **Limitations**

Although there were identifiable limitations, they were minimal. Muzzey, Cribb, and I identified that one resident often had anxiety attacks in the mornings if she was wearing a specific pair of jeans. We believed they were too tight or rough, leading to increased levels of sensory stimulation. To limit this and increase her opportunity to participate in morning activities, Muzzey talked with nursing staff to not encourage her to wear those pants. Another limitation was hospital visits. If a resident was taken to the hospital then later returned, it reduced the resident's level of interest in activities, leading them to require more encouragement to participate and attempt to return to their baseline. These limitations are valid but were unaccounted for during research preparation.

### **Discussion**

Activity participation is crucial for residents' days in a memory care neighborhood. Participating in activities provides meaningful engagement and a purpose for many residents while improving their QOL (Huang et al., 2020; Letts et al., 2011; Smit et al., 2016). However, I have identified that meeting the just-right challenge is necessary for all meaningful activities. Throughout the program development, I identified that if an activity was too challenging or there was no one to assist the resident, they may become frustrated and cease participating entirely.

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Utilizing the FBP to identify lower scoring individuals and provide appropriate intervention proved successful in contributing to increased QOL and small group engagement. Residents who utilized additional support during activities were inclined to participate and socialize throughout the activity more than prior to research interventions. Individuals participating either verbalized, nodded, or gave a thumbs up or down to report their small group activity enjoyment. Researchers identified that for some with more progressed dementia, observing someone participate provides the same level of satisfaction and socializing (Beerens et al., 2018). Two individuals often participated passively in this program development due to their medical status and progression. I maintained my level of assistance alongside the residents and observed resident satisfaction throughout the activities, more so than prior to the program development and implementation. These residents often held more eye contact with other residents that typically expected, as well as laughed more than employees have reported observing in some time.

To further summarize, I determined that activity participation for all residents, specifically residents with more progressed dementia, contributed to increased QOL and perceived satisfaction. It provides evidence that verbal, visual, and tactile cues contribute to more participation and comfort with activities in small groups. I believe having an additional life enrichment coordinator provides dignified support during activities, thus, leading more residents with progressed dementia to feel comfortable and willing to participate and enjoy their day, overall increasing their QOL.

### **Conclusion**

In conclusion, my research provides evidence that additional cues and support during activities can improve QOL and activity satisfaction among residents with more progressed

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dementia. St. Peters Clarendale activities coordinators benefitted from observing this research, improving many older adults' level of participation and satisfaction. Employees have learned how to adapt activities and offer additional support to meet the needs of every resident who wants to participate. Overall, residents with more progressed dementia had increased activity participation and reported satisfaction immediately following the activity. Further work on a larger scale is necessary to expand research on the benefits of increased activity participation on QOL among older adults with advanced dementia. However, this research is an excellent start to providing evidence that additional support during activities is not only an advantage but a crucial part of improving overall QOL among older adults with more progressed dementia.

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**Appendix***Doctoral Capstone Experience Project Weekly Planning Guide*

<b>Week</b>	<b>DCE Stage</b> (orientation, screening/evaluation, implementation, discontinuation, dissemination)	<b>Weekly Goal</b>	<b>Objectives</b>	<b>Tasks</b>	<b>Date complete</b>
<b>1</b>	<b>Orientation</b>       <b>Screening/Evaluation</b>	<ul style="list-style-type: none"> <li>• Complete orientation</li> <li>• Complete Needs Assessment</li> </ul>	<ol style="list-style-type: none"> <li>1. Complete orientation and tour by the end of the week</li> <li>2. Meet with Site Mentor and key personnel, introduce myself, provide education as to what my role is and intended DCE.</li> <li>3. Discuss workspace, dress code, dementia training course.</li> <li>4. Review and edit Needs assessment questions</li> </ol>	<ul style="list-style-type: none"> <li>• Identify key points to discuss in meeting with site mentor</li> <li>• Have a meeting with my site mentor</li> <li>• Discuss site's needs and plans for observing OTR</li> <li>• Get to know residents, understand their interests and level of function</li> </ul>	<b>1/15/22</b>
<b>2</b>	<b>Orientation</b>       <b>Screening/Evaluation</b>	<ul style="list-style-type: none"> <li>• Safety training</li> <li>• Observe residents, make notes</li> <li>• Complete literature search</li> <li>• Finalize MOU</li> <li>• Evaluate and score FBP, identify and</li> </ul>	<ol style="list-style-type: none"> <li>1. Finish identifying any new literature</li> <li>2. Establish outcome assessment tool</li> <li>3. Touch base with mentor regarding possible changes to MOU</li> </ol>	<ul style="list-style-type: none"> <li>• Organize new literature</li> <li>• Save outcome assessment tool, discuss it with mentor</li> <li>• Review MOU in greater detail</li> </ul>	<b>1/21/22</b>

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		compose list of residents who qualify, discuss results with mentor	<p>4. Become familiar with residents who qualify for research</p> <p>5. Observe qualifying residents</p>	<ul style="list-style-type: none"> <li>Complete screening on “just-right challenge” tasks for residents</li> <li>Discuss areas of interest for residents participating</li> </ul>	
3	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Provide cues and participate alongside residents with more progress dementia</li> <li>Utilize verbal and visual procedure to understand resident’s level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation</li> </ul>	1/28/22
4	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident’s level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation</li> </ul>	2/4/22
5	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	2/11/22

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		<p>functioning skills</p> <ul style="list-style-type: none"> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>			
6	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	2/18/22
7	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	2/25/22
8	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	3/4/22

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9	Implementation	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	3/11/22
10	Implementation	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	3/18/22
11	Implementation	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower</li> </ul>	1. Increase social participation amongst group members	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	3/25/22

## SOCIAL PARTICIPATION INTERVENTIONS, QUALITY OF LIFE, AND DEMENTIA

		<p>functioning skills</p> <ul style="list-style-type: none"> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>			
<b>12</b>	<b>Implementation</b>	<ul style="list-style-type: none"> <li>Complete small group social activities for memory care residents with lower functioning skills</li> <li>Utilize verbal and visual procedure to understand resident's level of satisfaction</li> </ul>	<ol style="list-style-type: none"> <li>Increase social participation amongst group members</li> </ol>	<ul style="list-style-type: none"> <li>Utilize verbal, visual, and tactile cues to maintain participation,</li> </ul>	<b>4/1/22</b>
<b>13</b>	<b>Discontinuation</b>	<ul style="list-style-type: none"> <li>Finish small group activity modifications and assist for residents with lower functioning skills</li> </ul>	<ol style="list-style-type: none"> <li>Collect/organize all information regarding activities, level of participation, and subjective feedback</li> </ol>	<ul style="list-style-type: none"> <li>Organize spreadsheet with residents (initials used for privacy), activities they participated in, their subjective rating of the activity, and how I perceived their participation, enjoyment, and satisfaction</li> </ul>	<b>4/8/22</b>
<b>14</b>	<b>Dissemination</b>	<ul style="list-style-type: none"> <li>Present findings to</li> </ul>	<ol style="list-style-type: none"> <li>Confirm date, time, and</li> </ol>	<ul style="list-style-type: none"> <li>Create handouts,</li> </ul>	<b>4/15/22</b>

## SOCIAL PARTICIPATION INTERVENTIONS, QUALITY OF LIFE, AND DEMENTIA

		leaders of memory care department regarding my findings	location of presentation, prepare notes, and handouts	answer any final questions, provide copies of handouts and relevant resources	
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