

Spring 5-18-2019

Leading the Play: Development of a Method Supporting Expression and Control with Adults with Dementia

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Leading the Play: Development of a Method Supporting Expression and Control with Adults

with Dementia

Capstone Thesis

Lesley University

02/24/2019

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Expressive Arts Therapy

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Abstract

This paper explores the concept of client-led play with older adults with dementia and its possible impact on an individual's ability to express enjoyment and sense of control. Expressive arts therapy is explored as a possible natural vehicle for providing client-led play groups to older adults with dementia. While research is limited regarding client-led play specifically, there has been significant research supporting the use of the creative arts with individuals with dementia, as it provides opportunities for non-verbal expression and spontaneous creativity. This paper argues that the arts have a natural connection to play through the use of the imagination and in-the-moment choice making. The author developed and implemented two play-based interventions with adults with dementia at an assisted living facility in Massachusetts. This paper will discuss the literature that informed the method, what took place during the implementation, and what was learned from observing and experiencing client-led play with adults with dementia.

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with Dementia

Introduction

While working with residents diagnosed with dementia living in an assisted living facility, I noticed that while activities are provided throughout the day, they are fairly repetitive, structured, and always dictated by staff. While some residents state being happy that there is “something to do, at least,” other residents sit through activities while stating how bored they are. This encouraged me to observe when residents were having fun and clearly enjoying themselves. I noticed that this occurred most often during instances of play.

According to Kontos, Miller, Mitchell, and Stirling-Twist (2017), the ability of persons diagnosed with dementia to be “deliberately funny, playful, and imaginative” is often overlooked (p. 46). I have seen this assumption being lived out at my internship site. Staff and residents are often laughing together, but it is rarely assumed that the person with dementia is actually attempting to be humorous. However, I was able to witness residents interacting through play on multiple occasions.

While some of this play occurred during a structured activity, residents expressed the most joy when they veered off the structured path spontaneously. For example, when using musical shakers during a movement group, residents began playing with the instruments on their own, banging them against their walkers, interacting with neighbors, and seeing what different types of sounds they could create. This moment was entirely created out of the creativity of the residents and they were more visibly excited than I had previously observed on site. This encouraged me to develop and implement a method based in client-led play with people with

dementia and to consider the impact this could have on their self-expression and on the sense of control and choices residents experience from day to day.

In order to explore whether client-led play has a positive impact on adults with dementia, it is important to consider how clinicians determine clients' enjoyment and interest levels during various activities and interventions. When examining the literature, "engagement" and "participation" are the most common framework for understanding clients' experiences. Cohen-Mansfield (2017) states that engagement does not have to mean active participation, but can be shown by giving "an appropriate answer, by taking materials when handed, by eye movement, or by not doing something else" (p. 375). On site, participation among residents varies from day to day, but an individual's level of participation does not always feel like a reliable measure of their enjoyment. Some residents do not actively participate in movement groups, but attend consistently with a smile. Other residents are frequently dancing and engaging, but it may be in order to please staff or other residents requesting them to join in.

I have found that an individual's level of engagement can vary so greatly that it feels assumptive to use as a measure of enjoyment. According to Moss and O'Neil (2017), it would be unethical to evaluate the impact that play has on those with dementia through engagement or participation on its own. For this reason, I decided to review other ways of communicating and understanding enjoyment, as well as how to do so in a way that puts some power and control back into the hands of those diagnosed with dementia. This literature informed the development and implementation of a client-led play group with adults with dementia, titled "playing with the arts."

The following sections of this paper describe the process of developing and implementing this group and the different steps along the way. I review the literature available related to client-

led play and individuals with dementia and how it informed the play-based group interventions. I discuss two different group sessions and discuss what I observed and learned from each session.

Literature Review

Overview of Dementia

Dementia impacts over 35.6 million individuals today, with that number projected to nearly double over the next twenty years. Dementia occurs in various different diseases impacting the brain, the most common being Alzheimer's disease (Alzheimer's Disease International & World Health Organization, 2012). Dementia is progressive, with symptoms becoming more noticeable over time. In fact, individuals diagnosed with dementia are often described as being in the early, middle, or late stage of the disease based on their symptom progression (Alzheimer's Disease International & World Health Organization, 2012). Individuals diagnosed with dementia are likely to experience declining function in their memory, comprehension, verbal abilities, judgement, orientation, and capacity for learning. In addition to these cognitive changes, individuals diagnosed with dementia are also likely to experience changes in their social behavior, emotional control, and motivation (Alzheimer's Disease International & World Health Organization, 2012).

Engagement and Quality of Life of those Diagnosed with Dementia

Connected to the lack of motivation experienced by many adults diagnosed with dementia is apathy. Ellis, Doyle, and Selvarajah (2016) define apathy as "an absence of responsiveness to stimuli, with lack of responsiveness demonstrated by a lack of self-initiated action" (p. 495). This passivity is experienced by an estimated 92% of those diagnosed with dementia and becomes more common as the disease progresses (Ellis et al., 2016). Not only is

apathy experienced by a large percentage of those with dementia, but Ellis et al. (2016) state that it is most prevalent among those living in nursing homes, suggesting that certain characteristics of residential care settings, such as lack of stimulation, could increase the symptoms experienced.

According to Cohen-Mansfield, Dakheel-Ali, and Marx (2009), the prolonged lack of stimulation experienced by those living in nursing facilities can be detrimental, as it may amplify symptoms of apathy. For this reason, Cohen-Mansfield et al. (2009) urge the importance of prioritizing engagement of individuals with dementia living in a residential care setting. Treadaway, Kenny, Prytherch, and Fennell (2016) state that “greater opportunities are needed for people with dementia to express their emotions as this can help build resilience and positivity” (p. 42). Unfortunately, the apathy experienced by individuals with dementia is often mistaken as a resistance to care or a lack of desire to engage by those caring for them, which could mean individuals not receiving the care and engagement required for positive quality of life (Ellis et al., 2016).

In 2010, the Alzheimer’s Society conducted research with the goal of better understanding what factors were important to the quality of life of those diagnosed with dementia. Self-reports were used to gather this information so that the data drew directly from the experiences of those with dementia, including groups that are seldom included in dementia research, such as minority ethnic groups and those in later stages of dementia. Recognizing that a self-report may have been difficult, those with more severe dementia were able to express their views by ranking image cards as ‘very important’, ‘quite important’, ‘not important’ (Alzheimer’s Society, 2010, p. 16). According to their findings reported by the Alzheimer’s

Society (2010), the following quality of life indicators were ranked as most important by individuals with dementia, in order of most to least important:

- (1) Relationships or someone to talk to;
- (2) Environment;
- (3) Physical health;
- (4) Sense of humor;
- (5) Independence;
- (6) Ability to communicate;
- (7) Sense of personal identity;
- (8) Ability or opportunity to engage in activities;
- (9) Ability to practice faith or religion;
- (10) Experience of stigma. (p. ix)

This research not only informs us about what is most important to those diagnosed with dementia, but reinforces that given the opportunity, even those with severe dementia are able to express their needs and points of view (Alzheimer's Society, 2010). Knowing from their own perspective what factors contribute to a positive quality of life helps better inform our outlook and goals when researching the most effective ways of engaging individuals with dementia. This turns the question from "How can I engage individuals with dementia?" to "How can I best support individuals with dementia to initiate their desired engagement?"

According to a study conducted by Ellis et al. (2016), the amount of apathy experienced by nursing home residents with dementia was correlated to participation in therapeutic activities, as residents who participated in many activities demonstrated the lowest levels of apathy. While these results are promising, I was left feeling curious about what types of activities would be most engaging for residents. I thought back to the quality of life indicators listed as most important by individuals with dementia and considered what types of activities could best facilitate those values.

Expressive Arts Therapy with Clients with Dementia

The use of expressive arts therapy has been researched among older adults with dementia. Kinney and Rentz (2005) studied the wellbeing of individuals while participating in an art making activity compared to other structured activities. In their study, twelve individuals participated in Memories in the Making©, which is an art program designed for individuals with dementia that uses the visual arts to encourage self-expression. Their results indicated that “significantly more interest, sustained attention, pleasure, self-esteem, and normalcy” (p. 220) were observed during participation in the arts program compared to other structured activities. However, this study used only participants in the early to middle stages of dementia, so individuals with severe dementia are not represented in these results.

Kaaniste, Linnell, Ollerton, and Slewa-Younan (2015) describe a pilot study measuring the impact of drama therapy on the quality of life of individuals with dementia. Core themes that emerged during participation in drama therapy groups included “a sense of connection with others, confidence to express feelings, spontaneous interaction, engagement of imagination, shared memories and motivation” (p. 41). Developmental Transformations (DvT) techniques were used in the drama therapy groups that the research was focused on. DvT is a technique used in drama therapy that is based on free play and is highly improvisational and spontaneous (Kaaniste et al., 2015). DvT offers a specified playspace where individuals with dementia can feel safe to communicate through movement and embody whatever they want to communicate. The nondirective activity and choice in engagement fosters both independence and personal identity (Kaaniste et al., 2015).

According to Nyström and Lauritzen (2005), dance movement therapy may also lend itself to creating a safe place between fantasy and reality where emotions and thoughts can be expressed symbolically through movement. Nyström and Lauritzen (2005) observed adults with

dementia participating in dance movement therapy groups in order to study how individuals with severe dementia and limited verbal abilities communicate non-verbally. They found that when different modes of expression are supported, individuals with dementia can communicate in way that is “rich and varied in expression and content” (p. 297). Nyström and Lauritzen (2005) found that even individuals with limited verbal abilities and severe dementia have the capacity to communicate using a wide variety of types of expression. When giving the opportunity to enter that playspace through dance movement therapy, individuals are able to express their creativity in addition to their thoughts and feelings, without speaking a word.

Kontos et al. (2017) state similarly in their research that “imaginative play does not require the presence of sensical language in order to communicate with, and connect to, residents” (p. 57). Their research discusses how the use of elder-clowns can promote presence and reciprocal engagement in individuals with dementia. Clowns use the imaginary to communicate when otherwise verbal limitations might have been a barrier. Kontos, Miller, and Kontos (2017) observed that when playfully engaging with elder-clowns, not only were individuals able to experience humor, but they were able to initiate that humor and present it in various ways, both verbally and non-verbally. Kontos et al. (2017) found in their research that elder-clowns will often rely on body-movements, including eye contact, quick and slow movements, and smiling, to communicate effectively with individuals with severe dementia. Residents are never expected to give an active physical response during clown activities. Instead, even simply observing can be perceived as communication and engagement (Kontos et al., 2017).

As discussed, there is promising research being conducted focusing on the use of the arts with individuals with dementia, however upon reviewing the literature, the lack of research

focusing on intermodal art with this population is apparent. Future research should focus on the use of intermodal art with individuals with dementia in order to fully understand the impact the arts could have on the population.

Play-Based and Client-Led Activities

Play-based activities felt like a natural way to support this population's high-ranking of social relationships and humor, as play is an important way for people of all ages to engage in fun, and is also fundamental for learning, expression, and positive connection (Treadaway et al., 2016). The accessibility of play across ages and ability levels could give rise to play as a useful, natural tool for working therapeutically with adults with dementia. Not only is play accessible, but it has been found to "alleviate boredom, release tensions, prevent aggression, and symbolize workgroup membership" (Swinnen & de Medeiros, 2017, p. 1), which are challenges present in the daily lives of many adults diagnosed with dementia.

Play is defined by Swinnen and de Medeiros (2017) as "a voluntary act whereby the player enters into a purposeful yet spontaneous imagination-based encounter" (p. 3). The word 'voluntary' stands out as an important nuance to the definition of play, especially when working with individuals with dementia. Treadaway et al. (2016) discuss how "verbal expression can be problematic" (p. 42), so I worry that for many adults with dementia, their choice in participating may not be clear to those facilitating. In these cases, are individuals playing of their own free will? In what ways are we able to offer the freedom of play to those diagnosed with dementia while also respecting their choices, especially for those individuals with diminished verbal abilities? According to Tseklevs, Bingley, Luján Escalante, and Gradinar (2018), creating opportunities for individuals with dementia to express and enact their own thoughts and ideas

regarding activities in itself “could arguably reflect an individual’s sense of self, as an expression of personhood” (p. 9).

Swinnen and de Medeiros (2017) spoke of a similar concept, stating that “Winnicott [...] argued that it is through the unscripted, imaginative nature of play that an “authentic” self is maintained” (p. 2). This description of play leads me to question- if through unscripted, spontaneous, creative play we are able to access our “authentic” self, then would it not make sense to allow those “selves” to be the ones leading and creating the play they require? Looking closely at our definition of play, I am led to believe that play can only be truly spontaneous, voluntary, and imagination-based if it is client led.

By client-led play, I am referring to the concept of offering playful opportunities that are directed and imagined spontaneously by participants with dementia. It has already been demonstrated that even individuals with severe dementia are able to express their share their feelings about what they find important to their quality of life if given appropriate supports and means of expression (Alzheimer Society, 2010). If given the proper supports and means of expression, individuals with dementia can share their feelings about which playful activities, and to what extent, they want to participate in. I believe it is only ethical to listen to the individuals we are claiming to support and place that choice and control back into their hands.

By applying this definition of play to adults with dementia, we are shifting our focus from individuals’ cognitive limitations to a lens emphasizing their capabilities. In doing so we are empowering individuals to “explore new potential for expression, meaning-making, and relationship-building in later life” (Swinnen and de Medeiros, 2017, p. 2). Utilizing this definition of play with adults with dementia would create opportunities for those aspects of quality of life deemed most important by the population. By playing in this way, individuals with

dementia would not only be engaging in activities, but would also be immersed in humor, social relationships, different communication styles, physical exercise, and even opportunities prompting independence and fostering self-identity. By taking the lead in how they choose to play and where the play goes, individuals with dementia are advocating for their needs and expressing their desires, facilitated and supported in a natural context through play. Despite this possibility, research on the possibilities of client-led play with adults with dementia is seriously limited, as demonstrated above. Therefore, in the sections that follow, I outline the development and implementation of a client-led play intervention to begin filling this gap.

Methods

In order to explore the topic of client-led play with adults with dementia, I began with a literature review to better understand what was being written about the topic in my field. In addition to taking notes, I processed the research by creating visual art and poetry. Whenever I felt something strongly in my body when researching, I processed it through art and writing. This process helped me understand what was impacting me and what felt most important to look into more deeply. After researching the topic, I began to explore what a client-led play intervention could look like with the adults with dementia I work with at my internship site. After preparing a general outline and session, I worked with the program director of the memory care unit to begin a new group. In addition to working with the program director, I relied on my experiences working with the residents at my internship site over the last six months, as well as the research found during my literature review in order to form the structure of this intervention.

Based on the definition of play offered by Swinnen and de Medeiros (2017), I knew the intervention needed to leave room for spontaneity, creativity, and humor. It was also clear from the research that adults with dementia will need time to learn how to play again (Swinnen & de

Medeiros, 2017; Treadaway et al., 2016), so it was necessary for the intervention to be scaffolded enough to offer support and leave enough space for participants to take the lead when ready. Additionally, research stated the value of the arts in providing a means of expression from participants, especially for those with limited verbal abilities (Ahessy, 2017; Killick & Kenning, 2015; Kontos et al., 2017; Kinney & Rentz, 2005; Nyström & Lauritzen, 2005; Treadaway et al., 2016). While I was not able to find a great deal of research about the sense of control felt by individuals with dementia, in order to create an intervention that was truly client-led, it felt important to put as much control, power, and choice into the hands of the participants as possible. Additionally, research stated that activities offered after dinner time are very rare (Buettner & Fitzsimmons, 2003), so it was agreed between the memory care program director and myself to offer this new group at 6:00 PM, shortly after meal time.

This new group, called “Playing with the Arts,” was based on the concept of client-led play. It was meant to encourage spontaneous, creative fun that was led by the participants and their interests, desires, and imaginations. Participants were residents living in the locked memory care unit within the assisted living facility in Massachusetts where I was completing my internship. Groups I had facilitated previously were predominantly female, with one male resident who attended regularly. Participants ranged in age from their sixties to one resident who was one hundred years old.

I had been facilitating various dance-movement groups and visual art groups with these residents over the previous six months and had established a friendly relationship with the residents over that time. During that time, I was able to witness what types of activities prompted the most active engagement and encouraged moments of spontaneous fun, in addition to what activities left residents disengaged and apathetic. This lived knowledge was combined with the

information gathered through the literature review research to create an intervention that promoted client-led play that might invite space for authentic expression of enjoyment and a true sense of control for the participants.

The planned intervention was to invite participants to explore various ways of playing with balloons, as this is an activity I have witnessed residents enjoying and feeling successful with in previous groups. There would be a large number of balloons available in various shapes and sizes. I planned to begin by starting with a small number of balloons on the table for residents to bop back and forth to each other to warm up. Once comfortable with the materials, residents would be in control of how they wanted to use the balloons and for how long. When residents were ready, I planned to continue weaving in play while utilizing the arts, inviting participants to paint onto a canvas using a balloon as their paintbrush. In order to provide a sturdy, accessible working surface, cleaned out pizza boxes would be made into easels ahead of time with canvas paper taped to each. Finally, I planned to invite residents to share their artwork and discuss what they saw in each other's creations.

After the first session, I wrote down everything that happened and how I was feeling. I wanted to better understand the session through journaling, walking myself through the group and noticing how my body felt and reacted to different moments and what those different feelings may mean or be calling me to look closer at, even through discomfort. I also created process art following the group based on my reactions and what was coming up for me throughout the process and afterwards. Based on these notes and my art making, I incorporated my new knowledge and experiences into the following session and made significant alterations. The following Friday, with permission from the program director and my co-facilitator, I decided to use our weekly visual arts group as an additional opportunity to bring in client-led play.

Because of the first session, I knew that this group would have more participants than the prior session and felt comfortable bringing in balloons again as an inspiration for play. However, I wanted to add to the experience, so I decided to utilize another tool that has prompted play and laughter in past movement groups, the parachute.

Therefore, I began by taping down large sheets of paper to the table before beginning the group. The table was covered with paper and the parachute laid out on top of it when the residents entered the space. I was hoping the parachute would provide an opportunity for participants to warm up to playing within a familiar context. I planned to begin by raising and lowering the parachute as a group, taking the time to greet one another and ease into the activity. I was hoping the parachute would also serve as an opportunity for client-led choices, such as the speed and height of their movements. After participants were comfortable, I added balloons to the parachute a few at a time until there were many balloons bouncing in the parachute. Once again, the rationale here was to provide opportunities for the residents to take the lead on how they wanted to play with the balloons and the parachute for as long as they wanted. The next step was to remove the balloons and hand everyone a marker, inviting participants to raise the parachute and draw whatever they wanted on the paper underneath before the parachute came back down. Once residents were finished, the parachute was removed, and we had a chance to look at the creations and discuss what everyone had drawn as a group.

Again, immediately following the group I journaled about what happened and everything that I was feeling throughout and following the session. I also created a visual art piece that reflected my thoughts and feelings about the group. Finally, I examined what I had written about the first session and took notes comparing the two different sessions. Additionally, I spoke to my on-site supervisor, as well as the program director of the memory care unit, after each session

about how I felt it went. I also discussed the group with my co-facilitator after the second session, comparing thoughts and ideas. I was hoping that reflecting with others who know work closely with the residents might offer valuable insight and multiple points of view, potentially expanding my understanding and viewpoint about each session.

In order to make sense of the information gathered throughout this process, I organized my notes about each session in a similar system to how I organized research articles during my literature review. In order to organize articles, I created multiple folders on my computer by subject. These subjects included play with individuals with dementia, client-led interventions, expression of enjoyment, sense of control for individuals with dementia, expressive arts interventions with individuals with dementia, and other recreation therapy information. When I looked through my notes following each session, I noted if there were any specific moments that could be categorized into one of those same subjects. As the literature review helped form the structure of my intervention, I expected these themes to appear during sessions, so having a system in place to make additional connections between my observations and the literature was an important step in helping to organize all of the information gathered.

Results

Group One

Upon arriving to set up for the first play-based group on Wednesday at 5:30 PM, I found that almost all of the residents were in bed or sitting in front of the television. After setting up, I invited all of the residents who were awake to come join me to do a playful activity and make some art. Three residents agreed to join me, however once we sat down, one resident became

agitated and no longer wanted to participate. When given the option to stay or leave, she decided to stay and watch, but remained agitated.

The use of balloons during movement groups has often proved successful in engaging residents, so I had decided to bring out a large number of balloons for residents to play with and explore for a while at their leisure. However, with only two active participants and only myself to gather and replace balloons, there was not a great deal of interaction between the two residents and residents were not very engaged with the activity. It did not feel authentic or client-led to keep pursuing this same activity, so I decided to move on to the arts-based portion of the intervention.

One resident that was participating required much more individualized care and attention during art activities, as she has tended to put supplies, including paint, into her mouth in the past. In order to keep everyone safe, I had to focus most of my attention on this one resident. While the other participant was able to complete the task after viewing a demonstration, I was not able to interact with her as much and the activity turned out to be neither playful nor client-led. Both participants were able to let me know when they were finished or if they wanted to add anything else to their painting, but it ended up feeling more like a unique art project than play.

The participant that I worked more closely with required frequent reminders and invitations before each step. While she would look excited and verbally agree about what to do, her body and movements did not follow the same steps. For example, I asked her if she wanted to use red, yellow, or blue paint and she replied, “yellow,” so I invited her to dip her balloon in the yellow paint and she said, “okay, yes.” During this moment, she kept eye contact with me without moving her arms or the balloon. When I invited her again she said, “yes, that’s right,” once again without moving. When I asked her if she had her balloon she said, “yes, I have it, it’s

right over there,” gesturing at the table, despite the balloon being in her hand. With her permission, I guided her by taking her arm and dipping the balloon into the paint with her and moving the balloon on the canvas together. She verbalized enjoying doing this, but as soon as I removed my hands, she would look at me instead of the canvas, her hand still moving the balloon on the canvas without notice. I tried to bring her attention back to the painting, but without my direct support she would quickly stop, asking me “I can stay with you, right?”

The second participant was able to understand my directions and complete the activity without as much support. At first, she held her balloon and looked at the paint and the canvases unsure what to do. When I verbally directed her, she said she understood, but she “just wasn’t sure what to do.” I demonstrated on my canvas as I described the activity and after seeing it, she was able to continue on her own. She chose a long, thin balloon and dipped it in red paint. She made carefully selected, long, curved strokes with her balloon. She worked slowly, pausing to examine it before adding anything else. When I would check in on her to see how she was feeling or if she wanted to try a different color, she would repeat, “I’m just not sure.” She ended up only using one color and when she was finished, she put her hands down on the table and said, “well, I just don’t think there’s anything else I could do with it,” and pushed her chair slightly farther back from the table. We looked at her painting together and quickly discussed what we saw in it, which included fire and faces. At this point, both residents reported feeling tired, so we finished up with one resident going to bed and one stayed until I cleaned up the materials.

Group Two

The second group took place in the same memory care unit at 2:00 PM. At this time, many more residents were awake and about, with most having had returned from their day

programs as well. This group began with five residents, four female, one male, with another female resident joining about half-way through. An additional female resident popped in and out of the room throughout the group, joining in the fun and then leaving as she pleased, but never sitting in the circle with the rest of the group.

Most participants were there as we set up the paper, some helping us tape the sheets onto the table. We then covered the paper with the parachute and all gathered around the table. Three residents were seated in chairs and two residents were seated in their wheelchairs. In addition to myself and my co-facilitator, one other staff member was present and participating throughout the group.

We began by having all participants hold onto the edge of the parachute, raising and lowering it at differing speeds and heights. We started off slowly, lifting the parachute above our heads and saying hello to as many people as we could before the parachute came back down. After repeating this motion for a few turns, some residents began putting the parachute over their heads, remaining underneath when it fell down, inspiring the group to join them. Shortly after, one resident noticed music in the background and began shaking the parachute slightly faster and sharper as she danced to the music. This encouraged other participants to shake the parachute faster, which was a very different feeling and visual effect. Instead of soft and slow, our arms were moving faster and less in sync with one another, bringing up feelings of wildness, freedom, and warmth, as opposed to the calm, safety, and anticipation for more than I felt with the slower movements. At this point, participants began laughing and I decided to begin adding a few balloons to the parachute, which I had blown up earlier and had waiting in the supply closet behind our circle.

We returned to slow movements with the parachute and watched the balloons roll around as we raised our arms up and down. When one of the balloons rolled towards a participant, they would automatically reach out and try to hit it back into the parachute. This led to residents bopping the balloons back and forth to each other and laughing. We then started moving the parachute at a faster speed, sending the balloons bouncing up and down more sporadically. The residents started verbalizing different scenes they were imagining taking place, such as “a storm at sea” and instantly other participants started making sound effects of thunder and crashing lightning, comparing the balloons to boats, and attempting to keep them up by hitting them back in.

I continued adding more balloons to the parachute, including long, skinny, wavy balloons. As I tossed one of these longer balloons towards the parachute, we all discovered together that these balloons floated for long distances. This led to an enormous amount of fun and laughter as we continued playing with the balloons in different ways. At various points during the session these long balloons were described and depicted as submarines, javelins, microphones, snakes, and baseball bats. Additionally, residents expressed enjoying seeing these balloons float and thought it was “beautiful”, so we took turns lifting up the parachute and trying to send them soaring across the table before it floated back down.

At this point there were a large amount of balloons in the parachute and most residents had taken it upon themselves to grab one of the longer balloons and were using them to hit the other balloons back into the parachute. At this time, another resident walked into the room to see what the noise was and immediately started laughing and smiling. She began tossing balloons that were on the floor back towards the other participants. I invited her to join us and she replied, “I already am!” After a few minutes, she went on her way, returning every so often to observe. It

was an important reminder of the varying roles of participation someone can choose to have. While some research might claim she was not engaged in the activity for much of the time, she was engaged as much as it made her happy and was able to express that and be in control of her time and choices in that moment.

Around this time, another resident returned from her day program and was hurriedly ushered to our group. After the long walk up, she was visibly exhausted, her face was bright red, she was shaking, and she was having trouble catching her breath. She was brought into the middle of a group with balloons everywhere and was clearly confused as to why she was there. I asked her if she needed a glass of water and she said she was okay, but she wanted to know what we were doing, as she was hesitant to join in. I told her that we were there to have fun, that we were playing around with balloons and that we would have the chance to make a little art if she wanted to. She said she did not want to do art, so I told her that was okay and she only had to do what she wanted to do and if she was not having fun or wanted to leave she could let us know at any point. She visibly brightened up at that point and began bouncing balloons with the rest of the group.

After about 30 minutes of playing with the balloons in various ways, the residents expressed that they were getting tired, so we agreed to move on to the arts-based portion of the group. While we removed all of the balloons from the table, we kept the parachute on top and handed everyone a marker. As we raised the parachute slowly, participants were invited to quickly draw, doodle, scribble, write, etc. anything they wanted to on the table. The next time we lifted the parachute, we looked at what everyone had drawn. We repeated this a few more times when I noticed that some residents were drawing on the table underneath the parachute, even

when they could not see. I invited other participants to attempt this, which some residents expressed was easier than trying to both lift the parachute and draw simultaneously.

The resident who expressed not wanting to do art earlier was hesitant during this portion and communicated with me that she was not sure what to do. I repeated to her that we were drawing on the paper underneath the parachute without looking and she said she did not want to. I told her that that was fine and she did not have to do anything if she was not having fun. She laughed and said, “If it’s not fun, then what’s the point?” After a few minutes of observing the group, I noticed her hand moving under the parachute. When we removed the parachute to reveal our artwork a few minutes later, she had drawn a small amount and expressed being surprised and proud of doing something she did not think she could do.

We spent a few minutes looking at each other’s drawings and commented about different things that we saw in them. This was not happening for very long when one resident began tapping her feet rhythmically and another resident joined in by tapping her hands on the table. Other residents quickly joined in by clapping their hands, adding sound effects, and singing. We ended up singing the song, “A Bushel and a Peck,” which is the song my grandfather used to sing to me, which I shared with the group. Other participants began reminiscing and sharing similar family stories as they came to them. We continued talking and laughing together for fifteen minutes after any physical activity had occurred. As we began cleaning up and gathering our materials, the participants thanked us for coming and for being there, calling us “wonderful girls.”

Process Art

I created multiple visual art pieces when researching the literature about client-led play with adults with dementia. As I was researching its impact on an individual's self-expression and sense of control, I found myself coming across the challenge of communication and expressing one's needs for those with dementia often in the literature. This felt very important to me and it is definitely present in the process art I created. The first piece I made is purple paper cut into the shape of a human head, with no facial features other than a mouth. On its forehead is a white thought bubble that has "thoughts" written on it. Coming out of its mouth is a speech bubble that says "words..." When rotated to the side, a spiral of black paper can be seen connecting the thought bubble to the speech bubble. There are letters scattered on various parts of the spiral of thoughts attempting to form words.

The second piece of art I created while researching was a wall hanging/mobile. This included four different panels, each made from a cardboard frame wrapped in yarn. The top panel has bright green background paper with images of flowers, coffee, and a type writing collaged onto it. There is a poem made up of words cut out from magazines and reads:

Possibilities everywhere
Moments seek stillness
Precious world journey
Beautiful adventure awakens your heart
Art is full of life
Sleeping soul enjoy this moment
Your wings collect hope
Your heart in this today
Love
Seek soul flowers

The second panel is clear, but has the phrase “other people’s schedules,” an image of a button that says “live and let live,” and an image of trees growing on top of a ruler. The third panel is clear and has the phrase “everyone has art in them,” with images of a compass and gears turning. The bottom panel is clear, says “create possibility” and “I will always have art,” with the image of a clock with wings.

I created my third piece of processing art after facilitating group one. I decided to attempt the same visual art activity that I asked the residents to attempt, painting using balloons as brushes and using only red, yellow, and blue paint. The canvas paper is almost entirely covered in paint, with bits of white coming through. There are many circles that have blended together, resulting in purple, blue, and orange color pops throughout.

After facilitating group two, I created a piece of art out of clay representing the play we engaged in and my feelings as it was taking place. I made a parachute out of clay, designing it with carved patterns, but leaving it unpainted. I added clay balloons, which I painted different colors. In order to add handles to the parachute, I used red, glittery pipe cleaners, which I cut into pieces and attached.

The final piece of art I created has an image of a sunrise and/or sunset in the background, with a circular mirror and gems representing the sun and/or moon. There is a poem made from words cut from magazines that reads:

The artist must journey with fortitude

Lost & found

Unravel to open minded

May love be the strength within

To garden blue ideas

Brewing your today

Drawing indigo night

Own your story, proud river

On the foreground there is a bird and a woman made from sticks and natural materials. The woman is holding a staff and walking off the page with the bird flying over the sun/moon behind her.

Discussion

There was such a drastic contrast between the two sessions, that I was immediately curious about what factors could have impacted the outcomes of each group. In this discussion section, I will compare these two groups in order to theorize what might be helpful guidelines for creating groups that are more conducive to client-led play. I will also provide some recommendations for future research.

One of the most drastic differences between the two sessions was the times the groups were held. The first group took place at 6:00 PM, while the second group took place at 2:00 PM. While most of the residents were in bed by 5:30 PM or were already comfortable in front of the television, most residents were still awake and active at 2:00 PM. Additionally, medication is given after dinner, which could have impacted how tired residents may were at the time. Another staff member stated that residents were used to this routine. However, it felt important to offer activities in the evening, as Buettner and Fitzsimmons (2003) stated that individuals with dementia expressed the importance of offering stimulating activities in the evenings, which are rarely available. Witnessing this routine being acted out in person reinforced my decision to offer the group after dinner. While there were few residents in attendance during the first session, having the group available still offered entertainment for those who wanted to be there.

The time of session impacted the number of residents who chose to participate in the group, which likely had an impact on how the two sessions differed. Having more residents present in the second group allowed individuals to interact with each other, as opposed to three residents being present without interacting in the first session. The larger group also allowed for more ideas coming directly from the residents that enabled us to hear their input and try out each other's suggestions without feeling insecure or unheard. Participants also appeared more comfortable playing and sharing their imaginative thoughts when there were others around them doing the same.

While I did not find research comparing the benefits of groups versus individualized care with adults with dementia, there was a large amount of research that stated positive benefits for individuals with dementia who engaged in group activities (Kinney & Rentz, 2005; Novy, 2018; Nyström & Laureitzen, 2005; Swinnen & de Medeiros, 2017; Treadaway et al., 2016). Novy (2018) states that in studies examining arts-based therapies and dementia care, the social benefits of the various art forms are often highlighted. The authors suggest that group art therapy, in particular, may increase social interaction between participants with dementia, both during and after sessions. According to Nyström and Lauritzen (2005), interactions between individuals, the facilitator, and other participants during dance movement therapy groups supported individuals in developing their body movements and “not withdraw into isolation or a state of confusion” (p. 311). Treadaway et al. (2016) found that the group atmosphere was especially helpful in facilitating play with older adults with dementia because it helped support individuals through the vulnerable aspects of play, such as spontaneous expression and putting oneself in a new situation. While there was research available stating the benefits of groups with individuals with

dementia, further research should be done comparing the use of groups versus individualized activities within the population.

Another difference between sessions that likely impacted how each group flowed was the number of staff members present. In the first session, I was the only facilitator and during the second session there were three staff members present. During the first session, it was necessary that I work very closely with one resident in order to keep everyone safe, as that resident tended to put items in their mouth. While the other participant was able to complete the art activity without much support, they were lacking the support needed to feel comfortable playing. While the ratio of staff to resident was close to the same in both sessions, having three staff members present during the second session allowed for each resident to be supported as needed. In addition to have three staff members present throughout the session, other staff members visited briefly to see what the noise was and interacted with the group for a few minutes at a time. These staff members included the program director of the memory care unit, one of the house keepers, and two of the CNA's that work in the memory care unit. There was much more interaction between staff and participants in the second session, which led to many moments of spontaneous joy and laughter. Therefore, I would recommend in the future having, at minimum, a co-facilitation model. This would allow participants to have more individualized support and feel successful while still benefitting from the social aspect of a group. Additionally, the more opportunities for positive connection between individuals and staff, the better. Ellis et al. (2016) state that "it is important that all staff working in residential aged care homes increase their interactions with all residents, especially those with dementia and not leave this aspect of care to the activities staff" (p. 504).

While the second session was much more focused on play, the first session ended up being more focused on the visual art portion of the intervention. During this session, painting became the goal or task to be accomplished. According to Swinnen and de Medeiros (2017), play cannot have an end goal, but instead exists “for its own pleasure” (p. 2). While the visual art portion was a positive experience for participants in both sessions, it was only playful in group two. This is because instead of the creation of an art product being an expected outcome, art was instead used as a vehicle for play and imagination. This freedom to play with art, as opposed to making a finished product, allowed participants to go even further than visual art and spontaneously create music together, leading to laughter and reminiscing about our families. While I attempted to begin with a more play-focused activity during the first session, the small number of participants, lack of staff presence, and an unfamiliarity with the way the materials were used made play a great challenge. The residents enjoyed the process of painting with the balloons, but the activity ended up being neither play nor client-led.

I decided to use balloons in the first group because I knew the residents were familiar with them and had enjoyed playing with them in the past. However, in the first session, we were using balloons as paintbrushes, which was a difficult concept to understand. Additionally, we had largely skipped over the play portion of the first session, so the participants did not have much opportunity to get used to playing with the balloons in different ways, so when immediately asked to use balloons to paint it was a challenge. During the second group, we were doing activities that the residents had done before and expressed enjoyment about previously, such as using the parachute and trying to keep balloons in the air, but once again these activities were expanded and used in new ways. There was enough comfort with the materials and enough time to ease into the concept of play that residents felt confident enough to try using the

parachute and balloons in new, imaginative ways. While there was no paint in the second session to watch out for, we still had to intervene when residents attempted to put markers in their mouths, but there was enough staff present to keep everyone safe while continuing to encourage play and humor.

Process Art

The art I created throughout my research and while implementing client-led play with adults with dementia greatly informed my knowledge and experience (see Appendix). The first piece I created represented to me the way I imagine communicating. I have a thought, and I say it. For those with dementia it is much more complicated than that, which can come with many different consequences. The spiral of thoughts that is hidden from plain sight represents the frustration that individuals often feel when unable to express their needs, leading me to consider the potential physical, mental, social, and emotional consequences of being misunderstood, unheard, or underrepresented.

I created the second piece when I was first attempting to find research on client-led play and was having difficulty finding many results. I thought about the obstacles to client-led play I was facing at my internship and hoping to find answers to in the research, such as “other people’s schedules” and “live and let live.” I was frustrated to see little research about self-control and choice with individuals with dementia and frustrated that I was seeing residents at my site being told what to do regardless of their own desires. I was finding information about using art to have fun and create possibility, so I imagined what it would be like to use the arts and engage in client-led play, which is what the poem on the top panel ended up representing.

When attempting the same visual art activity that I asked the residents to attempt in group one, I enjoyed the feeling of using the balloons and seeing different textures than what I am used to creating. However, it was nearly impossible to paint something on purpose, which I found frustrating. It was difficult not to imagine myself in the place of the residents who were not engaging in play and being asked to paint something that essentially had to be abstract, without much structure, using balloons instead of paintbrushes. I did not enjoy the feeling that took over my body when I imagined being in that situation, so I wanted to make sure that the next group I facilitated was more structured and supportive for residents.

When I created the clay parachute after group two, I wanted to represent the different energies I felt throughout the session and honor the residents that created it. I decided to leave the parachute unpainted because while it was a useful tool in providing familiarity and structure to the play, it was not what made the play, the residents were. I wanted the handles to be bright because I wanted to represent the magic that the participants were adding to the experience. It was their ideas that continued to evolve the play. I decided to paint the balloons bright colors to represent the imaginations and creativity of the residents that inspired so much laughter and joy.

When looking at the final piece I created and reading the poem, I am reminded that everyone has the capacity to share their story in some way. I have seen how the arts can support non-logical speech and represent their meaning with playful expression. It just requires an opportunity to create be given and someone there to see you and understand you, with or without logical speech. It also reminds me that this playful and imaginative space can allow us to find clarity in the unclear and move forward with confidence, taking the lead in expression and choice.

Future Recommendations

To best implement client-led play with adults with dementia, I recommend working with materials that are not only familiar to participants, but that can also be utilized and engaged with in multiple ways. I found it was helpful to give residents time to engage with a familiar item, in this case balloons, in a way they were used before expecting them to spontaneously start play all of a sudden. Doing so gave participants confidence and allowed them to engage in play gradually, at their own pace, and with support of their peers and facilitators. During group one, I asked residents from the start to play with the balloons without any other direction and they found it quite challenging, resulting in a relative lack of engagement. During group two, I used the same balloons, but began instead by using them in a way which I knew residents were familiar and had expressed enjoying previously. I also added the parachute to this session because I have observed residents happily use it in order to play with balloons previously. This initial structure helped residents engage in play in way that felt safe and comfortable. In doing so, residents began changing the play on their own without the need for further directive. They just needed the initial support and time to adjust to the world of play before diving in.

To best support client-led play and expression, I recommend using the ‘yes, and’ technique discussed by Kontos et al. (2017). ‘Yes, and’ is a technique originating in improvisation techniques, also used in elder-clowning which involves accepting whatever is offered to you by the resident and adding something to it, such as adding something musical to support their input, adding a new line or gesture, or dramatizing their words, in order to “further facilitate active rationality” (Kontos et al., 2017, p. 53). In my experience, once engaged in play, participants began initiating new play scenarios on their own. When a new use for the balloons was offered by a resident, I repeated it and added to it by acting out the movement with the balloon and repeating their words. When residents changed the movement of the parachute and

stated that it was “like the sea” I said “yes, it is! And the balloons are like ships!” I found that this method allowed the play to continue and for residents to be engaged with others for much longer than expected for individuals with dementia.

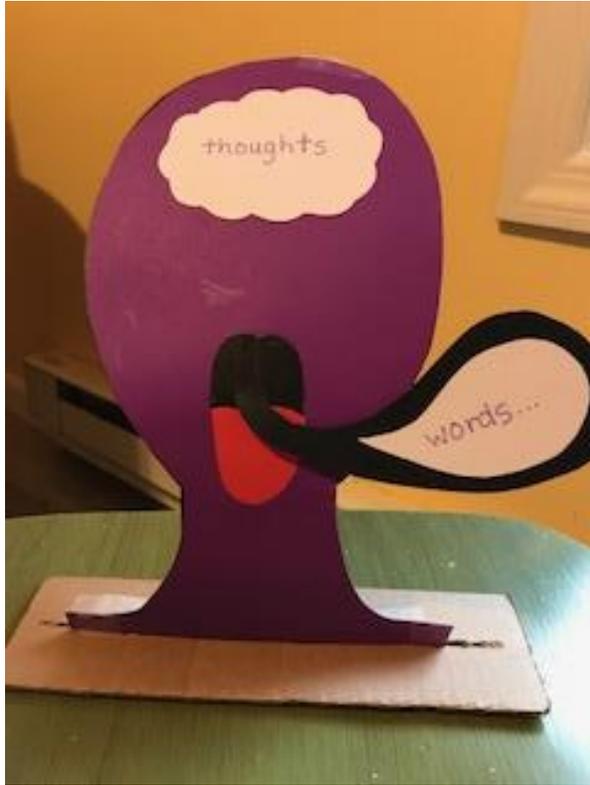
I also recommend that as many staff members are involved in play with residents as possible. Not only does having more facilitators help the activity run more smoothly and keep residents safe, but each interaction teaches the facilitators more about the residents, informing them for how to best prepare for and engage in future playful activities. In addition to group facilitators, other staff members such as nurses, aides, and directors should be engaging playfully with residents as often as possible. Each of these staff members engages with and understands the residents in different ways; they offer a different relationship with the residents’ families and caregivers. Each staff member also brings a world of experience and knowledge to the table and can help inform the play while providing a positive experience for the residents (Ellis et al., 2016). According to Novy (2018), there has been a recent trend extending arts-based therapies beyond therapeutic staff in residential care settings. Regular involvement of care staff in therapeutic, arts-based activities allows staff to engage with residents in new ways, informing their care with additional understanding, and was found to have a positive impact on the quality of care residents received.

After researching the literature and implementing client-led play with adults with dementia, I recommend further research be done specifically on the effects of client-led play with adults with dementia. It is important to include individuals with dementia in the planning and directing of their opportunities for expression. Future research should include and center the experience of individuals with dementia and investigate how to generate opportunities for individuals to take the lead. Individuals with dementia should not only be more represented in

the research, but should have more opportunity to represent themselves and what is important to them in the research. It is important that future research be more inclusive of adults with severe, late stage dementia, as they represent a significant part of the population and are often given the fewest opportunities to participate in activities (Buettner & Fitzsimmons, 2003). Additionally, I recommend continuing research utilizing the arts as a vehicle for play and self-expression, especially for individuals with dementia that have limited verbal abilities.

Appendix

Piece one- *Communication*



Piece Two- *Create Possibility*



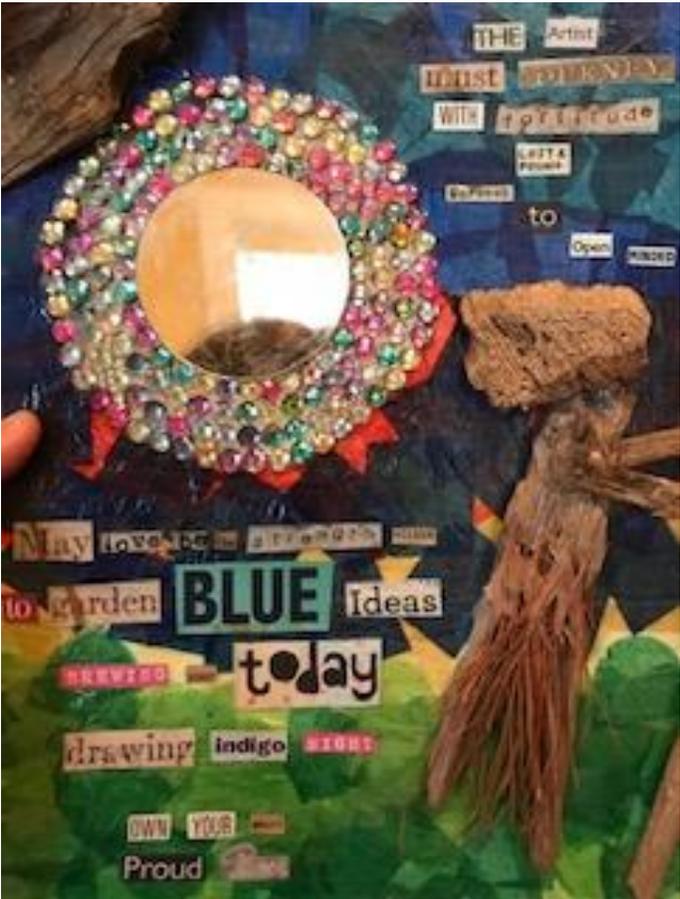
Piece Three- *Balloon Art*



Piece Four- *Parachute to the Moon*



Piece Five- *Unravel, proud river*



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THESIS APPROVAL FORM

Lesley University
Graduate School of Arts & Social Sciences
Expressive Therapies Division
Master of Arts in Clinical Mental Health Counseling: Expressive Arts Therapy, MA

Student's Name: Victoria Green

Type of Project: Thesis

Title: Leading the Play: Development of a Method Supporting Expression and Control with Adults with Dementia

Date of Graduation: 05/18/2019

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: Christine Mayor