

THE EFFECTS OF INTERGENERATIONAL PROGRAMMING ON OLDER ADULTS
WITH DEMENTIA

by

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Research has suggested that intergenerational interactions have the potential to improve the wellbeing and quality of life for adults with dementia. However, few studies have been conducted that determine the outcomes of intergenerational programs on these adults. This study examines the outcomes of participation in regular intergenerational programming (IGP) for adults who reside in a shared site facility where intergenerational interactions with children take place daily. The study examines adult participation and engagement in these intergenerational activities and explores the influences that their engagement patterns have on outcomes such as quality of life using the Menorah Park Engagement Scale (MPES) and Quality of Life (QOL) in Dementia Scale (QUALID). Results indicated a significant relationship between: (a) the type of engagement observed in IGPs and affect/behaviors among adults with dementia, (b) engagement outcomes and QOL, and (c) frequency of participation and QOL.

THE EFFECTS OF INTERGENERATIONAL PROGRAMMING ON OLDER ADULTS
WITH DEMENTIA

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by

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SECTION 1: MANUSCRIPT

Approximately one out of ten adults aged 65 and older are diagnosed with Alzheimer's disease or some type of unspecified dementia (Alzheimer's Association, 2017). Many of these individuals utilize adult day services or reside in long-term care facilities as their disease progresses (CDC, 2014). Thus, there is a need for more outcome-based healthcare approaches in treatment and care services due to the prevalence of this disease.

Most forms of dementia have similar symptoms that are manifested with comparable behaviors and distinctions. Traditionally, medications are utilized to reduce the common side effects and symptoms such as aggressive behaviors, confusion and anxiety that are caused by Alzheimer's and unspecified dementia. It has been projected that up to 90% of adults with dementia will exhibit some behavioral or psychological symptoms, which tend to be more prevalent in advanced stages of the disease (Trivedi, Goodman, & Dickinson, 2013). In cases where the memory loss is not reversible, as with Alzheimer's disease and most forms of dementia among older adults, the emotional adjustment to these changes may be difficult. Depression is prevalent amongst those diagnosed with Alzheimer's (Starkstein, Mizrahi, & Power, 2008). If left untreated, it can exacerbate the cognitive, psychiatric and behavioral symptoms experienced by individuals with Alzheimer's, which may further negatively impact their quality of life and result in more rapid disease progression (Starkstein et al., 2008). However, research has suggested that psychotropic medications used in treatment to combat side effects and symptoms of dementia might have no benefit to individuals with dementia and depression and may make patients feel worse due to additional side effects (Banerjee et al., 2011).

Research highlights the need for a greater use of effective, non-pharmacological treatment modalities and models to treat Alzheimer's and other types of dementia, particularly in long-term care settings. In general, nonpharmacological approaches are rarely used in clinical settings, but it has been suggested that effective non-pharmacological interventions could help improve quality of life and reduce the inappropriate use of antipsychotics in patients with dementia (Agency for Healthcare Research and Quality, 2016). Intergenerational programs are one type of non-pharmacological intervention that has been explored to address the needs of this population.

Benefits of Intergenerational Programming

Intergenerational programs (IGPs) facilitate the joining of two or more generations. IGPs allow formal and informal interaction in a setting where members of each generation can thrive. Intergenerational programming provides an environment where multiple generations receive services, treatment, and/or programming at the same time (Commission on Affordable Housing and Health, 2002). Intergenerational activities can occur when one generation visits the other in their typical environment (e.g., older adults volunteering in a school system) or can occur in shared site facilities, where intergenerational interactions are integrated into the daily routines of the participants (e.g., child daycare program located within a long-term care facility). Previous research has found that IGP is beneficial for both younger and older generations (Burgman & Mulvaney, 2016; Cook & Bailey, 2013; Hernandez & Gonzalez, 2008; Pinguart, Wenzel, & Weston, 2010). Early studies on IGP suggested that intergenerational activities increase social responses in persons with dementia (Newman & Ward, 1993).

Driven by the need to explore non-pharmacological treatments for dementia, several studies further examined the intergenerational interactions between younger generations and

older adults with dementia. Lee, Camp, and Malone (2007) investigated the use of intergenerational programming and the outcomes of this treatment modality on older adults with dementia. The study included 14 nursing home residents in a dementia skilled nursing facility unit and 15 children from the on-site childcare facility. Older adults were screened using the Myers Research Institute Engagement Scale to measure outcomes of engagement. Results indicated that in comparison to traditional programming, participation in intergenerational programming (IGP) prompted successful one-on-one engagement with higher levels of positive engagement (i.e., constructive engagement) and lower levels of non-engagement (i.e., non-focused activity). Findings were similar to those found by Jarrott and Bruno (2003), where positive affect was greater in IGP participants than non-IGP participants. In this study, individuals of all cognitive levels were likely to participate in IG programming, regardless of the severity of memory loss.

Other studies have noted benefits for adults with dementia as a result of participation in IGPs. Brownell (2008) conducted a study to evaluate the impact of participation in an intergenerational art program involving cognitive and emotional responses of older adults with dementia. He found no statistically significant changes regarding frequency of inappropriate behaviors or level of engagement during activity. However, participation in activities at an appropriate functional level was found to promote a sense of empathy and decrease the isolation seen with passive behaviors, agitation, and like behaviors (Brownwell, 2008). These findings relate to those of prior studies by O'Rourke (1999) and Camp et al. (1997) that indicated behaviors (e.g., aggression, disruption) of adults with dementia improved while engaged in intergenerational activities. When given the opportunity, older participants value being able to contribute to the development and education of younger generations, suggesting that activities

providing a meaningful social role are beneficial for elders with dementia receiving care in a treatment facility (Camp & Skrajner, 2004; Cook & Bailey, 2013; Jarrott, Gozali, & Gigliotti, 2008). Other benefits noted in the literature associated with IGP participation include increased joy or pleasure (Camp, Skrajner, & Gorzelle, 2015; Waggoner, 1996), increased active behaviors (McNair & Moore, 2010) and positive affect (Jarrott & Bruno, 2003). In addition, programming that focuses on the retention of functional abilities allows participants to fulfill more independent and successful social roles (McNair & Moore, 2010).

There is some discrepancy between the findings in these studies related to the outcomes and benefits of IGPs for older adults. While most studies have suggested an improvement in function for adults who engage in these programs (Jarrott & Bruno, 2003; McNair & Moore, 2010; Whitehouse, 2013), some study suggests the contrary. Doll and Bolender (2010) found that well-being was negatively affected for adults who participated in IGP and there was an increase in medication intake post IGP. George and Singer (2011) found that adults who participated in IGP experienced more stress post IGP. Gigliotti, Morris, Smock, Jarrott, & Graham (2007) found that some adults demonstrated higher levels of frustration and impatience when participating in IGP. Additionally, other researchers found that participation in IGP had no effect at all. Isaki and Harmon (2015), found that older adults did not express improved mood or communication post IGP. Brownwell (2008) indicated that participation in IGP did not affect the frequency of inappropriate behaviors or level of engagement.

Some of these studies have incorporated a qualitative component in their research to explore the effect of IGPs on adults' experiences and outcomes in more depth. Findings from the qualitative data indicate that compared to traditional programming, intentional intergenerational relationships had a greater effect on the health and overall well-being of older participants

despite findings of little to no statistically significant outcomes for the IGP participants (Doll & Bolder, 2010; Power, Eheart, Karnik, & Karnik, 2007). The lack of findings in some of the quantitative studies may be due to factors such as small sample sizes rather than the lack of a positive relationship between IGP participation and improvements in well-being, and research identifying negative effects of IGPs on outcomes may be a factor of adults' preferences and individual factors rather than the program itself. However, as evident from the studies discussed above, the findings related to the efficacy of intergenerational programs as a modality to improve the health and wellbeing of adults with dementia are mixed. Thus, researchers have suggested that just examining *whether* an individual participated in IGPs is not sufficient to determine the effects of IGP. More research needs to examine *how* the adults engage in these IGPs to determine the effects of these interventions.

Engagement

Engagement is described as a key element in addressing the negative side effects and symptoms associated with persons who have dementia. Successful nonpharmacological treatment must start with engagement to initiate positive interactions with other individuals and improve well-being (Camp et al., 2015). Lee et al. (2007) noted that positive IGP experiences involve “providing a mentoring role for older adults, voluntary participation, and client-initiated contact with children,” and “when combined with interacting with young children, the structure provided by this programming works to increase engagement” (p. 478). Engagement scales have served to gauge the various types of participation observed in individuals, as well as note environmental factors and personal attributes that may affect one's ability to engage. One instrument that has been used in studies exploring the IGP interaction of adults with dementia is the Menorah Park Engagement Scale (MPES). The MPES was designed to document various

types of engagement exhibited by individuals with dementia during meaningful activities. Camp and Skrajner (2004) found that participants had higher scores for positive engagement and pleasure during peer-lead activities when compared to standard programming. Jarrott, Gozali, and Gigliotti (2008) used the MPES to measure participants' engagement and demonstrated that more positive levels of engagement were evident in activities that provided a meaningful social role for individuals with dementia. Engagement is identified as the most influential element that affects overall connectedness exhibited by individuals with dementia (Camp et al., 2015).

Quality of life

Brooker, Woolley and Lee (2007) conducted a study to measure the effect that the Enriched Opportunities Program (i.e., non-pharmacological interventions and approaches that attempt to improve levels of engagement, well-being, and quality of life among other outcomes) had on residents with dementia. In their study, individuals were most likely to participate in activities that promoted well-being. There was no statistically significant change in QOL for adults in this study. However, depression levels decreased and there was an increase in levels of well-being after participating in Enriched Opportunity Programs. Those with less cognitive impairment were more likely to participate in more diverse activities than those with greater cognitive impairments. Other research has noted that adults' levels of well-being may increase significantly regardless of their level of cognitive impairment (Jarrott & Bruno, 2003).

Barca, Engedal, Laks, and Selbaek (2011) studied the quality of life amongst institutionalized elders with dementia. The most prevalent forms of behaviors exhibited by their participants were: appears sad (57.7%), apparent discomfort (52.6%), appears comfortable (42.9%), and makes statements or sounds that suggest unhappiness or discomfort (41.7%). Residents who had more impaired functions, more severe depressive scores, and more severe

dementia scores had a lower quality of life as assessed by the Quality of Life in Dementia Scale (QUALID). George and Whitehouse (2010) evaluated the effects of structured intergenerational volunteer programs on the quality of life (QOL) of persons with mild to moderate dementia. Eight residents from an assisted living facility, several of which were restricted to an “Alzheimer’s” unit, visited The Intergenerational School (TIS) of Cleveland, Ohio once a week and volunteered with children ages 5-14. Qualitative and quantitative research in this study demonstrated that older adults with dementia had lowered stress and an enhanced sense of purpose and usefulness as a result of being active members within the school community. Whitehouse (2013) suggests that IGP and health programming models create more well-rounded care that do not place dominance on one form of care.

Summary of Literature

Evidence from research indicates that intergenerational programs have effectively improved engagement (Camp & Skrajner, 2004; Jarrott & Bruno, 2003; Jarrott et al., 2008; Lee et al., 2007), improved levels of well-being (Doll & Bolender, 2010; Hernandez & Gonzalez, 2008; Power et al., 2007), improved quality of life (Chung, 2009; George & Whitehouse, 2010; George & Singer, 2011), improved quality of care (Cook & Bailey, 2013; Whitehouse, 2013), reduced levels of depression and/or anxiety (Chung, 2009; Hernandez & Gonzalez, 2008), and improved well-being (Doll & Bolender, 2010; Hernandez & Gonzalez, 2008; Power et al., 2007) among older adults with dementia. Intergenerational programs, as well as some other non-pharmacological interventions, utilize a multifaceted approach that not only address the ailment of the individual, but also focus on various aspects of overall well-being. Thus, IGPs may be an appropriate treatment option for maintaining or improving QOL and well-being in adults with dementia.

Unfortunately, there is limited quantitative evidence to support the benefits of IGP, creating a need for more evidence-based research. The literature needs to better explore differences in how adults engage in IGPs, and how this relates to their affect and behaviors. One study using the MPES found that the correlation between pleasure and constructive engagement was not significant (Jarrott et al., 2008). Thus, it is beneficial to explore *whether* adults participate in IGP or not. Then, one has the ability to indicate *how* the adults engage in IGPs (e.g., active engagement) and determine any outcomes that are associated with affect and behaviors (Jarrott et al.).

This research study will examine the effects of engagement in intergenerational activities on the health and wellbeing of adults with dementia at a facility with a shared site intergenerational program. Specifically, this study will explore the following research questions.

1. What is the relationship between the type of engagement observed in IGPs and affect among adults with dementia?
2. Do the type of engagement and related outcomes (i.e. affect, behaviors) in IGPs predict quality of life among adults with dementia?

Method

Setting

A continuing-care retirement community with a shared-site daycare program in Northwest Ohio was the site of data collection in this study. The daycare serves infants to children ages six years of age. Adults and children can interact both formally and informally as part of the intergenerational program. The long-term care facility and shared site childcare program provide structured intergenerational activities to residents in the memory care units at least two times daily. For this study, data were only collected during the formal, structured

programming for adults who resided in one of the two secured neighborhoods of the facility. All individuals involved in this study (e.g., children, staff, and older adults) had signed informed consent forms; in the case of the children and adults with dementia, the informed consents were signed by their legal guardian. Information about the study and informed consent forms were sent to the legal guardians of all the residents on these units a month prior to the start of the study. The administrator initially sent out a brief information letter and the informed consent letters to each guardian with the adult's monthly bill statement. After four weeks, only 5 consent forms were returned. Thus, the administrator then solicited help from the Directors of Nursing on both units as well as the social worker to contact guardians to attain consent forms for additional residents on each unit. The study protocol was reviewed and approved by two separate Institutional Review Boards – the hospital system that oversees the long-term care facility as well as the researcher's university.

Participants

A total of 64 residents lived in the two memory care units of the facility at the start of the study and were eligible to participate. Informed consents were returned for 30 individuals (29 residents and one adult who participated in the adult day program on one of the units). However, by the time data collection began, one of the residents had passed away. Of the 29 remaining adults, 15 individuals participated in the structured IGPs at the facility during the data collection period.

Intergenerational Program

The intergenerational program has been offered onsite at the long-term care facility (Birchaven Village Homes) since 2003 and participation in the IGP is voluntary for the residents. Structured intergenerational activities were provided each morning to the residents in both neighborhoods. The actual activities and the age of the daycare children who interacted with the

adults varied daily during the program. The frequency of the older adults' participation in the structured programs was tracked by the unit nursing staff as well as the researchers using an attendance roster during the 5-day study period. Informal interactions occurred in the afternoons on both units; however, these interactions typically did not last long enough to be objectively assessed with the engagement tool used in this study (i.e., a minimum of 5 minutes). Thus, these interactions were not recorded. The structured IGPs were videotaped daily for five days on each of the two units to observe the engagement patterns and responses of the older adults with dementia. This study only includes the adults in the facility with signed informed consents that participated in at least one day of the IGP program during the study period (N = 15).

Each unit is paired with children from a different classroom every day. Three age groups of children participated: infants, toddlers, and preschoolers. The structured program offered changes daily and depends on the age group of the children. For example, programming observed during the study period with the infants involved the older adults bottle feeding the infants, interacting with them as a staff member brought them over, and watching them play on the floor. Programming with the toddlers involved interactive songs with props that required the participation of the toddlers and adults as well as throwing balls back and forth to each other. Observed programming with the preschoolers involved an interactive story telling process in which the preschoolers and older adults participated in the collaborative story time; they also had a "free play" session where the children built with blocks and other toys in the center of the group. The structured programming for the day depended on the population and the preference of the teacher.

Study Design

The study period duration was five days total on each unit. On each unit, video cameras were set-up prior to the start of the morning IGP session and removed after each session. Researchers arrived at each unit at least thirty to forty minutes prior to start time to set up the video cameras and to assist on-unit staff with the seating arrangements of the participants to ensure that only adults with consent would be captured on camera. IGP sessions on both units began at approximately 10:30am. The sessions typically lasted anywhere from 30 minutes to an 75 minutes. The observed content was then reviewed by the two researchers. Researchers achieved 87% interrater reliability for the Menorah Park Engagement Scale (MPES) measurement prior to coding the sessions for the study. The data were coded using the MPES and entered in SPSS 24 for each observation period on the two units. During the week prior to the study, other measures such as the BIMS and PHQ-9 were collected by the facility social worker. The week following the conclusion of the IGP recordings, the frequency of participation data related to the intergenerational programming was completed with the help of the activity staff and QUALID data were completed by the nursing staff on each unit.

Measures

Independent variables for this study include type of engagement, affect/behaviors demonstrated during the IGP, and frequency of participation in the IGP. The dependent variables for the current study were the affect and behaviors during the IGP (Research Question 1) and quality of life (Research Question 2).

Frequency of participation. Data on the adults' frequency of participation attempted to address one aspect of participants' engagement in the IGPs; this was assessed in two different ways. First, to control for duration of participation in the IGPs prior to the start of this study, data

regarding how long each resident had typically been attending the programs was collected. This variable was measured on a Likert-type scale with response categories of 0 (never), 1 (less than 1 month), 2 (1 to 3 months), 3 (4 to 6 months), 4 (6 months to 1 year), and 5 (over a year). In addition, the number of sessions the residents attended during the five-day data collection period was summed to provide information about the frequency of the adults' engagement in the IGPs during the study period, ranging from one to five.

Menorah Park Engagement Scale. The MPES was used to assess the type of engagement adults exhibited during the IGPs as well as their affective and behavioral responses during their participation. It has demonstrated good validity and reliability in prior studies. Concurrent validity has been demonstrated when comparing the Observational Measurement of Engagement (OME) and the MPES, verifying that this instrument's measurements correspond to an instrument that was previously established to measure the same construct (Camp, 2010). Convergent validity is evident based on studies such as Skrajner et al. (2007) and Lee et al. (2007), in which scores on the MPES found that peer-led MPD resulted in higher levels of positive engagement as well as increased positive forms of affect when compared to traditional programming. Suggesting that measures of both constructs are theoretically related. Inter-rater reliability has also been established for the MPES (Camp, 2010; Camp & Skrajner, 2004; Volicer & Hurley, 2015), indicating that a degree of agreement is achievable among raters. This tool utilizes five-minute observation periods during activity programming for individuals with dementia. An 80% criterion agreement or greater for each of the 11 items is required (Camp & Skrajner, 2004). In this study, two study researchers coded all the observational data. There were a total of 47 five-minute observation periods possible per person during the intergenerational

interactions over the course of this study. An inter-rater reliability of 87% was achieved for the two researchers who scored the observations.

Measure of Engagement. The MPES was designed as a “low-tech” means to document various facets of engagement exhibited by individuals with dementia (Volicer and Hurley, 2015). The MPES measures four areas of engagement: constructive engagement (CE), passive engagement (PE), other forms of engagement (OE), and non-engagement (NE). CE is defined as any verbal or motor response exhibited during activity, PE is described as looking and listening behaviors focused on the activity, OE is defined as self-engagement or any other behavior that where the participant engages with one’s self or another outside of the activity, and NE is described as staring into space, having one’s eyes closed, or sleeping during the activity (Camp & Skrajner, 2004, pp. 428-429). Scoring of the MPES is conducted via direct observation and items are scored as 0 (never seen), 1 (seen up to half of the activity time), or 2 (seen more than half of the activity time) (Camp, 2010; Camp et al., 2015). Rather than develop a composite score, each type of engagement and affect/behavior has a specific and unique score (Volicer & Hurley, 2015). This feature makes the MPES easy to use in both research and practical settings, allows the measure to be sensitive enough to detect changes, and maintains high inter-rater reliability. All scored behaviors must occur for at least three seconds before being recorded, except for the observation of constructive engagement (Volicer & Hurley, 2015). This sets a standardized duration window to ensure that the behavior is recordable, as opposed to only merely being a momentary gesture. Observations were taken in five-minute periods throughout the duration of all intergenerational interactions. These periods began when the children arrived each day on each of the units and ended when they left. Average scores were computed for each of the items assessing type of engagement (i.e., constructive engagement, passive engagement,

self/non-engagement, and sleeping) for all observed measurements for that participant, and these scores were used in the data analysis.

Measure of Affect and Behaviors. Pleasure, anxiety/sadness, helping others and inappropriate behaviors are also assessed in the MPES and were used as to measure the affect and behaviors demonstrated by adults during the IGPs. When scoring for pleasure and anxiety/sadness, only blatant observations and obvious displays of the emotions are coded. Implications on how one assumes the participant feels are not to be recorded. Like the measures of engagement, an average score for each of these items was computed across all the observed data recorded for each individual participant. These average scores for pleasure, anxiety/sadness, and helping others were used in the analyses. No participants engaged in inappropriate behaviors during the observed interactions of the study period; thus, this variable was not examined in these analyses.

Quality of Life. The Quality of Life in Dementia Scale (QUALID) was used to assess the adults' quality of life (QOL) in this study. The QUALID is an 11-item scale developed to rate the quality of life for persons in the late stages of Alzheimer's disease and other dementia-related illnesses (Weiner et al., 2000). The instrument assesses the resident's behaviors during the past week. Each domain is scored with a descriptor that ranges from 1 to 5. The sum of all items is then calculated to depict the resident's overall quality of life. Scores range from 11 (best) to 55 (worst), with lower scores indicating a higher quality of life. This measure was completed for each participant the week after the completion of the study by facility staff. Weiner et al. (2000) concluded that the QUALID was both reliable and valid when used to determine QOL in persons with late-stage dementia and other unspecified, dementia-related illnesses.

Other Measures

Other variables were also collected for this study to control for the cognitive status and psychological wellbeing of the residents. This information was drawn from the residents' medical charts based on their most recent MDS assessment prior to the start of the 5 day study period, for those adults who received Medicaid. For private pay residents, these instruments were completed by facility staff prior to the start of the study. The Brief Interview for Mental Status (BIMS) was used in this study to assess the participants' cognitive impairment. Total possible BIMS scores range from 0 to 15. Adults with a score of 0-7 are considered "severely impaired", 8-12 indicates "moderate impairment", and a score of 13-15 suggests that the individual is "cognitively intact" (Mansbach, Mace, & Clark, 2014). The BIMS has both reliable and valid psychometric properties with this particular population (Mansbach et al., 2014). The Patient Health Questionnaire (PHQ-9) is used in the MDS to assess mood and depression. PHQ-9 scores of 0-4, 5-9, 10-14, 15-19, and 20-27 represent none, mild, moderate, moderately severe, and severe depression levels. Previous studies indicate that the PHQ-9 is both valid and reliable and had scores of 88% for sensitivity and specificity (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 is brief and easily administered in two different forms – self-assessed and staff assessed (which were both utilized in this study), which makes this instrument both practical and convenient to use in various settings.

Data Analysis

Quantitative data were collected regarding each participant and entered by the researchers into SPSS 24.0. Descriptive statistics were conducted for all study variables. Bi-variate correlation analyses were conducted between overall averages for all engagement types (i.e., constructive, passive, other engagement, and non-engagement) and the overall averages for

affect and behaviors (i.e., pleasure, anxiety/sadness, and helping behaviors). Correlation analyses were also conducted to explore the relationship between the residents' QUALID scores and overall averages for all engagement types as well as the frequency of their participation in the IGP. Finally, regression models were run to assess predictors of QOL. In the first model, the two 'positive' IGP engagement types (i.e., constructive engagement, passive engagement) were included as predictors of QOL. For the second model, other engagement and non-engagement functioned as the independent variables predicting residents' QOL. The final regression model included both variables of frequency of participation in IGP as predictors of the residents' QOL.

Results

Of the 15 participants who participated in this study, eight of the adults resided in the A/B neighborhood and six residents lived in the C/D neighborhood at the facility. One participant for the adult day program also attended some of the sessions that were held on the A/B unit. The mean age of the participants was 82.3 years, the mean years of dementia diagnosis was 3.16 years, and the mean years of admission was 3.68. There were 11 female participants and 4 male participants. All participants identified as White. Approximately one-third of the participants (33.3%) were married, 60% were widowed/divorced, and 6.7% were single/never married. The majority of the residents in this study had been attending the IGPs at the facility for over a year (76.7%). During the week of data collection, the average number of formal intergenerational sessions attended for this sample was 3.50. See Table 1 for more information about the descriptive characteristics of the sample, including their health status.

Results from the correlation analyses indicated a significant relationship between the type of engagement observed in IGPs and affect/behaviors among adults with dementia. The significant, positive correlation ($r = .75, p \leq 0.001$) (Table 3) between *constructive engagement*

and *pleasure* suggests that adults who engaged more constructively, or actively, in the IGP also exhibited more pleasure. There was a significant correlation ($r = .77, p \leq .001$) between *constructive engagement* and helping behaviors - indicating that those who constructively engaged were more likely to exhibit helping behaviors during the sessions. A significant, negative correlation ($r = -.85, p \leq .001$) between *non-engagement* and pleasure was also noted, suggesting that adults who did not engage (i.e., slept, had eyes closed) during the IGPs displayed less pleasure.

Table 1

Descriptive Statistics for the Sample of Adult Participants (N = 15).

	N	Minimum	Maximum	Mean	Std. Deviation
Age (years)	15	37	96	82.33	15.15
Months diagnosed with dementia	12	0	98	37.92	31.03
Months admitted to Birchaven	15	0	132	44.13	41.95
PHQ9 Total Severity Score	11	0	7	1.45	2.07
PHQ9OV Total Severity Score	4	1	9	5.50	3.32
BIMS Summary Score	11	2	15	8.45	4.70
QUALID Total	15	11	33	19.53	7.77

Results from the correlation analyses indicated a significant relationship between the type of engagement observed in IGPs and affect/behaviors among adults with dementia. The significant, positive correlation ($r = .75, p \leq 0.001$) (Table 3) between *constructive engagement* (AvgMPES4) and *pleasure* (AvgMPES8) suggests that adults who engaged more constructively,

or actively, in the IGP exhibited more pleasure during the programs. There was also a significant correlation ($r = .77, p \leq .001$) between *constructive engagement* and helping behaviors - indicating that those who constructively engaged were more likely to exhibit helping behaviors during the sessions. A significant, negative correlation ($r = -.85, p \leq .001$) between *non-engagement* and pleasure was also noted, suggesting that adults who did not engage (i.e., slept, had eyes closed) during the IGPs displayed less pleasure. Table 2 reports the results from these correlation analyses.

A correlation analysis was also conducted to assess the relationship between the types of engagement outcomes and residents' QOL. There was a positive correlation between *non-engagement* and QOL, ($r = .661, p \leq .01$). An increase in non-engagement was correlated with an increase in QUALID scores, which indicates a lower QOL. There was also a negative correlation between *pleasure* and QOL, ($r = -.647, p \leq .009$), suggesting that increased pleasure was associated with a decrease in QUALID scores, or a higher QOL.

Finally, a correlation analysis was performed to explore the associations between the frequency of the adults' engagement in IGPs and their quality of life. The frequency of the adults' participation during the study period was significantly correlated with their quality of life scores ($r = .61, p \leq .05$). The more programs an individual attended during the study period, the poorer their quality of life. Table 3 displays the correlations between the study variables and QOL.

Table 2

Correlation Matrix of Engagement Types and Behaviors.

	CE	PE	OE	NE	Pleasure	Anxiety/ Sadness	Helping Others
CE	--						
PE	-.21	--					
OE	-.10	.38	--				
NE	-.75***	-.40	-.35	--			
Pleasure	.75***	.33	.41	-.85***	--		
Anxiety/Sadness	.01	.07	.12	-.06	.00	--	
Helping Others	.77***	-.28	-.15	-.40	.63**	-.01	--

Note. ** $p \leq .01$, *** $p \leq .001$.

Table 3

Correlations Types of IG Engagement/Outcomes and QOL

	QUALID Total
CE	-.460
PE	-.353
OE	-.445
NE	.661**
Pleasure	-.647**
Anxiety/Sadness	.230
Helping others	-.137
Inappropriate behavior	-.126

**Correlation is significant at $p < .01$

Regression analyses were then conducted to determine if engagement and related outcomes (i.e. affect, behaviors) in IGPs predicted quality of life among adults with dementia. Due to the small sample size, these regression models were run separately for the “positive” and “negative” engagement types as well as the affect/behaviors observed in the sessions. In the first model testing the positive types of engagement, constructive engagement and passive engagement (i.e., listening) were entered into the analysis to predict QOL. This model only approached significance ($F = 2.74, p = .11$). However, the second model including the negative engagement types - *non-engagement* and *other/self-engagement* - significantly predicted residents’ QOL ($F_{(2,14)} = 5.15, p \leq .05$). Specifically, those adults that demonstrated more non-engagement, such as sleeping or having their eyes closed, had higher QUALID scores, indicating a poorer quality of life ($b = .58, p \leq .01$). Next, a regression was conducted including all three behavioral outcomes demonstrated during the IGPs in this study period. This model including pleasure, helping behaviors, and anxiety/sadness was also significant ($F_{(3,14)} = 3.90, p \leq .05$). Adults who demonstrated more signs of pleasure during the IGPs had better quality of life ($b = -.75, p \leq .01$). Finally, a regression model with both frequency of participation variables was used to predict residents’ quality of life. This model was significant as well ($F_{(2,14)} = 4.25, p \leq .05$), indicating that the more sessions the residents’ attended during the study period, the worse their quality of life ($b = .59, p \leq .05$). See Table 4 for the results from all the regression analyses.

Table 4

Regression Analyses Predicting Residents' Quality of Life.

	<u>Model 1</u>			<u>Model 2</u>			<u>Model 3</u>			<u>Model 4</u>		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
CE	-6.64	3.66	-.44	--	--	--	--	--	--	--	--	--
PE	-4.57	3.42	-.32	--	--	--	--	--	--	--	--	--
OE	--	--	--	-4.64	6.22	-.18	--	--	--	--	--	--
NE	--	--	--	6.89	2.84	.58*	--	--	--	--	--	--
Pleasure	--	--	--	--	--	--	-10.97	3.47	-.75**	--	--	--
Anxiety/ Sadness	--	--	--	--	--	--	83.29	69.60	.25	--	--	--
Helping Behaviors	--	--	--	--	--	--	3.71	4.39	.20	--	--	--
Participation during Study	--	--	--	--	--	--	--	--	--	3.14	3.54	.20
Overall Frequency of Participation	--	--	--	--	--	--	--	--	--	4.80	1.80	.59*
Adj. R ²		.20			.37			.38			.32	
F		2.74			5.15*			3.90*			4.25*	

Note. CE = Constructive Engagement, PE = Passive engagement, OE = Other forms of engagement, and NE = Non-engagement.

* $p \leq .05$, ** $p \leq .01$.

Discussion

Many of the findings from this research supported what has been reported in prior studies. Greater levels of constructive engagement during the IGP sessions was associated with greater pleasure/more positive affect in these residents. Other studies noted similar findings, suggesting that engagement levels might influence affect (Volicer & Hurley, 2015; Camp et al., 2015; Camp and Skrajner, 2004; Camp, 2010; Jarrott & Bruno, 2003; Waggoner, 1996). McNair and Moore (2010) found that participation in IGP resulted in increased active behaviors. Results from this study indicated that constructive engagement was associated with more active involvement with the children, particularly in the form of helping behaviors. As expected, older adults who were constructively engaged in the IGPs during this study were less likely to be inattentive (sleep, non-engagement etc.) while attending the activity.

Adults with dementia in this study who experienced more pleasure during the IGPs also had higher QOL scores. This is consistent with the findings from Chung (2009) and George and Singer (2011) where adult participants noted an improved quality of life. Findings are also consistent with George and Whitehouse (2010) that found older adults who participated in IGPs reported that their QOL was elevated through perceived health benefits, cognitive stimulation, enhanced mood, increased affect, improved sense of purpose and usefulness, and the development of meaningful relationships. Findings in this study indicated that those who were more engaged in the IGP had better quality of life, however, it was also noted that a higher frequency of participation was significantly predictive of poorer quality of life in this sample. Literature from previous studies also proposes discrepancies when attempting to address the relationship between IGP engagement and QOL. Brooker et al. (2007) found that there was little change in QOL as a result of IGP participation. These findings suggest that it is not participation

per se that is important (or *whether* an adult participates) to assess in IGP programs, rather, it is *how* they engage that is the determining factor for outcomes. Simply attending IGP is not a predictive indicator when assessing IGP. The types of engagement that are experienced during IGP sessions are better predictors when assessing IGP for potential outcomes. Based on study findings, it is important to note that it might be more beneficial to measure engagement than attendance, particularly among adults with dementia. It is very important to find activities and opportunities for this population to engage and interact in positive and meaningful ways. Even short-term engagement and interaction is beneficial for this group of individuals. Many measures only attempt to account for distal, or long-term, findings. However, proximal effects should be accounted for as well, because these effects are also critical in these adults' daily routines.

Pharmacological treatment for Alzheimer's disease and related dementias has been associated with potential dangerous side effects and negative symptoms. Medications that are not successful may have high risk for adults – either associated with the consumption of the more drugs / potential drug interactions or due to unwanted side effects. Thus, there is a continued need for non-pharmacological approaches that are patient-centered and effective to improve the quality of life for these individuals. This research study and others suggest that intergenerational programming is one potential approach to address such needs and concerns. IGP involves very low risk for these adults. If successful, studies indicate that IGP has ability to promote engagement, improve QOL, and increase overall well-being (e.g., Camp & Skrajner, 2004; George & Whitehouse, 2010; Power et al., 2007). If it is not successful in doing such things, there is virtually no risk – there is no harm inflicted upon the participants if they do not respond to this type of intervention.

In this study, none of the residents demonstrated inappropriate behaviors during the IGP session. Therefore, the association between these behaviors and engagement type or quality of life was not examined. Brownell (2008) indicated no statistically significant changes regarding frequency of inappropriate behaviors or level of engagement in his study. On the contrary, O'Rourke (1999) and Camp et al. (1997), indicated behaviors (aggression, disruption) of adults with dementia improved while being engaged in intergenerational activities. It is possible that the IGP encouraged more positive behaviors in the adults, and that is why no inappropriate behaviors were observed. However, it is also likely that adults who typically respond poorly to intergenerational activities were not encouraged to attend the daily IGPs on the units given that these activities are integrated into the daily routines at this facility and staff are aware of the residents' preferences.

It is important to note that this study was unable to address issues of causality. Although the findings suggest that frequent participation in IGP predicts lower QOL in the adult participants, participation in IGP alone is not determining the individual's QOL. The sample size in this study was small, and in the sessions, many of the participants were either non-engaged or were focusing on other things (i.e., self/other engaged) during the formal programming. Those who were constructively and passively engaged typically often only did so for brief durations throughout the activities, which is not unexpected given the length of some of these programs and the adults' cognitive functioning. Such findings emphasize the importance of monitoring and assessing *how* adults are engaging in activities rather than just recording their attendance, or frequency of participation, as is often assessed in long-term care settings. How these adults engage (CE, PE, OE, and NE) appears to be a better indicator of QOL, but this study was unable to determine whether participating in IGP led to improvements in QOL. During the observations

of the participations, it was evident that different types of activities resulted in different types of engagement for each resident. Thus, there is a need to continue the development and implementation of person-centered care in long-term care facilities in attempts to find the best interventions and approaches to enhance the wellbeing of each resident.

Strengths and Limitations

This study had both strengths and limitations that contributed to the findings. The primary strength of this study was that the measures of engagement type and behaviors were assessed by 47, five-minute observational periods (per participant) that were coded and averaged to compute the MPES composite scores. This approach ensured that each participant in the study had multiple data points for each of the variables in the study throughout the duration of the five-day study. This large quantity of data provided for a more accurate depiction of one's overall engagement in the IGP sessions. In addition, the long-term care and child-care facilities shared a site location, which meant that the adults and children were used to these types of programs and ensured that the intergenerational interaction between these groups occurred regularly and was sustainable after the completion of the study.

However, the low number of legal guardians who returned the informed consents for residents on these two units led to a small sample size, which is a major limitation to this study. This resulted in low statistical power for the analyses and affects the generalizability of the findings to all residents in these units or to adults with dementia in other facilities. In addition, there was not much diversity in the sample population – particularly regarding race since all residents identified as White. This facility also serves adults with a higher socioeconomic status, and thus findings might not be similar with diverse populations of older adults with dementia.

Future Implications

In future studies, it would be beneficial to try to capture the outcomes of informal IGP interactions that might not last for a duration of 5 minutes to determine if they are associated with health and wellbeing outcomes for adults with dementia. Unfortunately, this was not addressed in the current study as the MPES is unable to measure interactions of durations shorter than this period. However, some of the residents at this facility who did not attend the structured IGP sessions in the morning either regularly visit the day-care facility onsite and/or interact with the children often in an informal setting during afternoon visits. Such interactions were not accounted for in this study, but future research should examine whether there are differences in the effects of these informal interactions on the adults' wellbeing and affect/behavior.

This study suggests that *how* adults with dementia engage in IGPs may be more effective way to measure outcomes and potential benefits than *whether* they participate in the programs. This helps to explain why the findings from prior studies may have been mixed, as not all adults may enjoy or actively engage in these activities. Camp, Skrajner, and Gorzelle (2015) suggested that engaging older adults with dementia is key to establishing positive interactions and successful non-pharmacological treatment for symptoms of dementia. Engagement outcomes provide details on *how* adults participate in IGP. QOL outcomes indicate associations with greater expressions of pleasure during IGPs in this study. QOL was assessed based on the adults' affect/wellbeing specifically during the week of the study. Even the short-term benefits observed during the week of the interactions are positive and important for adults with dementia. Whether the benefits of IGPs are only immediate or whether they have the ability to be sustained over a longer duration is still unknown. However, any improvement of QOL with this population should be considered beneficial in terms of programming and providing treatment for this group.

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SECTION II: EXTENDED REVIEW OF LITERATURE

Introduction

Approximately one out of ten adults aged 65 and older are diagnosed with Alzheimer's disease or some type of unspecified dementia (Alzheimer's Association, 2017). Soon the Baby Boomer generation will comprise a substantial portion of our population, and by 2050 it is estimated that dementia costs could total as much as \$1.1 trillion dollars (Alzheimer's Association, 2017). Alzheimer's disease, the most common type of dementia, accounts for 60 to 80 percent of all dementia-related cases. (Alzheimer's Association, 2016). Lack of cure and difficult prognoses require a unique approach to person-centered care designed to treat Alzheimer's. Thus, there is a need for more outcome-based healthcare approaches in long-term care facilities due to the prevalence of this disease.

Alzheimer's is the most common type of dementia found in older adults. This disease is characterized by progressive brain deterioration, destroying memory and thinking skills. The onset of this disease typically occurs mid 60s (The National Institute on Aging, n.d.). There are different stages of Alzheimer's disease that are identified by specific characteristics. In the early stage, one may seem "normal" or free from both objective and subjective symptoms. Minimal signs such as forgetfulness may be deemed normal aged forgetfulness (Reisberg & Franssen, 1999). In the middle stage, the individual and other close friends and family members may begin to acknowledge subtle memory deficits that are now being exhibited. There may be an overall difficulty in mastering new tasks or in the ability to manage details of everyday tasks, such as bill paying and meal preparation (Reisberg & Franssen, 1999). In the mildest form, Alzheimer's disease can affect a substantial number of performance-based tasks and responsibilities. Moods may become flatter and reflect of lack of affect. Fear and denial are common emotions at this

stage (Reisberg & Franssen, 1999). In its later stages, Alzheimer's challenges one's ability to independently function day-to-day. Deficits are blatantly manifested and require various levels of supportive care (e.g., Activities of Daily Living, supervision, etc.). Individuals are typically unable to recall major life events and may forget basic day-to-day details. There is also a great challenge involved in obtaining newly learned information (Reisberg & Franssen, 1999). In the latter stages of prognosis, severe Alzheimer's disease requires continuous care and assistance. Speech and communication abilities diminish. Tasks such as sitting up may even become unobtainable, followed by the dissipation of many reflexes and transition to vulnerability caused by major health ailments that may ultimately result in mortality (Reisberg & Franssen, 1999).

Most forms of dementia have similar symptoms that are manifested with comparable behaviors and distinctions. In layman's terms, dementia is simply the loss of cognitive functioning (The National Institute on Aging, n.d.). Causes of unspecified dementia can vary and dementia also ranges in level of severity. Conditions such as stroke, medication side effects, tumors or infections in the brain, and Parkinson's disease can also cause dementia (The National Institute on Aging). Traditionally, medications are utilized to reduce the common side effects and symptoms such as aggressive behaviors, confusion and anxiety that are caused by Alzheimer's and unspecified dementia. It has been projected that up to 90% of adults with dementia will exhibit some behavioral or psychological symptoms, which tend to be more prevalent in advanced stages of the disease (Trivedi, Goodman, Dickinson, et al., 2013). In cases where the memory loss onset is not reversible, as with Alzheimer's disease and most forms of dementia among older adults, it may be difficult to adjust emotionally to these changes. This may be one reason why depression is prevalent amongst those diagnosed with Alzheimer's. If left untreated, it can exacerbate cognitive, psychiatric and behavioral symptoms; negatively

impacting quality of life and result in more rapid disease progression (Starkstein, Mizrahi, & Power, 2008).

Long-Term care and treatment of dementia

To improve the quality of life and wellbeing of those adults affected with this disease, there must be continued research on objectives and programs that improve care. Currently, most traditional health approaches in long-term care facilities are focused upon providing memory care, prescribing sleeping aids, and identifying ways to combat negative behaviors that result from the progression of Alzheimer's disease and related dementias (Gitlin et al., 2012). Research suggests that approximately 80% of residents with dementia experience some degree of behavioral and psychological symptoms, and negative behaviors exhibited by adults with dementia challenge staff in long-term care facilities (Agency for Healthcare Research and Quality, 2014). In most cases, pharmacology is utilized to treat the needs noted above. However, some pharmacological treatments used in dementia care have potentially devastating side effects, such as increased risk of mortality (Gill et al., 2007). Administering antidepressants to treat depression in adults with dementia appears to be relatively ineffective in this population (Bains, Birks, & Denning, 2002), and it might make patients with dementia feel worse due to a greater number of reported side effects (Banjeree et al., 2011). The positive effects of pharmacological treatment on cognitive, psychiatric, and behavioral symptoms are observed in only a minority of patients and individual results are highly variable (Gill et al., 2007; Maggini, Vanacore, & Racschetti, 2006). Thus, there is a need to explore non-pharmacological options that may benefit older adults with this disease.

Research highlights the importance for greater use of effective non-pharmacological treatment modalities and models to treat Alzheimer's and other types of dementia, particularly in long-term care settings. In general, non-pharmacological approaches are rarely used in clinical settings, but with education and training it has been suggested that effective non-pharmacological interventions could help reduce the inappropriate use of antipsychotics in patients with dementia (Agency for Healthcare Research and Quality, 2014). Intergenerational Programs are a type of non-pharmacological interventions that might be appropriate in these settings.

Intergenerational Programs

Intergenerational programs (IGPs) allow formal and informal interaction in a setting where members of each generation can thrive. Intergenerational programming is simply a facilitation design that is dedicated to the joining of two or more generations. IGPs provide environments where multiple generations receive services, treatment, and/or programming at the same time (Commission on Affordable Housing and Health, 2002). Intergenerational activities can occur when one generation visits the other in their typical environment (e.g., older adults volunteering in a school system) or can occur in shared site facilities, where intergenerational interactions are integrated into the daily routines of the participants (e.g., child daycare program located within a long-term care facility). In these settings, adults and children are accustomed to these types of programs and the intergenerational interaction between these groups typically occurs regularly. Studies have shown that intergenerational programming is beneficial for both children and older adults. Many of these studies focus on the general population of older adults and their interactions with youth. Research in this area has suggested that IGP decreases isolation, creates meaningful social roles, and encourages engagement in functional abilities

(Brownwell, 2008; Isaki & Harmon, 2015; Camp & Skrajner, 2004; Cook & Bailey, 2013; McNair & Moore, 2010; Camp & Skrajner 2004).

Hernandez and Gonzalez (2008) implemented a study to analyze the effects intergenerational programming (IGP) has on elders' well-being and stereotyped attitudes towards elderly people. Adults with slight depression (n=101; score of no more than 18 on the Yesavage Depression Scale) and 179 university students studying exercise or sport science were divided into groups; in each group, the students facilitated a 50-minute session of games focused on physical exercises. Scores on well-being and attitudes towards stereotypes were taken pre-treatment and post-treatment after the 32 sessions. Young people who did not participate in IGP did not have any extreme stereotyped attitudes towards elders, regardless of their lack of interaction with them. However, elders who did not participate in the experimental group had very extreme stereotyped attitudes towards themselves. Post-treatment, young people's perception of older adults improved as did the elder's opinions of themselves. There was a significant reduction in depressive symptoms for the experimental group of older adults involved in the IGP and an increase in depressive symptoms for those elders in the control group. Elders in the IGP group also reported an improvement in their overall well-being and feelings of usefulness. These findings support what other studies have shown – that in many IGP settings there are mutual benefits to the generations involved. Currently, much of the research on these programs is focused on younger participants' perception of age as a result of interactions with the aging population. Younger generations learn to perceive and appreciate older generations more post interventions (e.g. COAH, 2002; Isaki & Harmon, 2015; Gigliotti et al., 2007).

Intergenerational Programming and the Dementia Population

Early studies on intergenerational programming suggested that intergenerational activities increase social responses in persons with dementia (Newman & Ward, 1993). Lee, Camp, and Malone (2007) found that intergenerational programming between preschool children and older adults with dementia produced higher levels of positive engagement and lower levels of negative forms of engagement when compared to environments that did not provide intergenerational programming. Recent studies on IGPs in the dementia population have been driven by the need to explore non-pharmacological treatments for dementia, and there have been several studies examining the intergenerational interactions between younger generations and older adults with dementia.

Lee, Camp, and Malone (2007) investigated the use of intergenerational, Montessori-based programming and the outcomes of this treatment modality on older adults with dementia. The study consisted of 14 nursing home residents in a dementia skilled nursing facility unit and 15 children from the on-site childcare facility. Both generations were administered the Myers Menorah Park/Montessori Assessment System qualitative measure to determine which Montessori activity would be performed. In addition, older adults were screened using the Myers Research Institute Engagement Scale to measure outcomes of engagement. Results indicated that in comparison to traditional programming, participation in intergenerational programming (IGP) prompted successful one-on-one engagement with higher levels of positive engagement (i.e., constructive engagement) and lower levels of negative engagement (i.e., passive or non-focused activity). Findings are similar to those found by Jarrott and Bruno (2003), where positive affect was greater in IGP participants than non-IGP participants.

However, not all persons with dementia respond positively to IGPs (Griff et al., 1996; Gigliotti et al, 2007). One study suggested that individuals with a more advanced diagnosis of Alzheimer's or other specified dementias may experience greater challenges with gross and fine motor skills, cognitive decline, and the ability to adjust to generational behaviors (e.g., kids have frequent movement and older adults exhibited slower response times) (Griff et al., 1996). However, Jarrott and Bruno (2003) found that individuals of all cognitive levels were likely to participate in IG programming, regardless of the severity of memory loss. Doll and Bolender (2010) conducted both a quantitative and qualitative investigation to evaluate the outcomes of twenty-one residents who participated in an IGP that was offered at the Windsor Place nursing home. Twenty-one residents who chose not to participate in IGP served as the control group for this study. Regression analyses and comparisons of residents' MDS scores found no statistically significant evidence to support any differences in their cognitive functioning at the beginning, middle, or end of the intervention. The only significant statistical findings identified between the groups were related to their eating behaviors and medication usage. Residents in the IGP group had worse eating performance than those in the control group, and residents in the control group were found to use approximately 3.5 fewer medications than those in the experimental group. However, qualitative component was also included in this study, and several themes emerged from the review of that data that were more positive. The qualitative data suggested that the benefits of participation in the IGP included mood enhancement, health improvements, increased activity levels, and improved sense of worth and value in these residents. Thus, there is a discrepancy between the qualitative results (i.e., increased perception of health and overall well-being of elder participants) of some studies and quantitative outcomes for older adults (Doll & Bolder, 2010; Power et al., 2007).

Brownell (2008) conducted a study to evaluate the impact of participation in an intergenerational art program involving cognitive and emotional responses of older adults with dementia; he also found no statistically significant changes regarding frequency of inappropriate behaviors or level of engagement during activity. However, participation in activities at an appropriate functional level was found to promote sense of empathy and decrease the isolation seen with passive behaviors. When given the opportunity, older participants valued being able to contribute to the development and education of younger generations, suggesting that activities providing a meaningful social role are beneficial for elders with dementia receiving care in a treatment facility (Camp and Skrajner, 2004; Cook & Bailey, 2013; Jarrott et al., 2008). In addition, programming that focuses on the retention of functional abilities allows participants to fulfill more independent and successful social roles (McNair, 2010).

As evident from the studies discussed above, the findings related to the efficacy of using intergenerational programs to improve the health and wellbeing of adults with dementia are mixed. While some research suggests that there may be no significant change related to these programs (Brownell, 2008; Gigliotti et al., 2007), other research has identified negative effects (Doll & Bolender, 2010; Griff et al., 1996) and still more studies have suggested an improvement in function for those adults who engage in these programs (e.g., Jarrott & Bruno, 2003; McNair & Moore, 2010; Whitehouse, 2013). Thus, researchers have suggested that just examining whether an individual participated in IGPs is not enough, and more research needs to examine *how* the adults engage in these IGPs to determine the effects of these interventions.

Engagement in Intergenerational Activities

Engagement is said to be the most important element needed for successful nonpharmacological treatment in dementia (Camp, Skrajner, & Gorzelle, 2015). Engagement

scales have served to gauge the various types of participation observed in individuals, as well as note environmental factors and personal attributes that may affect one's ability to engage. One instrument that has been used in studies exploring the IGP interaction of adults with dementia is the Menorah Park Engagement Scale (MPES). The MPES was designed to document various types of engagement exhibited by individuals with dementia during meaningful activities. Previous studies found that engagement was the most influential construct affecting the connectedness exhibited by individuals with dementia, and as a result, the Menorah Park Engagement Scale was developed (Camp & Skrajner 2004).

Camp and Skrajner (2004) conducted a study to determine the effects of Resident-Assisted Montessori Programming on both leaders and participants. Four female residents (one diagnosed with Alzheimer's and three diagnosed with unspecified dementia) of the Menorah Park Center for Senior Living were trained to lead memory bingo for nine participants, all with more advanced stages of dementia. Leaders were trained and scored according to their ability to follow protocols. Player participants were scored using the Menorah Park Engagement Scale. Results indicated that leaders were able to maintain partial adherence to protocols with high frequency. Leaders expressed that they enjoyed their role and felt that their involvement was important, which increased their feelings of self-worth. Participants had higher scores for positive engagement and pleasure during the peer-lead activities when compared to standard programming. Findings are similar to those in Jarrott, Gozali, and Gigliotti (2008), in which measures of engagement were taken using the MPES and found that there were more positive levels of engagement in Montessori-based programming, suggesting activities that provide a meaningful social role are beneficial for individuals with dementia.

There is a great focus on the evolution of the use of Montessori educational methods as the basis for creating interventions for persons with dementia (Camp, 2010). Evidence has shown that Montessori Programming for Dementia (MPD) effectively increases constructive engagement and pleasure, and significantly reduces non-engagement compared to traditional dementia programming interventions that are led by staff members. MPD has also been used to facilitate intergenerational programming for residents with dementia. This modality allows the older adults to serve as mentors to young children and provides the residents with an opportunity to develop meaningful relationships that encourage positive types of engagement. Such findings are also evident in Skrajner and Camp (2007) and Lee et al., (2007), in which scores on the MPES found that peer-led MPD resulted in higher levels of positive engagement among older adults as well as increased positive forms of affect when compared to traditional programming.

Quality of life

Many aspects of the concept “quality of life” are important to an individual’s physical, mental, and social health. Psychosocial well-being is yet another critical component of overall health. It is important for all individuals to have psychosocial well-being, but this may be especially important for individuals with disabilities (Duvall & Kaplan, 2014). Positive psychosocial well-being can promote increased adjustment to disability and social functioning within the home and community in individuals with disabilities (Duvall & Kaplan, 2014).

Barca et al. (2011) studied the quality of life amongst institutionalized elders with dementia. The study took place between October 2008 and August 2009 and included 156 Norwegian patients over the age of 60 years with dementia that had been in institutions for at least 4 weeks. The most prevalent forms of behaviors exhibited were: appears sad (57.7%), apparent discomfort (52.6%), appears comfortable (42.9%), and makes statements or sounds that

suggest unhappiness or discomfort (41.7%) (Barca et al.). Residents who had more impaired functions, more severe depressive scores, and severe dementia scores had lower quality of life as assessed by the Quality of Life in Dementia Scale (QUALID). This suggests that quality of life outcomes for patients with dementia are associated with major depressive disorder, severity of functioning, and cognitive impairment (Barca et al.). The researchers also noted that quality of life can be improved, along with performance of activities, if there are efforts made to treat depressive disorders and target activities of daily living. Based upon an analysis of previous research, IGP may be a positive non-pharmacological approach to addressing the above concerns.

Brooker, Woolley and Lee (2007) conducted a study to measure the effect that the Enriched Opportunities Program had on residents with dementia. Enriched Opportunities Programs (EOPs) are non-pharmacological interventions and approaches that attempt to bring various elements together to form a sustainable, multi-level activity-based, models of care. EOPs should be desirable, obtainable and sustainable, and they are hypothesized to: 1) improve levels of engagement in activities, 2) improve levels of well-being, 3) improve quality of life, 4) improve quality of care, 5) reduce levels of depression and anxiety, 6) reduce the use of neuroleptics and other psychotropic drugs, and 7) improve physical well-being and reduce the number of hospital inpatient days (Brooker et al., 2007).

Potential for Intergenerational Programs to Affect Quality of Life

The theoretical construct of EOPs is comparable to the structure of Montessori-based intergenerational programs. Lee et al. (2007) notes that positive IGP experiences involved, “providing a mentoring role for older adults, voluntary participation, and client-initiated contact with children,” and “when combined with interacting with young children, the structure provided

by this programming works to increase engagement” (pg. 478). In the previously mentioned study conducted by Brooker et al. (2007), residents from three nursing homes (N = 127) participated in the initial study structured using EOP. Final measures were obtained from 99 residents, with 76 residents providing data at follow-up. Results indicated that patients were most likely to participate in activities that promoted well-being. There was little change in QOL for adults in this study. However, depression levels decreased and there was an increase in levels of well-being after participating in Enriched Opportunity Programs (Brooker et al.). Those with less cognitive impairment were more likely to participate in more diverse activities than those with greater cognitive impairments, but adults’ levels of well-being can increase significantly regardless of their level of cognitive impairment (Jarrott & Bruno, 2003). Various IGP and Montessori-based programming IGP have been found to fulfill the goals and hypotheses as outlined by Enriched Opportunity Programs.

George and Whitehouse (2010) facilitated a study to evaluate the effects of structured intergenerational volunteer programs on the quality of life (QOL) of persons with mild to moderate dementia. From January 2008 to May 2008, eight residents from an assisted living facility, several of which were restricted to an “Alzheimer’s” unit, visited The Intergenerational School (TIS) of Cleveland, Ohio once a week and volunteered with children ages 5-14. TIS is an intergenerational, free public school that serves students Kindergarten through eighth grade. The mission of the institution is focused on establishing successful multigenerational learning communities (The Intergenerational School, 2016). Qualitative and quantitative research in this study demonstrated that older adults with dementia had lowered stress and enhanced sense of purpose and usefulness as a result of being active members within the school community.

Whitehouse (2013) suggests that IGP and health programming models create more well-rounded care that do not place dominance on one particular form of care.

Summary of Literature and Need for the Study

Evidence from research indicates that intergenerational programs, including Montessori-based programming IGP, have effectively improved engagement (Camp & Skrajner, 2004; Jarrott & Bruno, 2003; Jarrott et al., 2008; Lee et al., 2007), improved levels of well-being (Doll & Bolender, 2010; Hernandez & Gonzalez, 2008; Power et al., 2007), improved quality of life (Chung, 2008; George & Whitehouse, 2010; George & Singer, 2011), improved quality of care (Cook & Bailey, 2013; Whitehouse, 2013), reduced levels of depression and/or anxiety (Chung, 2009; Hernandez & Gonzalez, 2008), and improved well-being (Doll & Bolender, 2010; Hernandez & Gonzalez, 2008; Power et al., 2007) among older adults with dementia. As of yet, there is no substantial supportive literature found that suggests that IGP or Montessori-based programming IGP reduces the use of neuroleptics and other psychotropic drugs or reduces the number of hospital inpatient days in this population, although this has been suggested.

Research suggests that non-pharmacological approaches are typically geared towards the maintenance and improvement of QOL and well-being (Brooker et al., 2007; Jarrott & Bruno, 2003; Whitehouse, 2013). Intergenerational programs, including those that use Montessori-based programming as well as other non-pharmacological interventions, utilize a multifaceted approach that not only addresses the ailment of the individual, but also focuses on various aspects of overall well-being. Given that quality of life is determined by a variety of biopsychosocial elements, it is essential that treatment modalities address the needs of the whole person.

Whitehouse (2013) addresses growing social changes in healthcare and the need for more holistic treatment for individuals with cognitive dysfunction and challenges. This advancement

can only be accomplished by critiquing current scientific approaches and offering a broader and more inclusive practice that blends natural and social sciences with arts and humanities.

Whitehouse identifies cognitive deficit not only as a loss of abilities, but more importantly as a challenge to continue social growth and encompass a full range of life. Medications, although helpful, also limit the abilities to address complexities involved with cognitive deficits. To challenge the notion that pharmacology is our main hope, it is important to explore healthcare models that encourage self-efficacy for those being treated and implement non-pharmacological methods for care. As evident in the literature, intergenerational programming and other learning communities offer another means of promoting the health and wellbeing of adults with dementia, particularly in long-term care facilities.

Unfortunately, there is limited quantitative evidence to support the benefits of IGP – creating a need for more evidence-based research. Currently the gap in the literature addresses the need to better explore differences in how adults engage in IGPs, and how this relates to their affect and behaviors. In previous studies, there has been no significant difference between the benefits adults’ experience from Montessori-based IG programming and traditional programming of IG activities. In addition, one study using the MPES found that the correlation between pleasure and constructive engagement was not significant (Jarrott et al., 2008). Thus, the question remains whether there is any difference in the association between how adults engage in IGPs (e.g., active engagement) and their affect and behaviors (Jarrott et al., 2008). This study aims to address this question by exploring how different types of engagement in IGPs is associated with the affect/behaviors that adults exhibit during these activities. In addition, the research will investigate whether adults’ engagement in IGPs is able to significantly predict their quality of life.

Appendix A

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Appendix B

Demographic Information

Participant's Age: _____

Sex/Gender: _____ Male

_____ Female

Ethnicity/Race: _____ White/Caucasian

_____ Black/African American

_____ Asian/Pacific Islander

_____ Hispanic/Latino

_____ Native American/American Indian

_____ Other

Marital Status: _____ Married

_____ Widowed/Divorced

_____ Single/Never Married

Neighborhood/Residence at Birchaven Village:

_____ Aspen-Birch

_____ Cedar-Dogwood

Year Diagnosed with Dementia: _____

Year Admitted to Birchaven Village: _____

Frequency of Intergenerational Programming Participation

This section of the survey aims to identify how long the participant has attended IGP programming prior to the start of this study as a resident at Birchaven as well as their participation during the study period.

Prior to the start of the study, the study participant attended intergenerational activities and programming at Birchaven for approximately:

- _____ **Never**
- _____ **Less than 1 month**
- _____ **1 to 3 months**
- _____ **4 to 6 months**
- _____ **6 months to 1 year**
- _____ **Over a year**

Please complete the chart below to note which Intergenerational activity sessions the participant attended during the study period. If the participant attended on that day/time, please place a check mark in the corresponding box. If the participant did not attend that particular session, please leave that box blank.

Time of Day	Week				
	M	T	W	Th	F
Morning Session					
Afternoon Session					

Menorah Park Engagement Scale (MPES)

(MPES page 7 of 8)

Observation # _____ Activity ID #: _____ Date: _____

Participant's ID #: _____ Facilitator: _____

Name of activity: _____

ID # of person filling out form: _____

Type of observation: 1 = Baseline 2 = Treatment

Time of day: 1 = A.M. or 2 = P.M. (circle one) Observation length (minutes): _____

1. Participated in target activity (either constructively or passively)

Did he/she take part in the activity?

0 = No (chart engagement on items 6 and 7) 1 = Yes (chart engagement on items 4, 5, 6, and 7)

2. Tried to leave on own (do not include staff who removed the client)

Did he/she try to leave the activity?

0 = No 1 = Yes

3. Left activity on own or with staff

Did he/she actually leave the activity?

0 = No 1 = Yes

Code no more than one "2" for items 4, 5, 6, and 7.

4. Did the target activity and/or commented on the activity.

How long did he/she participate in the activity by making comments, answering questions, talking about memories, discussing ideas, making gestures in response to the activity, or physically manipulating the materials? [Do not include looking and listening.]

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

5. Listened to and/or watched target activity (code after 3 seconds, but do not code if sleeping)

How long did the participant remain generally alert and spend time listening to and watching the target activity?

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

6. Did or attended to things other than target activity (code after 3 seconds, but do not code if sleeping)

How long did he/she attend to something beside the target activity? Include listening, watching, commenting, gesturing, talking, or physically manipulating any item not associated with the activity. Include self-engagement activities, such as toe- or finger-tapping, pointless manipulation of clothing or other belongings, etc. If the client is listening to or watching the target activity while manipulating an item not associated with the activity (e.g., a walker, bag, or shirt sleeve), code for listened to/ watched target activity.

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

7. Slept/kept eyes closed/stared into space (code after 3 seconds)

How long did the participant sleep or keep his/her eyes closed during the observation?

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

Code no more than one "2" for items 8 and 9.

8. Pleasure

How long did he/she express pleasure (laugh or smile) during the observation?

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

9. Anxiety/sadness

How long did he/she display anxiety or sadness during the observation? Include obvious displays of sadness through tearfulness, conversation, or clearly observable depressed affect. Anxiety should be coded for items such as hand-wringing, rocking, anxious vocalizations, or other psychomotor activity if seen in combination with an anxious facial display.

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

10. Helped others

How long did he/she help another player during the observation? Include behaviors such as pointing out answers on another player's card, assisting with the covering mechanism of the card-holder, giving clues to another player ("you have the word MOON"), helping the player read his/her card, etc.

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

Frequency: 0 = 0 1 = 1-2 2 = 3+

11. Acted inappropriately

How long did he/she say or do something inappropriate, disruptive, or aggressive during the observation?

0 = Not at all 1 = Up to half of the observation 2 = More than half of the observation

To view and download a copy of Lee, Camp, & Malone (2007), "Effects of Intergenerational Montessori-based Activities Programming on Engagement of Nursing Home Residents with Dementia, visit www.dovepress.com/getfile.php?fileID=1353

Quality of Life in Late-Stage Dementia (QUALID) Scale

Select the one descriptor from each category that best describes the resident over the past week:

<p>Smiles</p> <p><input type="checkbox"/> 1. spontaneously once or more each day</p> <p><input type="checkbox"/> 2. spontaneously less than once a day</p> <p><input type="checkbox"/> 3. only in response to external stimuli; at least once a day</p> <p><input type="checkbox"/> 4. only in response to external stimuli; less than once a day</p> <p><input type="checkbox"/> 5. rarely, if at all</p>	<p>Appears physically uncomfortable - he/she squirms, writhes, frequently changes position</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. less than once a day</p> <p><input type="checkbox"/> 3. at least once a day</p> <p><input type="checkbox"/> 4. nearly half the day</p> <p><input type="checkbox"/> 5. most of the day</p>
<p>Appears sad</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. only in response to external stimuli; less than once a day</p> <p><input type="checkbox"/> 3. only in response to external stimuli; at least once a day</p> <p><input type="checkbox"/> 4. for no apparent reason less than once each day</p> <p><input type="checkbox"/> 5. for no apparent reason once or more each day</p>	<p>Makes statements or sounds that suggest discontent, unhappiness, or discomfort (complains, groans, screams)</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. only in response to external stimuli; less than once a day</p> <p><input type="checkbox"/> 3. only in response to external stimuli; at least once a day</p> <p><input type="checkbox"/> 4. without cause less than once a day</p> <p><input type="checkbox"/> 5. without cause once a day</p>
<p>Cries</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. only in response to external stimuli; less than once a day</p> <p><input type="checkbox"/> 3. only in response to external stimuli; at least once a day</p> <p><input type="checkbox"/> 4. for no apparent reason less than once each day</p> <p><input type="checkbox"/> 5. for no apparent reason once or more each day</p>	<p>Is irritable or aggressive (becomes angry, curses, pushes, or attempts to hurt others)</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. only in response to external stimuli; less than once each day</p> <p><input type="checkbox"/> 3. only in response to external stimuli; at least once each day</p> <p><input type="checkbox"/> 4. without cause less than each day</p> <p><input type="checkbox"/> 5. without cause once or more each day</p>
<p>Has a facial expression of discomfort- appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)</p> <p><input type="checkbox"/> 1. rarely or never</p> <p><input type="checkbox"/> 2. less than once a day</p> <p><input type="checkbox"/> 3. at least once a day</p> <p><input type="checkbox"/> 4. nearly half the day</p> <p><input type="checkbox"/> 5. most of the day</p>	<p>Enjoys eating</p> <p><input type="checkbox"/> 1. at most meals and snacks</p> <p><input type="checkbox"/> 2. twice a day</p> <p><input type="checkbox"/> 3. at least once a day</p> <p><input type="checkbox"/> 4. less than once a day</p> <p><input type="checkbox"/> 5. rarely or never</p>
<p>Enjoys touching/being touched</p> <p><input type="checkbox"/> 1. almost always; almost always initiates touching</p> <p><input type="checkbox"/> 2. more than half the time; sometimes initiates touching</p> <p><input type="checkbox"/> 3. half the time; never initiates touching, but does not resist touching</p> <p><input type="checkbox"/> 4. less than half the time; often or frequently resists touching/being touched</p> <p><input type="checkbox"/> 5. rarely or never; almost always resists touching/being touched</p>	<p>Enjoys interacting or being with others</p> <p><input type="checkbox"/> 1. almost always; almost always initiates interaction with others</p> <p><input type="checkbox"/> 2. more than half the time; sometimes initiates interaction with others</p> <p><input type="checkbox"/> 3. half the time; never initiates interaction, but does not resist interactions with others</p> <p><input type="checkbox"/> 4. less than half the time; often or frequently resists interaction with others</p> <p><input type="checkbox"/> 5. rarely or never; almost always resists interaction with others</p>
<p>Appears emotionally calm and comfortable</p> <p><input type="checkbox"/> 1. most of the day</p> <p><input type="checkbox"/> 2. more than half the day</p> <p><input type="checkbox"/> 3. half the day</p> <p><input type="checkbox"/> 4. less than half the day</p> <p><input type="checkbox"/> 5. rarely or never</p>	
<p>Total Score (sum of all items: scores range from 11 to 55 with lower scores representing higher quality of life)</p>	<p>Resident Name _____</p> <p>Date: _____</p>
<p>Knowledge/familiarity of caregiver(s) with the resident</p> <p><input type="checkbox"/> 0 Very familiar; provides daily care</p> <p><input type="checkbox"/> 1. Somewhat familiar, often provides some care</p> <p><input type="checkbox"/> 2. Not very familiar; only minimal contact</p>	<p>Quality of Interview (Interviewer's Professional Judgement)</p> <p><input type="checkbox"/> 0 Interview appeared valid</p> <p><input type="checkbox"/> 2. Some questions about interview, but probably acceptable</p> <p><input type="checkbox"/> 3. Information from interview of doubtful validity</p>

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Brief Interview for Mental Status (BIMS)

Complete this version if the resident is able to communicate and does not demonstrate severe cognitive impairment. Ask the resident the questions and record his/her response accordingly.

If the resident is unable to complete this version, please use the Staff Assessment for Mental Status available on the next page. This information can be found in the patient’s chart in Section C of the MDS for those residents that have this assessment completed quarterly. Please use the MOST RECENT version of this assessment that was completed for this resident.

C1. Should Brief Interview for Mental Status be Conducted?—Attempt to conduct interview with all residents	
Enter <input style="width: 20px; height: 20px;" type="text"/> Code	0. No (resident is rarely/never understood) → instead complete C7-C10, Staff Assessment for Mental Status 1. Yes → Continue to C2, Repetition of Three Words
Brief Interview for Mental Status (BIMS)	
C2. Repetition of Three Words Ask resident: <i>“I am going to say three words for you to remember. Please repeat the words after I have said all three. The words are: sock, blue, and bed. Now tell me the three words.”</i> Enter <input style="width: 20px; height: 20px;" type="text"/> Code Number of words repeated after first attempt 0. None 1. One 2. Two 3. Three After the resident’s first attempt, repeat the words using cues (<i>“sock, something to wear; blue, a color; bed, a piece of furniture”</i>). You may repeat the words up to two more times.	C4. Recall Ask resident: <i>“Let’s go back to an earlier question. What were those three words that I asked you to repeat?”</i> If unable to remember a word, give cue (something to wear; a color; a piece of furniture) for that word. Enter <input style="width: 20px; height: 20px;" type="text"/> Code a. Able to recall “sock” 2. Yes, no cue required 1. Yes, after cueing (“something to wear”) 0. No —could not recall Enter <input style="width: 20px; height: 20px;" type="text"/> Code b. Able to recall “blue” 2. Yes, no cue required 1. Yes, after cueing (“a color”) 0. No —could not recall Enter <input style="width: 20px; height: 20px;" type="text"/> Code c. Able to recall “bed” 2. Yes, no cue required 1. Yes, after cueing (“a piece of furniture”) 0. No —could not recall
C3. Temporal Orientation (orientation to year, month, and day) Enter <input style="width: 20px; height: 20px;" type="text"/> Code Ask resident: <i>“Please tell me what year it is right now.”</i> a. Able to report correct year 3. Correct 2. Missed by 1 year 1. Missed by 2–5 years 0. Missed by > 5 years or no answer Enter <input style="width: 20px; height: 20px;" type="text"/> Code Ask resident: <i>“What month are we in right now?”</i> b. Able to report correct month 2. Accurate within 5 days 1. Missed by 6 days to 1 month 0. Missed by >1 month or no answer Enter <input style="width: 20px; height: 20px;" type="text"/> Code Ask resident: <i>“What day of the week is today?”</i> c. Able to report correct day of the week 1. Correct 0. Incorrect or no answer	C5. Summary Score Enter Numbers <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> Add scores for questions C2–C4 and fill in total score (00–15) Enter 99 if unable to complete interview

Staff Assessment for Mental Status	
Do not conduct if Brief Interview for Mental Status (C2-C5) was completed	
C7. Short-term Memory OK	
Enter <input type="checkbox"/>	Seems or appears to recall after 5 minutes.
Code	0. Memory OK 1. Memory problem
C8. Long-term Memory OK	
Enter <input type="checkbox"/>	Seems or appears to recall long past.
Code	0. Memory OK 1. Memory problem
C9. Memory/Recall Ability	
Check all that the resident was normally able to recall during the last 5 days:	
Check all that apply.	<input type="checkbox"/> a. Current season
	<input type="checkbox"/> b. Location of own room
	<input type="checkbox"/> c. Staff names and faces
	<input type="checkbox"/> d. That he or she is in a nursing home
	<input type="checkbox"/> e. None of the above were recalled
C10. Cognitive Skills for Daily Decision Making	
Enter <input type="checkbox"/>	Made decisions regarding tasks of daily life.
Code	0. Independent —decisions consistent/reasonable 1. Modified independence —some difficulty in new situations only 2. Moderately impaired —decisions poor; cues/supervision required 3. Severely impaired —never/rarely made decisions

Date Assessment Completed: _____

Reason for Completion:

_____ Intergenerational Program Research Study

_____ Annual/Quarterly MDS assessment

_____ Significant Change in status/MDS

Patient Health Questionnaire (PHQ-9)

Complete this version if the resident is able to communicate and does not demonstrate severe cognitive impairment. Ask the resident the questions and record his/her response accordingly. If the resident is unable to complete this version, please use the PHQ-9-OV (Observational Version) available on the next page.

This information can be found in the patient’s chart in Section D of the MDS for those residents that have this assessment completed quarterly. Please use the MOST RECENT version of the PHQ-9 that was completed for this resident.

Date Assessment Completed: _____

Say to resident: “Over the last 2 weeks, have you been bothered by any of the following problems?”	I. Symptom Presence If symptom is present, enter yes (1), then obtain symptom frequency in Column II.		II. Symptom Frequency If yes in column I, Symptom Presence, then ask the resident: “about how often have you been bothered by this?” Read and show the resident a card with the symptom frequency choices. Indicate response below.			
			1 Day “Rarely”	2–6 Days “Several days”	7–11 Days “More than half the days”	12–14 Days “Nearly every day”
a. Little interest or pleasure in doing things	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
b. Feeling down, depressed, or hopeless	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
c. Trouble falling or staying asleep, or sleeping too much	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
d. Feeling tired or having little energy	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
e. Poor appetite or overeating	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
f. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
g. Trouble concentrating on things, such as reading the newspaper or watching television	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
h. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
i. Thoughts that you would be better off dead, or of hurting yourself in some way ii) If “Yes”, check here to indicate that responsible staff or provider has been informed: <input type="checkbox"/>	Enter <input type="checkbox"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
D3. Total Severity Score						
Enter Numbers <input type="text"/> <input type="text"/>		Add scores for all selected frequency responses in Column II, Symptom Frequency. Score may be between 00 and 27. Enter 99 if unable to complete interview (i.e., “No response” to 3 or more items).				

Patient Health Questionnaire – Observational Version (PHQ-9-OV)

Complete this version if the resident is unable to communicate and demonstrates severe cognitive impairment.

This information can be found in the patient’s chart in Section D of the MDS for those residents that have this assessment completed quarterly. Please use the MOST RECENT version of the PHQ-9-OV that was completed for this resident.

Date Assessment Completed: _____

Say to staff: “Over the last 2 weeks, did the resident have any of the following problems or behaviors?”	I. Symptom Presence		II. Symptom Frequency			
			If yes in column I, Symptom Presence, select frequency.			
	If symptom is present, enter yes (1), then move to column II and select symptom frequency.		1 Day “Rarely”	2-6 Days “Several days”	7-11 Days “More than half the days”	12-14 Days “Nearly every day”
a. Little interest or pleasure in doing things	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
b. Feeling or appearing down, depressed, or hopeless	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
c. Trouble falling or staying asleep, or sleeping too much	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
d. Feeling tired or having little energy	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
e. Poor appetite or overeating	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
f. Indicating that s/he feels bad about self, is a failure, or has let self or family down	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
g. Trouble concentrating on things, such as reading the newspaper or watching television	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
h. Moving or speaking so slowly that other people have noticed. Or the opposite—being so fidgety or restless that s/he has been moving around a lot more than usual	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
i. States that life isn’t worth living, wishes for death, or attempts to harm self. ii) If “Yes”, check here to indicate that responsible staff or provider has been informed: <input type="checkbox"/>	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
j. Being short-tempered, easily annoyed	Enter <input type="text"/> Code	0. No 1. Yes → 9. No response	0	1	2	3
D6. Total Severity Score						
<input type="text"/> <input type="text"/> Enter Numbers		Add scores for all selected frequency responses in column II, Symptom Frequency. Score may be between 00 and 30.				

Psychotropic Medication Administration

Does this participant currently have a prescription for psychotropic medications to address behavioral symptoms associated with their dementia? _____ Yes _____ No

If yes, is this medication taking daily or is it only provided to the participant as needed (i.e., PRN, only when symptoms are evident)? _____ Taken daily _____ PRN

During the study period, please identify the days and times when this medication was administered to the participant. If there were any changes in medications or the resident's environment that might have influenced the individual's behavior on these days (e.g., changes in roommates, family visits, room change, change in health status), please note that information in the table as well.

Week:

	Medication Administered? (Y/N)	Time of Day Administered	Changes in Patient Health, Medications, or Environment
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Appendix C

Marilyn & Gordon
MACKLIN
INTERGENERATIONAL
INSTITUTE
15100 Birchaven Lane
Findlay, OH 45840
419-425-3043
www.mackliniginstitute.org



EXECUTIVE BOARD

Brigette Sadowski
President

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June 20, 2017

Dear Dr. Janke,

The Macklin Intergenerational Institute Board of Directors is excited to partner with East Carolina University for this research study. We look forward to learning about the effects that our shared site daycare program with Birchaven Village has on the health and wellbeing of the residents and children in our facility.

This letter is to acknowledge our support for the research study that will explore the effects of intergenerational interactions on the wellbeing of the residents in our memory care units. We believe that our daily intergenerational program has the potential to positively impact the lives of the residents with dementia, and the Macklin Intergenerational Institute looks forward to collaborating with you on this endeavor. We are committed to helping by informing our parents/guardians about this study and obtaining their approvals as well as assisting with the intergenerational programs that will be studied in this research project. We look forward to future studies that will continue to explore the effects of these programs on the children who attend our daycare program.

Sincerely,

Brigette Sadowski
President, Board of Directors

Appendix D



**Parental/Legal Guardian, Legally Authorized Representative
Permission to Allow Your Child to Take Part in Research**

Information to consider before allowing your child to take part in research that has no more than minimal risk.

Title of Research Study: Intergenerational Programming Study

Principle Investigator: Megan C. Janke, PhD, LRT/CTRS
Institution: East Carolina University
Telephone #: 813-375-2831
Email: jankem@ecu.edu

Participant Full Name: _____ Date of Birth: _____
Please PRINT clearly

Birchaven Village, a part of the Blanchard Valley Health System, Marilyn's Lifelong Educational Center (Macklin Intergenerational Institute), and faculty at East Carolina University have partnered together to study the effects of the intergenerational program offered at our shared site facility to the participants. To do this, we need the help of volunteers who are willing to take part in research.

Your child is being invited to take part in this research study because s/he is currently enrolled in Marilyn's Lifelong Educational Center and regularly attends intergenerational programming at Birchaven Village. The decision for your child to take part in this research will also depend on whether your child wants to participate. By doing this research, we hope to learn how these intergenerational activities affect the health and wellbeing of those involved. All children enrolled at Marilyn's Lifelong Educational Center are being asked to participate in this study.

Your child should not take part in this research project if you are uncomfortable or unwilling to have their interactions with the older adults digitally recorded for observation purposes, as this is a part of the research project.

Your child can choose not to participate in this research. The research will be conducted during regularly scheduled intergenerational activities at Birchaven Village. During the research study, your child's interactions with the older adults will be recorded to observe the adults' levels of engagement and responses to these activities. Only members of the research team and administrators of Marilyn's Lifelong Educational Center and Birchaven Village will be given access to these digital files. The video recordings will be kept on file for one year. After this time, all digital files from these recordings will be permanently deleted. The digital recordings from this research study will **not** be used for any case / study presentation, advertising, or other media purposes – they will only be used for the proposed research project.

There are no known risks (chances of harm) associated with this research project. Any risks that may occur with this research are no more than what you would experience in everyday life. We do not know if your child will benefit from taking part in this study. There may not be any

personal benefit to your child, but the information gained by doing this research may help others in the future.

Blanchard Valley Hospital System (Birchaven Village), Marilyn's Lifelong Educational Center, and faculty/students at East Carolina University may know that your child took part in this research. It is possible that your child will be identifiable on the digital recordings of the intergenerational activities that are recorded as part of this study. These digital files will be stored in password-protected files on password-protected computers, and will be kept on file for one year. As noted above, after one year, these files will be permanently deleted.

Your child can stop participation in this study at any time after it has already started. There will be no consequences if s/he stops and s/he will not be criticized or lose any benefits that s/he would normally receive as a student at Marilyn's Lifelong Educational Center.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principle Investigator at 813-375-2831 (Monday through Friday, 8am to 5pm).

If you have questions about your child's rights as someone taking part in research, or any concerns or complaints about this study, you may call the Blanchard Valley Health System's Ethics Committee at 419-429-6463 (weekdays, 8am – 5pm).

I have decided my child can take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following, and if you agree, you should sign this form:

- I acknowledge that I have read this consent in its entirety, or it has been read/translated to me
- I have had the opportunity to ask questions about it and understand it.
- I know that my child can stop taking part in this study at any time.
- By signing this informed consent form, my child is not giving up any of his/her rights.

Date: _____

Participant's Printed Name: _____

Parent or legal guardian Printed Name: _____

Parent or legal guardian Signature: _____

**Parent or legal guardian name and signature is required for individuals under 18 years old



**Legal Guardian, Legally Authorized Representative
Permission to Allow Your Older Adult to Take Part in Research**

Information to consider before allowing the older adult in your care to take part in research that has no more than minimal risk.

Title of Research Study: Intergenerational Programming Study

Principle Investigator: Megan C. Janke, PhD, LRT/CTRS
Institution: East Carolina University
Telephone #: 813-375-2831
Email: jankem@ecu.edu

Participant Full Name: _____ Date of Birth: _____
Please PRINT clearly

Birchaven Village, a part of the Blanchard Valley Health System, Marilyn’s Lifelong Educational Center (Macklin Intergenerational Institute), and faculty at East Carolina University have partnered together to study the effects of the intergenerational program offered at our shared site facility to the participants. To do this, we need the help of volunteers who are willing to take part in research.

Purpose of this research:

The older adult under your legal care is being invited to take part in this research study because s/he is currently a resident at Birchaven Village. By doing this research, we hope to learn how these intergenerational activities affect the health and wellbeing of older adults with dementia. All adults residing in the Aspen-Birch or Cedar-Dogwood neighborhoods of Birchaven are being asked to participate in this study.

You should not allow the older adult in your care to take part in this research project if you are uncomfortable or unwilling to have their interactions with the children digitally recorded for observation purposes, as this is a part of the research project.

You can choose to not have your older adults participate in this research. If the older adult does not participate in the research study, it will not affect his/her ability to participate in the intergenerational activities offered at Birchaven Village. The research will be conducted during regularly scheduled intergenerational activities at Birchaven Village. During the research study, the adults’ interactions with the children will be recorded to observe the adults’ levels of engagement and responses to these activities. A few assessments will be collected related to the older adults health and wellbeing, including their level of cognitive status/impairment, mood, and quality of life. In addition, staff at Birchaven will review information in the adults’ chart (e.g., administration of psychotropic medications, changes in environment/medications/health, prior assessments on cognitive status and mood) to investigate if there is an association between participation and engagement in the intergenerational activities and health outcomes.

Only members of the research team and administrators of Marilyn’s Lifelong Educational Center and Birchaven Village will be given access to these digital files. The video recordings will be kept on file for one year. After this time, all digital files from these recordings will be permanently deleted. The digital recordings from this research study will **not** be used for any case /study presentation, advertising, or other media purposes – they will only be used for the proposed research project.

There are no known risks (chances of harm) associated with this research project. Any risks that may occur with this research are no more than what the adult would experience in everyday life. We do not know if the older adult will benefit from taking part in this study. There may not be any personal benefit to the older adult, but the information gained by doing this research may help others in the future or guide future program planning at Birchaven Village.

Blanchard Valley Hospital System (Birchaven Village), Marilyn’s Lifelong Educational Center, and faculty/students at East Carolina University may know that the older adult took part in this research. It is possible that the adult will be identifiable on the digital recordings of the intergenerational activities that are recorded as part of this study. These digital files will be stored in password-protected files on password-protected computers, and will be kept on file for one year. As noted above, after one year, these files will be permanently deleted.

The older adult can stop participation in this study at any time after it has already started. There will be no consequences if s/he stops and s/he will not be criticized or lose any benefits that s/he would normally receive as a resident at Birchaven Village.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principle Investigator at 813-375-2831(Monday through Friday, 8am to 5pm).

If you have questions about your older adult’s rights as someone taking part in research, or any concerns or complaints about this study, you may call the Blanchard Valley Health System’s Ethics Committee at 419-429-6463 (weekdays, 8am – 5pm).

I have decided my older adult can take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following, and if you agree, you should sign this form:

- I acknowledge that I have read this consent in its entirety, or it has been read/translated to me
- I have had the opportunity to ask questions about it and understand it.
- I know that my older adult can stop taking part in this study at any time.
- By signing this informed consent form, my older adult is not giving up any of his/her rights.

I am familiar with this person and his/her wishes. I am, therefore, giving permission for _____ **[print participant’s name]** to take part in this research because I believe it is the choice he /she would make, if able.

Legally Authorized Representative (PRINT)

Signature

Date



Staff Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Intergenerational Programming Study
Principle Investigator: Megan C. Janke, PhD, LRT/CTRS
Institution: East Carolina University
Telephone #: 813-375-2831
Email: jankem@ecu.edu

Participant Full Name: _____ Date of Birth: _____

Please PRINT clearly

Birchaven Village, a part of the Blanchard Valley Health System, Marilyn's Lifelong Educational Center (Macklin Intergenerational Institute), and faculty at East Carolina University have partnered together to study the effects of the intergenerational program offered at our shared site facility to the participants. To do this, we need the help of volunteers who are willing to take part in research.

Purpose of this research:

By doing this research, we hope to learn how the intergenerational activities offered at Birchaven affect the health and wellbeing of older adults with dementia. All adults residing in the Aspen-Birch or Cedar-Dogwood neighborhoods of Birchaven are being asked to participate in this study.

You should not take part in this research project if you are uncomfortable or unwilling to have your interactions with the children and older adults digitally recorded for observation purposes, as this is a part of the research project.

You can choose to not participate in this research. If you do not participate in the research study, it will not affect your ability to work at Marilyn's Lifelong Educational Center, Birchaven Village, or participate in the intergenerational activities at Birchaven Village. The research will be conducted during regularly scheduled intergenerational activities at Birchaven Village. During the research study, the adults' interactions with the children will be recorded to observe the adults' levels of engagement and responses to these activities. It is possible that you will be inadvertently filmed as you assist with these activities as part of your position at Marilyn's Lifelong Educational Center or Birchaven Village. However, your involvement

is not the focus of these video recordings and will not be evaluated or assessed as part of the research project.

Only members of the research team and administrators of Marilyn's Lifelong Educational Center and Birchaven Village will be given access to these digital files. The video recordings will be kept on file for one year. After this time, all digital files from these recordings will be permanently deleted. The digital recordings from this research study will **not** be used for any case/study presentation, advertising, or other purposes – they will only be used for the proposed research project.

There are no known risks (chances of harm) associated with this research project. Any risks that may occur with this research are no more than what you would experience in everyday life. We do not know if there are any benefits to the older adults, children, or staff from taking part in this study. There may not be any personal benefits to you, but the information gained by doing this research may help others in the future or guide future program planning at Birchaven Village.

Blanchard Valley Hospital System (Birchaven Village), Marilyn's Lifelong Educational Center, and faculty/students at East Carolina University may know that you took part in this research. It is possible that you will be identifiable on the digital recordings of the intergenerational activities that are recorded as part of this study. These digital files will be stored in password-protected files on password-protected computers, and will be kept on file for one year. As noted above, after one year, these files will be permanently deleted.

You can stop participation in this study at any time after it has already started. There will be no consequences if you stop and you will not be criticized or lose any benefits that you would normally receive as a staff member at Marilyn's Lifelong Educational Center or Birchaven Village.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principle Investigator at 813-375-2831 (Monday through Friday, 8am to 5pm).

If you have questions about your older adult's rights as someone taking part in research, or any concerns or complaints about this study, you may call the Blanchard Valley Health System's Ethics Committee at 419-429-6463 (weekdays, 8am – 5pm).

I have decided to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT)

Signature

Date

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT)

Signature

Date



**Legal Guardian, Legally Authorized Representative
Permission to Allow Your Older Adult to Take Part in Research**

Information to consider before allowing the older adult in your care to take part in research that has no more than minimal risk.

Title of Research Study: Intergenerational Programming Study

Principle Investigator: Megan C. Janke, PhD, LRT/CTRS
Institution: East Carolina University
Telephone #: 813-375-2831
Email: jankem@ecu.edu

Participant Full Name: _____ Date of Birth: _____
Please PRINT clearly

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Purpose of this research:

The older adult under your legal care is being invited to take part in this research study because s/he is currently a resident at Birchaven Village. By doing this research, we hope to learn how these intergenerational activities affect the health and wellbeing of older adults with dementia. All adults residing in the Aspen-Birch or Cedar-Dogwood neighborhoods of Birchaven are being asked to participate in this study.

You should not allow the older adult in your care to take part in this research project if you are uncomfortable or unwilling to have their interactions with the children digitally recorded for observation purposes, as this is a part of the research project.

You can choose to not have your older adults participate in this research. If the older adult does not participate in the research study, it will not affect his/her ability to participate in the intergenerational activities offered at Birchaven Village. The research will be conducted during regularly scheduled intergenerational activities at Birchaven Village. During the research study, the adults’ interactions with the children will be recorded to observe the adults’ levels of engagement and responses to these activities. A few assessments will be collected related to the older adults health and wellbeing,

including their level of cognitive status/impairment, mood, and quality of life. In addition, staff at Birchaven will review information in the adults' chart (e.g., administration of psychotropic medications, changes in environment/medications/health, prior assessments on cognitive status and mood) to investigate if there is an association between participation and engagement in the intergenerational activities and health outcomes.

Only members of the research team and administrators of Marilyn's Lifelong Educational Center and Birchaven Village will be given access to these digital files. The video recordings will be kept on file for one year. After this time, all digital files from these recordings will be permanently deleted. The digital recordings from this research study will **not** be used for any case/study presentation, advertising, or other media purposes – they will only be used for the proposed research project.

There are no known risks (chances of harm) associated with this research project. Any risks that may occur with this research are no more than what the adult would experience in everyday life. We do not know if the older adult will benefit from taking part in this study. There may not be any personal benefit to the older adult, but the information gained by doing this research may help others in the future or guide future program planning at Birchaven Village.

Blanchard Valley Hospital System (Birchaven Village), Marilyn's Lifelong Educational Center, and faculty/students at East Carolina University may know that the older adult took part in this research. It is possible that the adult will be identifiable on the digital recordings of the intergenerational activities that are recorded as part of this study. These digital files will be stored in password-protected files on password-protected computers, and will be kept on file for one year. As noted above, after one year, these files will be permanently deleted.

The older adult can stop participation in this study at any time after it has already started. There will be no consequences if s/he stops and s/he will not be criticized or lose any benefits that s/he would normally receive as a resident at Birchaven Village.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principle Investigator at 813-375-2831 (Monday through Friday, 8am to 5pm).

If you have questions about your older adult's rights as someone taking part in research, or any concerns or complaints about this study, you may call the Blanchard Valley Health System's Ethics Committee at 419-429-6463 (weekdays, 8am – 5pm).

I have decided my older adult can take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following, and if you agree, you should sign this form:

- I acknowledge that I have read this consent in its entirety, or it has been read/translated to me
- I have had the opportunity to ask questions about it and understand it.

- I know that my older adult can stop taking part in this study at any time.
- By signing this informed consent form, my older adult is not giving up any of his/her rights.

I am familiar with this person and his/her wishes. I am, therefore, giving permission for _____ **[print participant's name]** to take part in this research because I believe it is the choice he/she would make, if able.

Legally Authorized Representative (PRINT)

Signature

Date



**Parental/Legal Guardian, Legally Authorized Representative
Permission to Allow Your Child to Take Part in Research**

Information to consider before allowing your child to take part in research that has no more than minimal risk.

Title of Research Study: Intergenerational Programming Study

Principle Investigator: Megan C. Janke, PhD, LRT/CTRS
Institution: East Carolina University
Telephone #: 813-375-2831
Email: jankem@ecu.edu

Participant Full Name: _____ Date of Birth: _____

Please PRINT clearly

Birchaven Village, a part of the Blanchard Valley Health System, Marilyn's Lifelong Educational Center (Macklin Intergenerational Institute), and faculty at East Carolina University have partnered together to study the effects of the intergenerational program offered at our shared site facility to the participants. To do this, we need the help of volunteers who are willing to take part in research.

Your child is being invited to take part in this research study because s/he is currently enrolled in Marilyn's Lifelong Educational Center and regularly attends intergenerational programming at Birchaven Village. The decision for your child to take part in this research will also depend on whether your child wants to participate. By doing this research, we hope to learn how these intergenerational activities affect the health and wellbeing of those involved. All children enrolled at Marilyn's Lifelong Educational Center are being asked to participate in this study.

Your child should not take part in this research project if you are uncomfortable or unwilling to have their interactions with the older adults digitally recorded for observation purposes, as this is a part of the research project.

Your child can choose not to participate in this research. The research will be conducted during regularly scheduled intergenerational activities at Birchaven Village. During the research study, your child's interactions with the older adults will be recorded to observe the adults' levels of engagement and responses to these activities. Only members of the research team and administrators of Marilyn's Lifelong Educational Center and Birchaven Village will be given access to these digital files. The

video recordings will be kept on file for one year. After this time, all digital files from these recordings will be permanently deleted. The digital recordings from this research study will **not** be used for any case/study presentation, advertising, or other media purposes – they will only be used for the proposed research project.

There are no known risks (chances of harm) associated with this research project. Any risks that may occur with this research are no more than what you would experience in everyday life. We do not know if your child will benefit from taking part in this study. There may not be any personal benefit to your child, but the information gained by doing this research may help others in the future.

Blanchard Valley Hospital System (Birchaven Village), Marilyn’s Lifelong Educational Center, and faculty/students at East Carolina University may know that your child took part in this research. It is possible that your child will be identifiable on the digital recordings of the intergenerational activities that are recorded as part of this study. These digital files will be stored in password-protected files on password-protected computers, and will be kept on file for one year. As noted above, after one year, these files will be permanently deleted.

Your child can stop participation in this study at any time after it has already started. There will be no consequences if s/he stops and s/he will not be criticized or lose any benefits that s/he would normally receive as a student at Marilyn’s Lifelong Educational Center.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principle Investigator at 813-375-2831(Monday through Friday, 8am to 5pm).

If you have questions about your child’s rights as someone taking part in research, or any concerns or complaints about this study, you may call the Blanchard Valley Health System’s Ethics Committee at 419-429-6463 (weekdays, 8am – 5pm).

I have decided my child can take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following, and if you agree, you should sign this form:

- I acknowledge that I have read this consent in its entirety, or it has been read/translated to me
- I have had the opportunity to ask questions about it and understand it.
- I know that my child can stop taking part in this study at any time.
- By signing this informed consent form, my child is not giving up any of his/her rights.

Date: _____

Participant's Printed Name:

Parent or legal guardian Printed Name: _____

Parent or legal guardian Signature: _____

**Parent or legal guardian name and signature is required for individuals under 18 years old

Appendix E



part of the
Jack Schaefer Retirement Community

15100 Birchaven Lane, Findlay, Ohio 45840
419.424.3000 • Fax 419.425.3070

April 13, 2017

Dear Dr. Janke,

Birchaven Village, as part of the Blanchard Valley Health System, is excited to partner with East Carolina University for this research study. We look forward to learning about the effects that our shared site daycare program (the Macklin Institute) has on the health and wellbeing of the residents in our facility.

This letter is to acknowledge our support for the research study that will explore the effects of intergenerational interactions on the wellbeing of the residents in our memory care units. We believe that our daily intergenerational program has the potential to positively impact the lives of our residents with dementia, and Birchaven Village looks forward to collaborating with you on this endeavor. We are committed to helping with participant recruitment, data collection, and providing access to relevant resident information as needed in this study.

Sincerely,

A handwritten signature in cursive script that reads "Bridgett Mundy".

Bridgett Mundy, LNHA, CEAL
Administrator

Institutional Review Board (IRB) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution/Organization A):

Blanchard Valley Health System

FWA #: FWA00005157

Name of Institution Relying on the Designated IRB (Institution B):

East Carolina University

FWA #: FWA00000658

The Officials signing below agree that East Carolina University may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (check one)

This agreement applies to all human subjects research covered by Institution B's FWA.

This agreement is limited to the following specific protocol(s):

Name of Research Project: "An Intergenerational Programming Study"

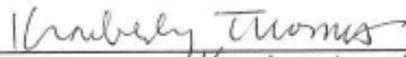
Name of Principal Investigator: Megan C. Janke, PhD, LRT/CTRS

Sponsor or Funding Agency: _____ Award Number, if any: _____

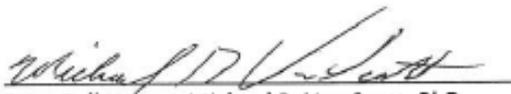
Other (describe > : _____

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

 Date: 8/7/17
Print Full Name: Kimberley M. Thomas Institutional Title: Dir. of Risk Mgmt
in house legal counsel

Signature of Signatory Official (Institution B):

 Date: 01 August 2017
Print Full Name: Michael R. Van Scott, PhD
Institutional Title: Senior Associate Vice Chancellor and Institutional Official



1900 South Main Street
Findlay, Ohio 45840

419.423.4500
www.bvhealthsystem.org
Fax 419.423.5358

June 29, 2017

Megan C. Janke, PhD, LRT/CTRS
East Carolina University
jankem@ecu.edu

Re: Intergenerational Programming Study

Dear Dr. Janke,

The Institutional Review Board has reviewed the proposed study: an Intergenerational Programming Study, to be conducted in collaboration between Macklin Intergenerational Institute and Birchaven Village under the direction of Megan Janke, PhD, LRT/CTRS and I'Yanna Purnell. We understand that this study was initiated by the Board of Macklin Intergenerational Institute and will also serve as partial fulfillment of Ms. Purnell's Masters of Science through East Carolina University

By electronic review and voting the BVHS IRB has approved this study, effective Thursday, June 29, 2017.

Sincerely,


Elizabeth Kelly, Chair
BVHS Ethics and IRB

Cc: East Carolina University

