

Spring 2017

# Activities and Quality of Life for Persons with Dementia

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ACTIVITIES AND QUALITY OF LIFE FOR  
PERSONS WITH DEMENTIA

by

Cassidy Rose

A thesis submitted in partial fulfillment  
of the requirements for the degree

of

MASTER OF SCIENCE

in

Family, Consumer, and Human Development

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2016

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## ABSTRACT

## Activities and Quality of Life for Persons with Dementia

by

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Utah State University, 2016

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Department: Family, Consumer, and Human Development

This study was conducted to better understand how activities may impact quality of life on dementia care units. Based on the Quality of Life for Persons with Dementia definition provided by Brod, Stewart, Sands, and Walton (1999), researchers observed dementia care units, and looked into how different activity types impacted emotional affect in the person with dementia, and how they elicited different levels of positive staff interaction. Results indicated that there were significantly higher levels of positive affect from participants on certain activity types, compared to no activity. The largest levels of positive affect were displayed during music therapy, motor activities, and activity centers. Activity types were also associated with differing levels of positive staff interaction (music therapy and motor activities had the highest levels of positive staff interactions, as well). Based on field notes and the data analysis, defining characteristics of a quality activity were established, and the Quality Activity for Persons with Dementia Scale

(including 5 subscales) was developed. I concluded that quality activities should consider the environment, staff ratio, staff communication and interaction, engagement of clients, and adaptability to the individual interest and ability of client. These findings have implications for activities coordinators and recreation, who can use these findings to identify more effective and higher quality activities for their clients with dementia.

(89 pages)

## PUBLIC ABSTRACT

By Cassidy Rose

This study was conducted to better understand how activities may impact quality of life on dementia care units. Researchers observed dementia care units, and looked into how different activity types impacted emotional affect in the person with dementia, and how they elicited different levels of positive staff interaction. Results indicated that there were significantly higher levels of positive affect from participants on certain activity types, compared to no activity. Activities that had high levels of staff to client interactions had more positive affective outcomes. Researchers concluded that quality activities should consider the environment, staff ratio, staff communication and interaction, engagement of clients, and adaptability of the activity to the individual interest and ability of client.

## ACKNOWLEDGMENTS

I would like to thank my major advisor, Dr. Elizabeth B. Fauth, for being a patient and encouraging mentor throughout the process of completing this thesis. She is a great advisor who always provided direct and constructive feedback, was patient with my edits and process, and took the time to help me succeed. I am grateful for her dedication to her students and their accomplishments. I would like to thank both Dr. Maria C. Norton and Dr. W. David Robinson for their input and willingness to serve on my committee. All three of these individuals provided essential feedback and support, and I am grateful for the input and direction I received.

I want to thank all the friends, colleagues, and professors I was able to work with throughout this process. All of the rich discussions, insight on writing, and help with research techniques added to the study and thesis, greatly benefitting me in this process. A special thank you to the research team Keirstin Meyer, Jacob Stacey, Crista Vance, and Bergen Lindauer.

My family is the greatest support system and was a constant source of comfort. The example of education throughout my family encouraged me to pursue a graduate degree, and I'm grateful for the culture of self-improvement I was raised with. I am grateful for the example of hard work and education provided by both my parents. I would not have been able to complete this without their love, support, and example.

Cassidy Rose

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## **CHAPTER I**

### **INTRODUCTION**

In 2010 the number of adults over the age of 65 in the United States was just over 40 million (U.S. Census Bureau, 2011). Population trends suggest that the population of older adults will continually increase over the next 35 years, and by 2050 the population of adults over the age 65 will be nearly 90 million (U.S. Census Bureau, Population Division, 2008). With the increase in older adults, dementia will become a more prevalent disease. The Center for Disease Control (CDC) has suggested that by the year 2050, 14 million older adults will have Alzheimer's disease, which is the most common form of dementia. Proportional to the population trends, this is a three-fold increase within 37 years; the United States will experience a dementia epidemic (Center for Disease Control and Prevention, 2014). The World Health Organization (WHO) reports similar global trends (World Health Organization, 2012).

Dementia is a disease often associated with cognitive and memory decline in late life. Dementia includes Alzheimer's disease, vascular dementia, Parkinson's disease, Lewy bodies dementia, prefrontal cortex dementia, and others. Alzheimer's disease is the most prevalent form of dementia accounting for approximately 60-80% of all dementias (Alzheimer's Association, 2015). While the medical field continues to develop pharmaceutical interventions, and persistently tries to understand causal factors of Alzheimer's and other forms of dementia, we currently have no cure. Therefore, current "treatment" includes caring for the physical and emotional needs of the person. The goal of dementia care is not to cure the disease or reverse the cognitive damage, but to manage

the symptoms and maximize quality of life (Kaldjian, Shinkunas, Bern-Klug, & Shultz, 2010; van der Steen et al., 2014).

When dementia progresses such that the person is unable to perform activities of daily living without assistance, and/or the person's safety is comprised, caregivers are faced with the choice to continue to provide care in a home setting, or to look for supplemental formal help. Dementia care units are designed to work specifically with persons with dementia to meet their care needs and provide safety (Morgan & Stewart, 1999; O'Sullivan, 2013). While care for physical needs is in the forefront, many of the dementia care units also recognize the emotional and social needs of the person with dementia, including the importance of quality social interactions and stimulation, such as providing activities that are both engaging (despite cognitive decline) and age-appropriate (Marshall & Archibald, 1998; Morgan, Semchuk, Stewart, & D'Arcy, 2003). In order for recommendations for socioemotional health to be developed, more empirical support is needed for how specific interaction styles and activities maintain, or even increase, aspects of quality of life for persons with dementia.

Gaining a better understanding of how to increase quality of life in persons with dementia through activities and staff-client interactions is a central focus of this study. To provide this depth of knowledge, we will examine the activities that are associated with increased positive affect in persons with dementia (where positive affect is seen as a central component to measuring quality of life; Brod, Stewart, Sands, & Walton, 1999). We will also evaluate which activities illicit high levels of positive interactions between staff and clients. Finally, we will use the qualitative data from field notes to define a

“quality” activity scale, framed in ways that are interpretable by staff on dementia care units.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

With the increasing number of individuals living past age 85, the incidence and prevalence of dementia is also increasing (Alzheimer's Association, 2015). With no known cure for Alzheimer's or most other dementias, it is important to find ways to maximize quality of life (QoL) for persons living with dementia. Many dementia care units have activities that aim to increase quality of life by promoting not only cognitive and physical stimulation, but also social interactions. Although activities are often considered beneficial, research is limited on understanding the types of activities that elicit the most favorable responses in clients, or how activity type may impact quality of life. Activities may improve quality of life for persons with dementia by increasing positive affect and promoting positive social interactions. First I will look into what is quality of life for persons with dementia. Next I will discuss how it has been measured in other studies; finally, I discuss how different activities and social interactions have been found to impact quality of life for persons with dementia.

#### **Quality of Life in Persons with Dementia**

Quality of life is important across the lifespan. At every age, individuals desire to feel that their needs are met, to feel comfortable, and to have a sense of belonging. Despite a general agreement on the broad conceptualization of quality of life (QoL), specifically in persons with dementia, there are different dimensions emphasized by

researchers and family caregivers. For example, some researchers propose that quality of life in this population is associated with identity (Hilgeman, Allen, Snow, Durkin, DeCoster, & Burgio, 2014). As individuals become more impaired and less able to care for themselves, their identity and sense of self may be diminished. Care providers may see them as less of who they were, and begin to treat the disease more than the individual. Alternatively, family caregivers may have a different view of quality of life for their care recipients. A qualitative study was conducted where caregivers were asked how they perceived quality of life in their loved ones with dementia, specifically those living in long-term care facilities (Moyle, Murfield, Venturto, Grimbek, McAllister, & Marshall, 2014). Quality of life themes frequently focused on the care given to the person with dementia, and how this impacted well-being. Activities that encouraged individuals to attend and participate were considered by caregivers to increase QoL, as well as efforts of the staff in getting to know the client as an individual (Moyle et al., 2014).

In a more comprehensive model, Brod and colleagues (1999) conceptualized quality of life for persons with dementia as consisting of eight major domains (see Table 1): physical functioning, daily activities, discretionary activities, mobility, social interaction, interaction capacity, bodily well-being, and sense of well-being. Within each of these major domains are subdomains. Because of the broader, multidomain approach, I chose the definition provided by Brod et al. as the accepted theoretical framework for this analysis. In particular, three of the domains (and subdomains) are relevant for the purpose of this study. In this definition, sense of well-being has the greatest number of subdomains, and includes self-esteem, feeling loved, anxiety, loneliness, frustration, boredom, happiness, sense of humor, calm or peacefulness, sense of control, depressed



mood, and feelings of belonging, with happiness and peacefulness (positive affect) and anxiety and depressed mood (negative affect) most relevant here. Social interactions include intimacy and social participation. Finally, discretionary activities include hobbies, recreational activities, work and productivity, and in general, being active. The domains of (1) well-being, (2) social interactions, and (3) discretionary activities are amenable to observational approaches within dementia care settings, as will be described below. First, however I review measurement issues related to the assessment of QoL in persons with dementia.

Table 1

*Adaptation of Domains of Quality of Life Conceptualization Provided by Brod, Stewart, Sands, & Walton, 1999*

<b>Domain</b>	<b>Subdomain</b>
<b>Social interaction and relationships</b>	<b>Intimacy, participation</b> , happiness with family
<b>Performance of discretionary activities</b>	<b>Productivity, hobbies, recreational activities, vacations, activity level</b>
<b>Well-being (sense of, and bodily)</b>	Self-esteem, feelings of belonging, <b>boredom, anger, sense of humor, happiness, calm</b> , feeling useful, sense of control, feeling loved, <b>anxiety, worry, depression, peaceful, fatigue, sleep</b>
Physical functioning and ability	Self-care activities, walking, bending, reaching, stairs, IADL, ADL
Sense of aesthetics	Enjoying nature and surroundings. Artistic and creative expression and appreciation.
Overall perception	Self-rated health, life satisfaction

*Note:* Bolded areas are particularly relevant to, and therefore included in the current analysis.

## **Measurement of Quality of Life in Persons with Dementia: Self or Proxy Report**

There are multiple ways that quality of life in persons with dementia has been measured, including self-report, caregiver report, or observational data. The approach taken depends, to some extent on the population or sample's stage of dementia. Self-report is the preferred method for studying individuals in early stages of dementia (Logsdon, Gibbons, McCurry, & Teri, 2002), because this method gives voice to the person with dementia, and validates him or her as a person. For example, Hilgeman and colleagues (2014) measured quality of life in early stage persons with dementia using two different measurements, the Quality of Life in Alzheimer's Disease and the Bath Assessment of Subjective Quality of Life in Persons with Dementia (Hilgeman et al., 2014). Both of these measures are self-report; however, the first also allows caregivers to provide answers, as well as the person with dementia.

In later stages of dementia, when individuals become nonverbal or speech is unintelligible, self-report measures are difficult or impossible to administer (Albert, Del Castillo-Castaneda, Sano, & Jacobs, 1996). In these cases, proxy reports are often utilized, typically with a family or professional caregiver reporting on the quality of life of the care receiver. One measure used as both self-report (in early stages of dementia) and caregiver report (at all stages of dementia) to measure QoL in persons with dementia is the QUALIDEM (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007). QUALIDEM defines quality of life via the presence or absence of positive affect, negative affect, low levels of restless tense behavior, having a positive care relationship, positive social relations, lower social isolation, having a sense of "feeling at home" having something to do, and a positive self-image. Bouman, Ettema, Wetzels, van Beek,

de Lange, and Dröes (2011) reported validity with the QUALIDEM measure with proxy report data from mild to even severe levels of dementia.

Self-report and proxy data are also collected via the Quality of Life Alzheimer's Disease scale (Black, Johnston, Morrison, Rabins, Lyketsos, & Samus, 2012). Comparisons of proxy and self-reports on the Quality of Life Alzheimer's Disease scale suggest that proxies reported significantly lower levels of quality of life compared to the self-report measures, even when controlling for cognitive level in the care receiver (Huang, Chang, Tang, Chiu, & Weng, 2009). This identifies a concern with the validity of proxy reports by family caregivers. In general, while caregiver reports aid in gaining an understanding of quality of life when individuals are unable to provide information for themselves, there are factors that impact caregivers' scores, potentially introducing biases into proxy-reported QoL ratings. Researchers have suggested that medical professionals evaluate the relationship between the caregiver and the person with dementia when receiving proxy reports for QoL ratings (Huang, Chang, Tang, Chiu, & Weng, 2009). If the care dyad relationship is better understood, medical professionals may be able to recognize biases in caregiver proxy reports of QoL for the care receiver.

### **Quality of Life and Well-being: Affect in Persons with Dementia**

As stated earlier, three domains from Brod and colleagues (1999) conceptualization of QoL in persons with dementia are amenable to observational approaches within dementia care settings. One of these domains is well-being. Because self-report of well-being may not be possible for individuals with moderate or late-stage

dementia, and because caregiver proxy reports may be biased and may be difficult to collect once the person with dementia is institutionalized, observational assessments of well-being in persons with dementia have been considered as an effective approach (Ettema et al., 2007). Observational approaches are highly suited to Brod and colleagues (1999) multidomain conceptualization of quality of life (see Table 1), as many of their defined aspects of QoL are directly measurable via observations of behavior in the person with dementia. The Sense of Well-Being domain (Brod et al., 1999) involves emotional states, however, these emotions are often conveyed via facial expressions and observable behaviors. Although an individual may be too cognitively impaired to answer a question on his or her level of anxiety, facial expressions (grimacing, tension in facial muscles) or agitated behaviors (pacing, repeating questions, wringing of hands) may indicate that he or she is experiencing anxiety or agitation. In sum, observational measures of affect and behaviors related to quality of life in the person with dementia are appropriate alternatives to self- and proxy-report of QoL, particularly in moderate or mid-to-late stage dementia.

One accepted approach in assessing emotional affect via observations of behaviors and facial expressions is the Philadelphia Geriatric Center Affect Rating Scale (ARS), which maps onto six different affect categories: pleasure, interest, content, sadness, anxiety, and anger (Lawton, Van Haitsma, & Klapper, 1996). The development of this measure included observation periods where researchers watched participants one at a time, and recorded the affect present over a ten-minute period, recording both the intensity and duration of affect. To initiate the development of the measure, observers were given guidelines of affect categories, but were also permitted to write in other

emotional responses they observed. The scale has been validated in subsequent studies with discriminant and convergent tests conducted on mean ratings of 16 different occasions. Here researchers found validity; pleasure and anxiety were negatively correlated ( $r = -.48, p < .001$ ) and interest and contentment were positively correlated ( $r = .56, p < .001$ ; Lawton et al., 1996). Snyder and colleagues (1998) found the ARS to be significantly correlated with the Apparent Emotion Rating scale ( $r = .303, p < .001$ ), suggesting content validity in the scale. Because the ARS assesses observable facial expressions and behaviors of affect in institutional settings where self- and proxy-report are less feasible, and because of the scale's accepted psychometric properties, it was chosen as the affective measure of QoL for the current study.

### **Quality of Life and Discretionary Activities in Persons with Dementia**

As defined by Brod et al., discretionary activities are an integral part of QoL in persons with dementia. Leisure activities provide an opportunity for individuals to feel positive emotions, develop relationships, and acquire knowledge and skills. In research on older adults without dementia, participation in leisure activities is shown to increase social connectedness (correlations range from  $r = .064, p < .01$  to  $r = .153, p < .01$ ; Toepoel, 2013). Lacking or low levels of social leisure engagement is correlated with reduced subjective well-being via decreased functional status (Simone & Haas, 2013), whereas participation in leisure activities and increased engagement improves subjective well-being (Brajša-Žganec, Merkaš, & Šverko, 2011).

For persons with dementia, participation in leisure activities has been studied in community, non-institutional settings (e.g., at senior centers) and in institutional settings (general units or dementia care units). Researchers conducting a qualitative study were interested in better understanding the experience of persons with dementia. They interviewed eight community-dwelling individuals to discover the importance of activities and time spent. All eight participants mentioned the importance of leisure and recreational activities, noting that it allowed them to keep a routine and sense of identity. These researchers found that involvement in activities increased their enjoyment and pleasure, connection and belonging, autonomy, and identity (Phinney, Chaudhury, & O'Connor, 2007). Similarly, other researchers found that attendance and participation in activities at a senior center helped increase the number of meaningful activities that community-dwelling persons with dementia participated in (Söderhamn, Landmark, Eriksen, & Söderhamn, 2013). An evaluation of persons with cognitive impairment found that being unable to participate in leisure activities was related with an increase in depressive symptoms (Chiu et al., 2013.)

While research supports that leisure activities, in general, are beneficial for persons with dementia, research on care and activities in persons with dementia has also identified specific activities that are particularly relevant to this population, as they are appropriate for persons with impaired cognition, age-appropriate, safe, and associated with positive outcomes.

## **Music**

Music is a leisure activity that can engage an individual with dementia by

stimulating the mind and increasing cognitive activity (Hong & Choi, 2011) as well as increasing physical activity through dance or playing an instrument (Hamburg & Clair, 2008). In one intervention, a singing group for persons with dementia was created, where researchers measured functional ability (via performance of activities of daily living), cognitive status, psychological problems, and quality of life. Based on the qualitative results, the intervention helped maintain quality of life for both the person with dementia and the caregiver, despite the expected age and dementia-related decrease in other areas (Camic, Williams, & Meeten, 2013). Another study found that music was beneficial in decreasing agitation among persons with dementia. Attendance at regular group music therapy was associated with a decrease in agitated behavior, physically aggressive and non-aggressive behavior, as well as verbally non-aggressive behavior (measured using the Chinese version of the Cohen-Mansfield Agitation Inventory; C-CMAI) by decreasing at an average of .47 between the first measurement and 6 month follow up, on a scale ranging from 1 to 7 on agitation ( $p < .001$ ; Lin et al., 2011). Music activities are also appropriate for mid- or even late-stage dementia. As individuals' cognitive, physical, and social capacities decreased over a 15-month period, researchers identified that they were still able to participate in music therapy, and individuals stayed engaged in the group activity, even with significant cognitive impairment (Clair & Bernstein, 1990).

There is an important distinction between music activities and music therapy, although both kinds of music activities are utilized in dementia care units. Music therapy utilizes a certified musical therapist and aims to improve communication, enhance memory, manage stress, and create activities that are unique and allow for meaningful interactions with persons with dementia (American Music Therapy Association, 2006).

Music therapy activities are associated with positive interactions between clients and staff, and increased quality of life (Mathews, Clair, & Kosloski, 2001). An intervention designed by researchers interested in decreasing agitation and resistance during care situations for persons with dementia involved singing to a person with dementia was created by Hammar, Emami, Götell, & Engström (2011). They found that individuals who had music therapeutic caregiving interactions demonstrated less resistant behaviors, for example pulling away ( $\Delta \bar{x}$  : 148.8 seconds to 49.3 seconds,  $p < .01$ ) and showed more positive emotions throughout the process ( $\Delta \bar{x}$  : 281.8 seconds to 1387.5 seconds,  $p < .01$ ).

Beyond music therapy, musical performances are also beneficial for persons with dementia. Although observing musical performances is often less physically or cognitively stimulating than music therapy, music performance may still contribute to quality of life. Persons with dementia who were audience members during dance performances reported positive attitudes towards the experience, and mentioned forgetting their physical ailments while focusing on the performance. Having others around during the performance allowed them to have a discussion later on about the performance, which contributed to positive social engagement (Ravelin, Isola, & Kylmä, 2013). Live musical performances help to increase positive emotions and human contact (Van der Vleuten, Visser, & Meeuwesen, 2012). Music in an unstructured context, has also been linked to positive outcomes in persons with dementia, even though these are not organized activities, per se. For example, singing with or to a person with dementia while providing care has been found to decrease behavior such as pulling away or



grabbing during caregiving times (Pulling away:  $\bar{x}$  :148.8 seconds to 49.3 seconds,  $p < .05$  ; Grabbing:  $\bar{x}$  : 142.5 to 64.3,  $p < .05$ ; Hammar et al., 2011).

## **Art**

Art activities are also considered appropriate for persons with dementia, as they can be adapted for many levels of cognitive ability, are age-appropriate, safe, and engaging (Camartin, 2012). Art activities provide ways for individuals to learn or develop new skills. When art activities are done on a regular basis they may help individuals learn and retain a skill, especially when the participants appear to be enjoying the activity (Seifert & Baker, 1999). Art activities may also involve viewing or discussing art. Camic, Tischler, and Pearman (2014) integrated art discussions and art creation in a combined intervention. Persons with mild dementia attended an art gallery and discussed with others the artwork viewed, followed by an hour of art creation. Although no statistical evidence was found other than trends, a thematic analysis revealed that participation in the weekly intervention increased levels of social inclusion, as well as stimulated cognitive processes. Art programs that encourage self-expression were found to increase self-esteem in persons with dementia. They also helped sustain attention, increased individual interest in the activity, and yielded more pleasure than activities commonly found on dementia care units (Kinney & Rentz, 2005).

## **Cognitive Activities**

Cognitively stimulating activity participation in late life plays an important role in cognitive health for persons with dementia. Each day of self-reported cognitively stimulating activities one participated in, delayed the onset of memory decline by 0.18

years (Hall, Lipton, Siliwinski, Kats, Derby, & Verghese, 2009). Because people in memory care units may be at varying levels of cognitive impairment (i.e., mild, moderate, or severe), cognitive activities typically need to be adjusted for different stages of dementia. Activities appropriate for mild forms of dementia may be too challenging and inappropriate for late stages of dementia.

Most research on cognitive activities and dementia focuses on links between stimulating activities and dementia prevention or delayed onset. Pillai, Hall, Dickson, Buschke, Lipton, and Verghese (2011) conducted a study on crossword puzzles and cognitive decline after onset of dementia, where they controlled for education and IQ. Researchers found that the use of crossword puzzles at the onset of dementia may delay memory decline, with individuals who identified as puzzlers experience accelerated memory decline on average 2.54 years later than the non-puzzlers. Crossword puzzles and other stimulating activities may not be appropriate for persons with existing impairment, as they may be too challenging or induce frustration. Research on cognitive activities in individuals with existing dementia suggest that some cognitively stimulating activities are appropriate when they are accompanied by assistance and interaction from staff. For example, when participants were working on an activity (e.g., meal planning and preparation), they were more successful and able to participate in advanced activities when working together with staff and other participants (Hydén, 2014). Having a collaboration where an individual is prompted to participate and aided with memory and decision-making may be a cognitively stimulating activity.

Persons with dementia with higher levels of participation in cognitively stimulating activities showed slower disease progression compared to those with lower

levels of participation (Sobral & Paúl, 2013). Some cognitively stimulating activities are associated with reductions in agitation. Reminiscence activities bring in aspects of clients' past, such as music or activities they may have experienced in their youth, and have often been used to decrease agitation (Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009). Snoezelen therapy takes participants into a sensory stimulating room where they may interact with relaxing music, scent, and a variety of objects, such as bubble machines, a light board, and different textures. This sensory stimulation is effective in reducing agitation by increasing stimulation in a relaxing environment, and reducing tension (Bemis, 2013). It is reported in this study to be equally as effective as reminiscent type interventions in reducing agitation (Baillon et al., 2004).

### **Physical Activities and Exercise**

Although older adults may not be able to perform strenuous activities as well as they have been in the past, the benefits from these activities indicate the importance of implementing less strenuous physical activities on dementia care units. Modified exercise programs are appropriate for this population, however activity directors may need to consider that limitations change over the course of the disease. For individuals in earlier stages of dementia, the difficulty in physical tasks may be related to decision-making involved in that task. Persons in moderate-to-late stage dementia often experience a decline in physical abilities because of loss of function and movement (Giebel, Sutcliffe, & Challis, 2015).

Often the experience of being outdoors can be valuable to persons with dementia, who report that outside activities are associated with feelings of self-worth (Olsson et al.,

2013). One study looking into the importance of everyday activities reported that 62% of residents in a residential care unit participated in outdoor walks as part of their everyday activities. These individuals measured significantly higher quality of life, and cognitive outcomes compared to those who did not regularly participate in everyday activities, such as outdoor walks (Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014).

Walking groups have been established to increase activity, and have been found to be protective against further cognitive decline in persons with dementia (Kemoun et al., 2010). Individuals with dementia who participated in regularly scheduled Tai Chi classes maintained cognitive test scores, whereas those who had not participated in the Tai Chi exercise group experienced decline over a 12 week period (Cheng et al., 2014). Exercise may also help improve quality of sleep in persons with dementia, as well as decrease agitation, wandering, and even depression (Thuné-Boyle, Iliffe, Cerga-Pashoja, Lowery, & Warner, 2012).

### **Social Activities**

Social activity and social engagement are important throughout the lifespan, and are no less important in persons with dementia. The number one activity preference for persons with dementia is socializing (Menne, Johnson, Whitlatch, & Schwartz, 2012). Persons with dementia who participated in social activities showed higher levels of attentiveness ( $t_{192} = 6.22, p < .01$ ), were engaged for longer ( $t_{192} = 8.87, p < .01$ ), and had a more positive attitude compared to those who participated in non-social activities ( $t_{192} = 12.86, p < .01$ ). Even activities that attempted to simulate social interactions with nonhuman social stimuli showed less positive outcomes than those using human stimuli

in social activities (Cohen-Mansfield, Thein, Dakheel, Regier, & Marx, 2010).

Individuals living in dementia care units show higher levels of social engagement compared to those living on psychogeriatric units. Along with the increase of social engagement observed, lower levels of depression among those living in dementia care units was noted, as well (van Beek, Frijters, Wagne, Groenewegen, & Ribbe, 2011).

### **Structured Versus Unstructured Activities**

There are many times throughout the day where there are no planned activities on dementia care units. In some cases, the environment or objects within the unit have been specifically added to provide some stimulation, despite the lack of structure. An example of environmental influences comes from a study where aquariums were introduced onto dementia care units. Both residents and staff reported improvements in behavior and well-being after the installation of the aquarium. Residents were more cooperative, more rational, sleep improved, and inappropriate behaviors were decreased ( $F = 15.60, p < .001$ ). The level of satisfaction amongst staff increased as well ( $F = 35.34, p < .001$ ; Edwards, Beck, & Lim, 2014). Having access to baby dolls may help persons with dementia have a sense of connection and social interaction, or help to fulfill their attachment needs (Bisiani & Angus, 2013). This form of intervention, often referred to as Doll Therapy, is often criticized for its infantilization of persons with dementia (Andrew, 2006). However, others report that it increases autonomy and engagement with others (Mitchell & Templeton, 2014).

Not everything in the environment adds to or increases quality of life for persons with dementia. Televisions are often found on dementia care units in common areas.

However, when evaluating levels of engagement during television time, de Medeiros, Beall, Vozzella, and Brandt (2009) found that the majority of time spent watching television participants were dozing off, or otherwise not engaged. After the television program had ended, many participants continued looking at a blank screen, suggesting that perhaps individuals were not so much engaged in the program, as they were, simply, present while it was turned on (de Medeiros et al., 2009). In all planning and preparation for activities or unstructured activities it is important to take into account the individual. Understanding past preferences helps to create activities or events where an individual will be more engaged (Cohen-Mansfield, Marx, Thein, & Darkheel-Ali, 2010). Television programming is the same. If programming is chosen based on the individual level, and helps to stimulate rather than overwhelm their cognitive processes, it has been found to be an effective and engaging past time (Heller, Dobbs, & Strain, 2009).

Campo and Chaudhury (2012) suggest that there are many factors that facilitate meaningful social interactions: individual and psychological factors, past history and situational factors, social environments, and physical environments. They also found that the built environment, such as the placement of the nursing station, has an impact on the quality of social interactions. When a nursing station was situated near the common area, unstructured social interactions came more naturally. The care and nursing staff considered social interactions a key part of their role, and having a nursing station in close proximity to clients allowed them to naturally fulfill this responsibility (Campo & Chaudhury, 2012).

## **Summary of Activities and Quality of Life for Persons with Dementia**

In sum, there is research to support that activities offer meaningful experiences for persons with dementia, and may combat some symptoms of dementia, such as agitation. It is likely, however, that not all activities have the same positive outcomes for person with dementia, yet activities are nearly always studied independently of one another, making comparisons difficult. Comparative research can examine what types of activities have more frequent or longer duration of positive/negative/neutral outcomes for persons with dementia.

A deeper understanding is also needed on the specific elements or characteristics included in more positively-received activities. For example, activities may elicit fewer displays of anger in clients when there is a focus on the individual preferences of a client ( $F[1.168] = 5.68, p < .01$ ; Van Haitsma et al., 2015). The concept of personalizing activities or care to an individual's preferences or needs is becoming more prevalent in dementia care, and is often explained through Person Centered Care models.

### **Quality of Life and the Role of Quality Social Interactions**

A term that is often found in the literature of quality care in persons with dementia is Person Centered Care (PCC). When working with persons with dementia, PCC is focused on maintaining the individuality and integrity of the individual with cognitive impairment. Terada et al. (2013) found that PCC is positively correlated with aspects of quality of life for persons with dementia living in geriatric facilities. Person

Centered Care is particularly relevant to the current study for its focus on quality of life and promoting well-being through quality social interactions.

Training that focuses on teaching caregiving staff the importance, and methods, of communicating positively and engaging with persons with dementia is needed (Carpiac-Claver & Levy-Storms, 2007). For example, therapeutic models that include elements of social interaction have been found to be effective in decreasing agitation among persons with dementia (Bédard, Landreville, Voyer, Verreault, & Vézina, 2011). Success has been found with the PCC model with persons with dementia when training is focused on interpersonal engagement and improving the social world for each individual (Stein-Parbury et al., 2012). Also, within the PCC framework, staff education models including empathy training are beginning to be developed to increase quality interactions (Bayne, Neukrug, Hays & Britton, 2013). Ward and colleagues (2008) stated that communication with care staff and persons with dementia is essential, even down to the planning of care level. They argued that persons with dementia are both able and interested in being involved in the conversations on care planning. The ability to connect socially to an individual's emotions may be the most important aspect of caregiving (Meyer, Ashburner, & Holman, 2006).

As a degenerative disease, dementia can impact an individual's sense of self, and an individual's identity may experience changes over time. Working with adults who have dementia can be increasingly difficult, and often caregivers are unsure of how to interact with those who are losing their identity (Emilsson, 2008). This can lead to care problems because there may be difficulty for caregivers in recognizing individual needs.



Getting to know an individual through social interactions can increase the quality of care provided for them.

Based on Brod and colleagues' (1999) definition of quality of life, meaningful social interaction plays a critical role in an individual's quality of life, throughout the lifespan. The quality of interactions between staff and persons with dementia on care units can greatly impact the quality of life for an individual. Interactions that are not task oriented, and involving an element of individualization based on a client's history and preferences, are considered person centered care (PCC) oriented. These interactions are seen as positive and beneficial; however, if they are followed by task oriented conversation that is not seen as PCC, the positive impact is diminished (Savundranayagam, 2014). Medical models of care often de-emphasize the need for person-to-person interaction, which is why many long-term residential nursing facilities turn to social models. However, within some social models it has been observed that staff begin to interact with clients as family, and over time privacy may not be maintained, or the persons with dementia may become treated as children (Liou & Jarrott, 2013). If a social model is constructed around PCC, the individuality of a person may be maintained throughout social interactions. An example of this is seen in increasing the relationship between caregiving staff and relatives of the person with dementia. This may help increase the quality of interactions between staff and persons with dementia (van Beek, Wagner, Frijters, Ribbe, & Groenewegen, 2013). Recognizing the individuality of the person is supported by Ericsson, Hellström, and Kjellström (2011) as well; being sensitive to the needs of persons with dementia increases social interactions.

Cooney et al. (2014) recognized the benefit of positive social interactions on quality of life in persons with dementia, and designed activities to increase these interactions. Activities often provide the opportunity for persons with dementia to have the social interaction that they need to feel included in a social network (Evans, Fear, Means, & Vallely, 2007). Reminiscence activities provided a way for staff to learn more individuals, and begin to see them beyond the dementia. Compared to different activities like music, reading, task oriented, and so forth, activities that increase live social interaction have the most impact on affect in persons with dementia. The higher the cognitive functioning, the more likely social interaction activities increase pleasure in persons with dementia; however, across cognitive abilities social interaction has been found to increase levels of positive affect (Cohen-Mansfield, Marx et al., 2010).

As quality social and care interactions from staff becomes more central in discussions of PCC and quality of life, defining and measuring “quality” in interactions is essential. The Quality Interaction Scale (QUIS) was developed as an observational tool to better understand the interactions between staff and persons with dementia living in residential units (Dean, Proudfoot, & Lindesay, 1993). The QUIS looks at interactions in three aspects: positive, neutral, and negative. Positive interactions include pleasure and interest, both of which are typically found in definitions of quality of life, including the one provided by Brod and colleagues (1999; the central conceptualization used throughout this paper). Neutral interactions are those where brief interaction takes place, such as placing a plate down without acknowledging an individual during a mealtime. Negative interactions involve those that occur during care, defined as negative protective, and occur when care is given in a socially-improper way, such as failing to provide an

explanation. The other negative interaction is negative restrictive. This is where caregiving staff has an interaction that is unnecessary and negative, for example, moving a person in a wheel chair without asking or explaining, when no immediate need is obvious. The interactions that are considered positive are aimed at increasing quality of life for persons with dementia.

It is important to note that depression and anxiety are often comorbid with dementia, and may have additional impact on QoL. Older adults, in general, may be less likely to access mental health resources leading to lack of treatment (DiNapoli, Cully, Wayde, Sansgiry, Yu, & Kunik, 2015). Under-treatment may be increased in an impaired population who may be less able to communicate their needs. In fact, depression and anxiety are four times more likely to occur in adults with dementia compared to those without it (Jawaid, Pawlowicz, & Schulz, 2015). Looi, Byrne, Macfarlane, McKay, and O'Connor (2014) stated that 28% of individuals in their study with dementia experienced depressive symptoms, with 10% having a diagnosis of major depressive disorder. These comorbidities may make it difficult for individuals to engage socially with others outside of activities, and we note that individuals with depression or anxiety in addition to dementia, may not prefer to be in common areas to participate in the activities, which may bias studies that rely on observations in common areas (such as the current study).

### **Summary and Purposes of the Study**

Earlier in this review I discussed how quality of life in persons with dementia includes well-being or positive affect. We next discussed how discretionary activities and quality social interactions in dementia care settings have the potential to improve well-

being and quality of life in persons with dementia. One purpose of the current study is to expand this research by conducting a comparative approach to see the types of activities that are associated with more positive emotions in persons with dementia.

I then reviewed the literature on how interactions with staff are related to person-centered care and quality of life in persons with dementia, ending with examples of interactions studied during activities. The second purpose of this study is to describe and compare the types of activities that are associated with higher quality staff interactions.

The final purpose of the study is to combine the knowledge gained from (1) the examinations of activities and emotions in the person with dementia, and (2) the examinations of activities and quality staff interactions, together with qualitative field notes, to more descriptively define “quality” in activities within a dementia care setting. Defining a scale of quality from 1-7 will be incorporated into the specific aims and purposes of the larger, parent study for which this data was collected (Quality of Life in Memory Care Settings Study; PI: Elizabeth Fauth); the parent study seeks to develop standard scales of quality across multiple domains of dementia care. These findings also will have implications for dementia care units, who can use the reports to make more informed decisions in selecting high quality activities for their residents.

### **Research Questions**

(1) What activity types are related to the proportion of observed positive, neutral, and negative emotions in the person with dementia?

(2) What activity types are related to the proportion of observed positive, neutral/no, and negative interactions from the staff?

(3) Using results from questions one and two, along with qualitative field notes, how can we define “quality” in activities in dementia care units?

- a. What might a scale of 1-7 (7 = highest quality) look like for an observational rating of activities in dementia care units?
- b. What characteristics (terms, descriptive, features) of activities can be used to help discriminate between higher or lower quality activities?

## **CHAPTER III**

### **METHODS**

The data for this study come from a larger study called Quality of Life in Memory Care Settings, which is designed to use observational data on affect and interactions to create standard scales of quality across multiple domains of dementia care. The purpose of this current analyses was to better understand how activities (one domain of quality of life in persons with dementia) are associated with two other domains of quality of life for persons with dementia: emotional affect, and social interactions with staff. Quantitative observational assessments of activities, affect, and staff interaction provided additional data for research questions one and two. Qualitative field notes provided additional data for research question three. Below is the description of the participants, measurement, data collection procedures, and the data analytic plan.

#### **Participants**

Originally two facilities were included for observation in this study: the Sunshine Terrace Foundation, and the Cache Valley Day Center for Seniors (CVCS). Observations began at CVCS, where the observation sheet (data collection tool) was refined to meet our needs. After three weeks of observation this facility closed due to lack of funding. Thus, while this facility was used for the development and training of observers on our measure, data from this site are not included in any analyses. All data for the current analyses were collected at Sunshine Terrace Foundation Memory Lane Unit, which is a residential long-term care facility, in a wing of the facility dedicated to care of persons

with dementia. Consent was obtained by mailing a letter to clients' power of attorney or family care proxy, explaining the purpose of the study. The study was approved by the Institutional Review Board for Utah State University.

All participants in the study had a clinical diagnosis of dementia prior to moving into the dementia care unit. The unit is set up to care for individuals in a safe setting as it uses a key code to enter and exit the wing, thus minimizing the chance for residents to wander. In total, the study had twenty-two participants, consisting of 10 males and 12 females. Of the 22 participants, 16 of them had available scores on the Brief Interview for Mental Status (BIMS), which averaged 4.5 (a score below 7 indicates severe dementia; Chodosh et al., 2008). Protocols outlined by the Health Insurance Portability and Accountability Act (HIPPA) prohibited the sharing of diagnoses or clinical health records to the research team, as we did not have HIPPA consent included in the research consent process. Therefore the research team did not have access to specific dementia diagnoses (e.g., vascular dementia, Alzheimer's, etc.) or precise levels of cognitive impairment at the level of the individual participants (i.e., only aggregate BIMS scores were able to be shared with the research team). Although the clients' consent was obtained through their power of attorney or primary decision-maker, if a client seemed uncomfortable with being observed, he or she was no longer observed on that day. To ensure confidentiality was maintained, participants were assigned an identification number for data entry and analysis.

### **Measures**

To better understand how different activity types on dementia care units are

associated with positive/negative/neutral affect in persons with dementia, observations of staff interactions and participant affect were collected. Information on activity type, staff to client ratio, and brief qualitative field notes were collected as well for each observation period. Existing measures were used for data collection, however these measures were designed independently, and our goal was to be able to collect interactions, activities, and affect simultaneously; therefore, slight modifications were made to the existing observational tools to facilitate concurrent assessment of activities, staff interactions, and affect. An affect measurement and an interaction measurement were combined into one data collection sheet, which observers used to collect data. The original measures are presented first, followed by the adaptation to the measures used in the current study.

### **Philadelphia Geriatric Center Affect Rating Scale**

The Philadelphia Geriatric Center Affect Rating Scale (ARS) is a 6-item scale that measures emotional affect by observing facial expressions, and categorizing them into 6 different categories: pleasure, interest, content (positive affect) and sadness, anxiety, anger (negative affect; Lawton et al., 1996). It allows researchers to focus on observational methods of data collection, and was designed specifically for a population of older adults who may be unable to complete a self-report measure (due to cognitive impairment). By observing facial expressions, non-verbal behaviors, and other specific behaviors, raters categorize emotional affect in the client. Tests of inter-rater reliability for the original development of the scale resulted in high levels of Kappa across all six coded categories (ranging from .76 to .89). Validity of constructs was measured in prior



studies by using exploratory factor analysis of the six constructs, which resulted in two factors of positive and negative affect (Lawton et al., 1996).

### **Quality Interaction Scale**

Quality Interaction Scale (QUIS; Dean et al., 1993) is an observational measure developed by Dean et al. (1993) to classify interactions with staff and clients in long-term care settings. The scale categorizes staff interactions in three main categories: positive, neutral, and negative. Positive interactions include two subcategories: positive social and positive care. Neutral interactions are those interactions that are brief and not individualized. Negative interactions include negative protective interactions, where the interaction is for the care or benefit of the client's physical needs but lacks communication or explanation of what is occurring. Negative restrictive interactions are those interactions deemed as unnecessary and uncaring towards clients. Psychometric properties of the scale indicate that positive interactions yielded the highest levels of inter-rater reliability ( $k = .91$ ) whereas neutral interactions received the lowest ( $k = .60$ ).

### **Measurement Adaptations for the Purpose of Study**

To observe staff interactions and client affect concurrently, the two observational measurements listed above were combined into one charting document, with affect categories listed in columns and interaction types in rows, allowing for a grid system to chart both simultaneously. The original QUIS included positive social and positive care categories for staff interactions. However, structured activities create opportunities for interactions that are not easily categorized as either care or social. That is, when assisting

a client with an activity and engaging with them, care is not necessarily being provided.

Likewise, the interactions do not fit the QUIS definition of positive social, (interaction involving good, constructive conversation or companionship; Dean et al., 1993).

Therefore, positive activity assistance was created as a third positive interaction type for this study, to document when staff or volunteers were having positive interactions with clients in relation to the activity.

The ARS was adapted for our study as well. Initially *interest* was categorized as one affective response. However, to better understand what interactions and activities were eliciting higher levels of interest, we separated this category into high and low interest. High interest was categorized as engagement, body or vocal response (e.g., to music), turning body or move towards a person or object, as well as facial, motoric or verbal feedback to others. Low interest was categorized as eyes following an object, fixation on object or person, visual scanning, eye contact maintained, wide angle subtended by gaze, eating food routinely without enthusiasm, and a lack of affective response but levels of interest shown. Resting also added as a new category for periods of time when the observed client fell asleep, or shut their eyes for extended periods of time. The final adapted scales are presented in the figures below (see Figure 1 and Figure 2).

### **Research Team**

To establish inter-rater reliability, observers initially conducted observations in pairs. Observers included both undergraduate research assistants, as well as graduate student researchers (and initially, the principal investigator on the project). The research team would discuss any discrepancies or need for clarification at weekly research

Facility 1=SunT 2=CVADC 3=Other			Order of Observations for Today:			Date	Start	End	RA	
Client	Activity	Staff Interaction	Client Response							
			Pleasure	Interest		Content	Anxiety	Sad	Anger	Resting
				Low	High					
	Structure 1= Un 2=Semi 3= <b>Struc</b>	+ Social <small>#staff: 0=Client 0=Other Us/Volunteer</small>								
		+ Care								
		+ Activity Assistance								
	#staff/ volunteer	Neutral								
		- Protective								
		- Restrictive								
	#client	NO INTERACTION								
Client	Activity	Staff Interaction	Client Response							
			Pleasure	Interest		Content	Anxiety	Sad	Anger	Resting
				Low	High					
	Structure 1= Un 2=Semi 3= <b>Struc</b>	+ Social <small>#staff: 0=Client 0=Other Us/Volunteer</small>								
		+ Care								
		+ Activity Assistance								
	#staff/ volunteer	Neutral								
		- Protective								
		- Restrictive								
	#client	NO INTERACTION								
<p>What were the negative behaviors observed?</p> <p>How long did they last (minutes)</p> <p>How was the behavior <u>resolved</u></p> <p>Notes on the Activity</p> <p>Other notes:</p>										

Figure 1: Objective rating sheet.

Facility	Date	Start time	End Time	RA
		Reasons why it wasn't lower	Reasons why it wasn't higher	Key words/Anchors for this rating
<b>Staff Interactions</b>				
1 2 3 4 5 6 7				
<b>Activity 1</b>				
What was the activity:				
(rate each one separately)				
1 2 3 4 5 6 7				
<b>Activity 2</b>				
What was the activity:				
1 2 3 4 5 6 7				
<b>Physical environment</b>				
1 2 3 4 5 6 7				
<b>Client Autonomy</b>				
1 2 3 4 5 6 7				
<b>Person centered care</b>				
1 2 3 4 5 6 7				

Figure 2: Subjective rating sheet.

meetings. The observations continued in pairs until establishing high inter-rater reliability ( $k = .808$ ); after which observers began collecting data independently. Graduate researchers and the principal investigator were responsible for training undergraduate researchers as they joined the team. After completing CITI's human subject research certification, researchers were trained in the field for data collection on this study. The training was done by pairing with experienced graduate student researchers with and shadowing data collection. When the observations from the experienced researcher and the individual being trained were consistent, they could begin collecting data on their own.

At the end of the data collection process inter-rater reliability was checked again by having raters work together in pairs, once again, to establish if interrater reliability "drift" had occurred. The Kappa at the end of the study suggested that reliability was maintained over the study (kappa scores on the final 10% of the data averaged .851). To gain a better understanding of the impact activities had on interactions and affect, observers targeted a variety of observation times throughout the day. Observations were conducted during activities, mealtimes, and unstructured periods. Completed assessments were immediately brought to a locked research office, where they were kept in a locked filing cabinet, to ensure confidentiality.

### **Data Collection**

Observations were conducted in 15 minute increments. Prior to beginning the observation, researchers recorded the current activity taking place, staff to client ratios,

and date/time/order of observation for the day. The observer selected two consented clients that were present in the common areas, and recorded the affective response and concurrent staff interaction every minute for each client. The data collection sheet (see Figure 1) also included a section to collect notes on the activity, disruptive behaviors, how the behaviors were resolved, and a general note section. When the 15-minute observation was completed, researchers stepped away from the observation area, and completed an open ended response/field note section on the back side of the data collection sheet (see Figure 2). This included a section where researchers rated a number of factors on a 1-7 scale, and then provided their rationale. Environmental factors, activity, person centered care, and staff interactions were all evaluated in this method. Observers were not required to fill out all fields on this field note section; they included notes and ratings as they felt were relevant to the observed timeframe.

### **Analyses**

Before analysis could begin the data needed to be reconstructed into variables appropriate to address the research questions. The first step was to categorize the activities observed into different “activity type” groups. These groups were created based on the literature review and the activities observed throughout data collection. The activity type variable included 11 categories, also defined as to whether or not they were unstructured, semistructured, or structured activities. *No activity* was the only unstructured category. Semistructured activity types included movies, activity centers which included domino games and sensory quilts, and staff initiated activities which included snack time or a trip out to the garden. Structured activities included those that

were organized, prescheduled, and/or on the calendar, including presentations, music therapy, music or dance performance, motor activity, art/crafts, and structured meal time.

### **RQ1**

The next step was categorizing the variables from the modified ARS into three categories: positive affect, neutral affect, and negative affect. Positive affect included pleasure and high interest. Neutral affect included low interest, content, and resting. Anger, anxiety, and sadness were grouped together as negative affect. Total minutes during the observed period for each individual were summed for each of the affect groups. If cell sizes for negative affect were determined to be small (i.e., very few occurrences of negative client behavior), the negative and neutral affect categories would be collapsed together, such that there would be only two categories: *positive* affect and *negative/neutral* affect.

### **RQ2**

Staff interactions (from the modified QUIS) were also categorized in similar ways; as either positive, negative, or neutral/no interaction. Positive included positive social, positive care, and activity assistance. Negative encompassed negative protective and negative restrictive. Both *neutral* interactions and no interactions were combined as well. Total number of minutes were summed for each of the three staff categories. If cell sizes for negative interactions were determined to be small (i.e., very few occurrences of negative staff these types of interactions), the negative and neutral/no interaction categories would be collapsed together, such that there would be only two categories: *positive* interactions and *negative/neutral/no* interactions. The dataset was restructured

into a “stacked” format such that each row indicated a minute of observation. The minute/row included the client, the activity, and during that minute whether the affect was positive/negative/neutral and whether the staff interaction was positive/negative/neutral or no interaction.

Descriptive statistics and *Z* scores for proportions were computed to better understand how different activity types are more or less likely to elicit varying levels of positive, neutral, and negative affect in persons with dementia. This analyses assessed how different activity structures, and activity types, are associated with proportions of positive, neutral, and negative affect. The same descriptive statistical procedures were used to assess how proportions of staff interaction types differed by different activity types.

### **RQ3**

The final research question involved defining quality in activities and creating a scale of 1-7. Analyses for this research question came from incorporating qualitative field notes of activity descriptions, qualitative and quantitative data from the Subjective Rating Sheet (SRS; Figure 2), as well as other general descriptive for the activity. Qualitative analyses were conducted using immersion/crystallization (Miller & Crabtree, 1994), which involves a review of the qualitative data (field notes), and constructing themes based on the review. After the common themes have been formed, the notes are sorted into the categories or themes. As notes are being sorted themes may be altered, expanded, or subthemes may be created to accurately categorize the notes. Once qualitative analyses were completed, I used these data to create an overall definition of the themes

and characteristics included in high quality activities, and from there I used the field note language and SRS ratings to create the 1-7 scale of quality activity.



## CHAPTER IV

### RESULTS

#### General Results on Observations

In total, 527 sessions were observed. The vast majority (409; 77.6%) of these sessions were 15 minutes in length, and the remaining 118 sessions (22.4%) were less than 15 minutes, due to the observed clients leaving the area of observation. This yielded a total of 6,999 minutes of observation. While 22 clients were included in the observations, they did not contribute equivalent proportions of data. In total, 22 clients were observed for the purpose of this study; 10 males and 12 females. However, data was not collected evenly on the sample due to health and activity participation of individuals. For example, two clients were only observed for only one session (they passed away shortly after being consented for the study). The person contributing the most data was observed for 104 sessions (1,560 minutes). The five most observed clients comprised 65.7% of the minutes of observation.

#### Activity Types and Observed Affect in Persons with Dementia

My first research question involved determining if activity types are related to the proportion of positive, negative, and neutral affect in the person with dementia. Of all minutes observed (regardless of activity type), the occurrence of negative affect was low ( $n = 152$ ; 2.17%). Therefore, I elected to collapse the negative affect category in with the neutral affect category for activity comparisons. This yielded a total of 3,120 minutes

observed of positive affect (44.6% of all minutes observed) and 3,879 minutes of neutral/negative affect (55.4% of all minutes observed).

I first compared activities from a more macroperspective – comparing the proportion of positive affect that occurred during structured, semistructured, and unstructured activities. The total number of minutes observed in semistructured activities was 1,298 minutes (18.5% of all minutes observed). Positive affect occurred during 602 of these minutes (46.4% of semistructured). Total number of minutes spent in unstructured activities (i.e. the ‘no activities’ category) was 2,169 (31.0% of all minutes observed), and positive affect was observed during 703 of these minutes (32.4% of unstructured). *Z* tests indicated that clients showed proportionally higher levels of positive affect during semistructured activities, compared to unstructured activities ( $z = -8.22, p < .001$ ). Structured activities were observed for a total of 3,532 minutes (50.5% of all minutes observed), with positive affect in clients occurring for 1,815 of those structured minutes (51.4% of structured). *Z* tests indicated that clients also showed proportionally higher levels of positive affect during structured activities, compared to unstructured activities ( $z = -14.01, p < .001$ ). When comparing semistructured and structured activities, *z* tests indicated that clients showed proportionally higher levels of positive affect during structured activities, compared to semistructured activities ( $z = -3.09, p < .001$ ).

I next conducted a more microlevel comparison of activities. As shown in Figure 3, out of the 2,169 minutes where no activity observed, 703 minutes had concurrent positive affect in the client (32.4%). Activities such as music therapy, motor activities, and cognitive activities showed much higher levels of positive affect with percentages of

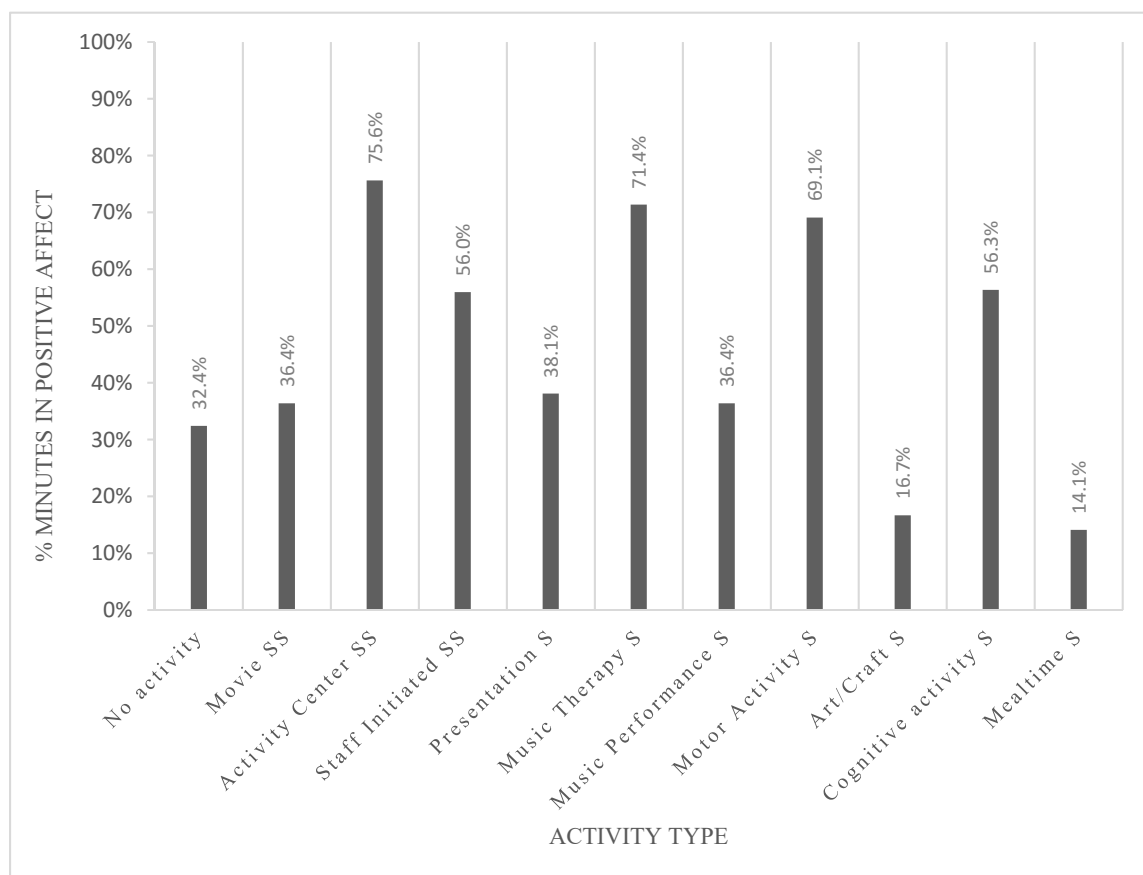


Figure 3: Percentage of minutes of positive affect based on activity type.

Note: SS indicates that this was a semistructured activity. S indicates that this was a structured activity.

positive affect ranging from 56% to 75.6% of total minutes observed during those activities.

To compare these activity types, first a chi-square analysis was done with the 11 different activity types, computing the percentages of time clients were observed eliciting positive versus neutral/negative affect. The chi square was statistically significant,  $\chi^2(10, N = 6999) = 1082.76, p < .001$ , indicating that overall, activities differed in their proportion of positive versus neutral/negative affect in the clients. Next, separate  $z$  scores were calculated comparing the 10 activity categories against the no activity category.

Table 2 shows the number of minutes (and percentages) of positive affect and negative/neutral affect for each activity, and the  $z$  scores and  $p$ -values resulting from comparisons with the no activity category. There were several activity types that indicated statistically significant  $z$  scores. The activity type that had the highest  $z$  score difference in positive affect (compared to no activity) was music therapy ( $z = -23.43, p < .001$ ). The activity with the next highest  $z$  score difference with no activity was motor activity ( $z = -13.67, p < .001$ ) followed by activity centers ( $z = -12.31, p < .001$ ), structured mealtimes ( $z = 9.41, p < .001$ ), staff initiated activities ( $z = -7.42, p < .001$ ), cognitive activities ( $z = -4.21, p < .001$ ), presentations ( $z = -2.63, p < .01$ ) and movies ( $z = -2.07, p < .05$ ). I note that mealtimes yielded a positive  $z$  score, indicating that positive affect was statistically lower during mealtimes than during no activities. All for all other categories, the negative  $z$  score indicates that positive affect occurred more often during these activities than during no activity. Categories of activities where proportion of positive affect was not different (statistically significant) from no activity were music or dance performances ( $z = -1.07, p = .28$ ) and art and craft activities ( $z = 1.83, p = .07$ ).

### **Activity Types and Observed Staff Interactions**

To address my second research question and analyze staff interactions during different activity types I began with a macrolevel analysis. Staff interactions were categorized as positive, neutral, and negative. Of the total minutes observed (6,999) a small percentage was considered negative (0.8%). Therefore, the neutral and negative interaction categories were collapsed together. Overall, the total number of minutes of positive staff interactions was 1,266 (18.1% of observations) and of neutral/negative

Table 2

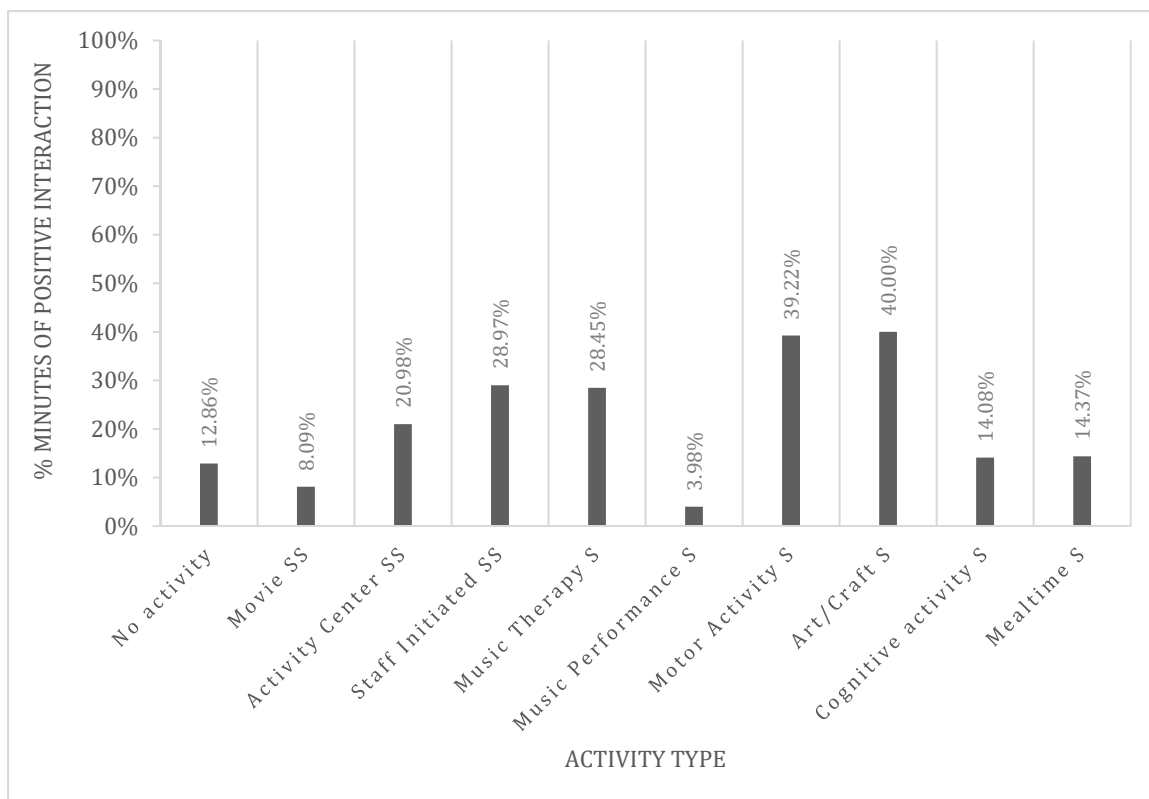
*Proportional Differences for Positive and Neutral/Negative Affect in Person with Dementia by Activity Type: z Score Comparisons with Positive Affect During No Activity*

Variable	Neutral/negative		z score	p value
	Positive Affect	Affect		
	Minutes (% minutes within activity)		Comparing proportion of positive affect with <i>no activity</i> category	
No activity	703 <sub>a</sub> (32.4%)	1466 <sub>b</sub> (67.6%)	-	-
Movie <sup>ss</sup>	306 <sub>a</sub> (36.4%)	535 <sub>b</sub> (63.6%)	-2.07	.04*
Activity center <sup>ss</sup>	155 <sub>a</sub> (75.6%)	50 <sub>b</sub> (24.4%)	-12.31	<.001**
Staff initiated <sup>ss</sup>	141 <sub>a</sub> (56%)	111 <sub>b</sub> (44%)	-7.42	<.001**
Presentation <sup>s</sup>	235 <sub>a</sub> (38.1%)	382 <sub>b</sub> (61.9%)	-2.63	.01*
Music therapy <sup>s</sup>	1106 <sub>a</sub> (71.4%)	444 <sub>b</sub> (28.6%)	-23.43	<.001**
Music performance <sup>s</sup>	64 <sub>a</sub> (36.4%)	112 <sub>b</sub> (63.6%)	-1.07	.28
Motor activity <sup>s</sup>	266 <sub>a</sub> (69.1%)	119 <sub>b</sub> (30.9%)	-13.67	<.001**
Art/craft <sup>s</sup>	5 <sub>a</sub> (16.7%)	25 <sub>b</sub> (83.3%)	1.83	.07
Cognitive activity <sup>s</sup>	40 <sub>a</sub> (56.3%)	31 <sub>b</sub> (43.7%)	-4.21	<.001**
Mealtime <sup>s</sup>	99 <sub>a</sub> (14.1%)	604 <sub>b</sub> (85.9%)	9.41	<.001**

*Notes:* <sup>ss</sup> indicates that this was considered a semistructured activity. <sup>s</sup> indicates that is was considered a structured activity. \*p < .05, \*\*p < .001 <sub>a</sub> and <sub>b</sub> indicate whether proportions of positive and neutral/negative staff interaction within that activity were statistically different from each other at a level of p < .05. That is, the <sub>aa</sub> combination indicates that proportion of positive affect was not different (statistically significant) from the proportion of neutral/negative affect within that specific activity, whereas the <sub>ab</sub> combination indicates that proportion of positive affect was different (statistically significant) from the proportion of neutral/negative affect within that specific activity.

interactions was 5,733 (81.9%). Figure 4 below shows the percentage of positive interaction based on each activity type.

Z scores were calculated to compare the proportion of time where positive interactions occurred, across (1) no activity and semistructured activities, (2) no activities



*Figure 4: Percentage of minutes where positive staff interactions were observed based on activity type.*

*Note:* SS indicates that this was a semistructured activity. S indicates that this was a structured activity.

and structured activities, and (3) semistructured and structured activities. The proportion of positive affect occurring during semistructured activities and no activity were significantly different ( $z = -10.30, p < .001$ ), as was the proportion of positive affect occurring during structured activities compared to no activity ( $z = -9.23, p < .001$ ). When comparing semistructured and structured activities, it was found that that structured activities had proportionally more positive staff interactions ( $z = 4.17, p < .001$ ).

To study activities and staff interaction on a microlevel, I began by conducting a chi square analysis on the activity types and whether positive or neutral/negative interaction from staff and researchers were different across the 11 activity types. The chi-square was statistically significant  $\chi^2(10, N = 6999) = 397.403, p < .001$ . This indicated that overall, activities differed in their proportion of positive vs neutral/negative staff interactions. Z scores were also calculated to further evaluate which activities yielded proportionally higher positive interactions. All activity types were compared against the no activity category, and the results of both minutes and percentages are shown in Table 3 below. Motor activities showed the most proportional difference from no activity in terms of the positive staff interactions ( $z = -12.74, p < .001$ ), followed by music therapy ( $z = -11.86, p < .001$ ), staff initiated activities ( $z = -6.87, p < .001$ ), art and craft activities ( $z = -4.36, p < .001$ ), movies ( $z = 3.68, p < .001$ ), music performances ( $z = 3.33, p < .001$ ), and activity center ( $z = -3.24, p < .001$ ). Some activities showed no statistical difference in proportion of positive staff interactions compared to the no activity category: presentations ( $z = -0.17, p = .87$ ), cognitive activities ( $z = -0.30, p = .76$ ) and mealtimes ( $z = -1.02, p = .31$ ).

### **Qualitative Analysis and Immersion/Crystallization: Defining Quality in Activities in Dementia Care Units**

Before data analysis began on the qualitative data, it was reviewed and all field notes discussing activities were marked, and separated from the rest. The analysis done was only on those notes pertaining to activities. The first step in the qualitative analysis is

Table 3

*Proportional Differences for Positive and Neutral/Negative Staff Interactions by Activity**Type: z Score Comparisons with Positive Interactions During No Activity*

	Positive Staff Interaction	Neutral/Negative Staff Interaction	z score	p value
	Minutes (% minutes within activity)		Comparing proportion of positive interactions with <i>no</i> <i>activity</i> category	
No activity	279 <sub>a</sub> (12.9%)	1890 <sub>b</sub> (87.1%)	-	-
Movie <sup>ss</sup>	68 <sub>a</sub> (8.1%)	773 <sub>b</sub> (91.9%)	3.68	<.001**
Activity center <sup>ss</sup>	43 <sub>a</sub> (21%)	162 <sub>a</sub> (79%)	-3.24	<.001**
Staff initiated <sup>ss</sup>	73 <sub>a</sub> (29%)	179 <sub>b</sub> (71%)	-6.87	<.001**
Presentation <sup>s</sup>	81 <sub>a</sub> (13.1%)	536 <sub>b</sub> (86.9%)	-0.17	.87
Music therapy <sup>s</sup>	441 <sub>a</sub> (28.5%)	1109 <sub>b</sub> (71.5%)	-11.86	<.001**
Music performance <sup>s</sup>	7 <sub>a</sub> (4%)	169 <sub>b</sub> (96%)	3.33	<.001**
Motor activity <sup>s</sup>	151 <sub>a</sub> (39.2%)	234 (60.8%)	-12.74	<.001**
Art/craft <sup>s</sup>	12 <sub>a</sub> (40%)	18 <sub>b</sub> (60%)	-4.36	<.001**
Cognitive activity <sup>s</sup>	10 <sub>a</sub> (14.1%)	61 <sub>a</sub> (85.9%)	-0.30	.76
Mealtime <sup>s</sup>	101 <sub>a</sub> (1.4%)	602 <sub>b</sub> (85.6%)	-1.02	.31

*Notes:* <sup>ss</sup> indicates that this was considered a semistructured activity. <sup>s</sup> indicates that it was considered a structured activity. \* $p < .05$ , \*\* $p < .001$  <sub>a</sub> and <sub>b</sub> indicate whether proportions of positive and neutral/negative staff interaction *within that activity* were statistically different from each other at a level of  $p < .05$ . That is, the <sub>a a</sub> combination indicates that proportion of positive affect was not different (statistically significant) from the proportion of neutral/negative affect within that specific activity, whereas the <sub>a b</sub> combination indicates that proportion of positive affect was different (statistically significant) from the proportion of neutral/negative affect within that specific activity.

to review the qualitative data and identify main themes. After this initial review, my themes that emerged were environment, staff ratio, staff adequacy, engagement of client, and meeting clients wants. While themes were developed, field notes were sorted into the different themes: this process is referred to as immersion/crystallization. Throughout the



sorting process, if field notes didn't seem to fit in an existing theme, themes were altered or expanded to make sure notes had a place. As the field notes were sorted, it became apparent that even though we were not sorting based on the SRS data collection (SRS qualitative data and field notes were combined for this review) the themes that were emerging were similar to the areas that were targeted for the SRS. Five themes emerged from this process.

### **Environment**

Environmental factors were a specific area on the SRS, and were confirmed as a theme when evaluating the activity field notes and SRS responses. Often the environment added to the effectiveness of the activity, for example, "Outside activity on a nice, sunny day. Clients seemed to enjoy the fresh air." Some notes mentioned environment factors facilitating interaction with clients; "Seating was good for clients to interact." While others drew attention to how poor environment may make activities difficult for an individual to enjoy the activity or gain anything positive from it, where they may have if the environment was different. The following shows an example of this scenario: "Those in front are participating, but those in back were sleeping & disengaged."

### **Staff Ratio**

On each observation, the staff ratio was collected at quantitative data. However, staff ratios were frequently mentioned in field notes discussing activities as well. It seems that having an adequate number of staff is necessary to make any activity function. If there is a low number of staff, it can be difficult for staff to keep clients engaged, or even present at the activity: "Because of the low staff-client ratio, when memory care clients

tried to leave the room staff yelled across the room for them to come back.” When there are fewer clients per staff member, it allows for staff to interact more frequently with clients, and may decrease the stress of staff, possibly increasing the warmth of interactions, for example, “Staff interacted with all of the clients. Wonderful ratio - warmth and patience in every interaction and all clients seemed to feel valued.” There were times when there were fewer staff, but the staff was still focused on trying to engage with clients. The field note shows that it was something they had to work to try and interact with all clients in these circumstances, “Ratio was low with only two staff members. But the staff were very engaging and tried to engage all clients.”

### **Staff Interaction and Communication**

After further review of notes that were originally classified as staff ratio, an additional theme emerged: Staff Interaction and Communication. In other words, there were notes that went into detail far more than adequate or inadequate staff ratios, specifically this category contained notes that were specific to interactions with staff during activities. For example: “Staff approached with soft touch. Lots of interaction.” Other examples showed how the interaction from a staff could diminish the impact of activities and social interactions may have on QoL, possibly through lack of communication. “Clients were not asked if they wanted to play a bell, they were just placed upon them. Music therapists didn't ask clients before drawing on their hands.”; “Staff talked about clients as if they weren't there. Staff not really paying attention to the clients they were helping.”

## **Engagement of Clients**

The way activities impact quality of life is not only through the social interaction that activities provide, but through the engagement of the activity itself. Field notes suggested that activities that engaged the clients, or had high levels of interest or participation, were perceived as positive by the observers and seemed to have positive affective responses from clients. Depending on a client's ability, different activities may be engaging in different ways, but the opportunity for a client to engage and staff assisting is important to the quality of activity, for example, "The activity allowed everyone to participate. All clients seemed to enjoy playing dominoes, whether they were setting it up, stacking, or just observing." When activities are not planned with the client's level of engagement in mind, it may bore the clients and not have the positive benefit one would hope for in activities. Some field notes stated that activities were boring to clients, that there were too many participants and limited opportunities for the clients to participate and be engaged.

## **Respect/Attention to the Individual**

In the field of dementia care there is an emphasis on person centered care, which includes respecting an individual's wishes. Respecting client wishes is also a facet of the definition of quality activity that was represented in our observations. Field notes suggested that when client's autonomy was not respected, anxiety in the person with dementia was observed: "Clients were showing anxiety and making requests that were recognized but ignored; it was clear clients were not enjoying the activity, and yet staff did not meet their interests". There were times when clients were given choices, such as

choosing what keychain they wanted, and the clients seemed to appreciate the choices presented to them.

### **Defining Quality Activity**

The next step in field note analysis involves a detailed review of the content within each theme. After each theme had been defined, an extensive review of the notes was conducted to address research question three. The detailed notes from this analysis lead to the defining characteristics of a high quality activity. Each theme became an element to the finalized definition of quality activity, and a subscore for quality activity as shown in table 4 below.

A quality activity is conducted in an environment that allows for clients to see and engage in the activity taking place, but also be free to leave the area or move about if they are able to, and/or desire to do so. Quality activities include an appropriate number or ratio of trained staff to facilitate participation and interaction with clients. Staff should communicate with clients using warmth, and consideration of the clients' autonomy, for example by asking permission before assuming the client wants to participate in a task. Staff should not communicate with others in a negative way in the presence of clients, and should seek to include clients in their conversations where possible. Staff should use the affect and interest in the clients to evaluate clients' levels of engagement, and adjust the activities to the individual interests and abilities of the clients.

Once the defining characteristics of a high quality activity were defined, the Quality Activity for Persons with Dementia Scale was developed and is presented in Tables 4-9 in appendices. Each defining characteristic served as the basis for an item,

where low, moderate, and high anchors are provided to help evaluators give a score from 1-7 on the quality of the component of an activity. An average of the 5 subscores served as the overall Quality Score for an activity.

## CHAPTER V

### DISCUSSION

This study observed clients engaging in various structured, semistructured, and unstructured activities in a dementia care unit. Observers coded client affect and staff interactions during these activities. The study found that different activities elicited different affective responses in people with dementia and different proportions of positive staff interactions. On a macrolevel, structured activities, which are those that are organized, prescheduled, and/or on the calendar, and semistructured activities, which were those activities that were made available to clients, but not necessarily organized a priori, such as movies, activities left out for clients, or impromptu snacks or a trips to the garden, were both found to result in more positive client affect and more positive staff interactions than unstructured time (where there were no specific activities occurring). Structured activities also had higher proportions of positive affect and positive staff than semistructured activities.

These findings are promising, suggesting that when an activity is developed intentionally, as structured activities are, they are likely developed with the purpose of engaging clients in one way or another, and staff are aware that their purpose is to interact with clients. These findings also suggest that even having activities available to clients and/or having staff initiate impromptu activities (semistructured activities), is more likely to yield positive interactions and client affect as compared to doing, or having nothing, at all.

Microlevel analyses of the 11 activity types revealed that certain activities were more likely to yield higher proportions of positive affect and positive interactions. A similar study done by Wenborn et al. (2013) found similar results showing that activities on dementia care units can increase quality of life. Researchers found that with statistically significant differences in staff interactions, the positive impact on quality of life decreased. Music therapy and motor activities were the two activities that yielded the highest proportions of positive affect and positive interactions, and these activities also had the largest differences in positive affect and positive interactions compared to no activity. Music therapy activities engage clients in many different ways. Clients are experiencing a cognitive stimulation from music, often paired with the physical movement involved in swaying to a rhythm, using an instrument, clapping hands, and so forth. The majority of music therapy that we observed had a high staff to client ratio. Ratios like this allowed for much one-on-one interaction. Field notes supported this as high quality activity, with notes such as “Staff included everyone and helped them play music, ratio of 3 staff to 8 clients.”

Motor activities are another set of activities where clients are being engaged beyond just visual stimulation. Clients are encouraged to participate with movement as well as cognitive interaction. These findings support previous dementia research recognizing the importance of motor stimulation in increasing positive affective response (Cruz, Marques, Barbosa, Figueiredo, & Sousa, 2013). The field notes and qualitative review on motor activities suggested specific ways in which these were particularly effective. For example, one note mentioned the importance of having activities that were adaptable to the client’s needs and abilities, by describing an activity where staff played

volleyball with the clients, but used a balloon instead of a volleyball so more clients could participate.

Activity Center activities are an example of an activity type that yielded high proportions of positive affect, but low proportions of positive staff interactions. One field note indicates that having activity centers available may increase interest in clients without the assistance of staff interaction, for example: “A client sitting at dining room table playing with a wooden puzzle.” Recognizing that there will be times in a care facility when staff ratios are low, these kinds of activities may be a way to engage clients and maintain high levels of affect, even without the presence of positive staff interactions.

Movies are an example of an activity that did little to engage the person with dementia, and seemed to illicit little/no staff interaction. While clients elicited statistically significantly more positive affect during movies than during no activity, there was actually a lower proportion of positive staff interactions during movies as compared to no activity. Field notes discussing movies often mention a high number of clients that were sleeping, and or other sensory problems, such as the volume being too low to be heard, or occasionally too high for staff to hear clients requests.

Mealtimes were a time when there were more neutral/negative affect observed, as compared to no activity (positive staff interactions did not differ statistically from no activity). Similar to the findings of Wenborn et al. (2013), when there were low levels of staff interaction the impact of activities was diminished. Thus, while one could argue that meals simply aren't like other activities because they aren't necessarily designed for leisure time, our field notes suggest that this might not be the reason why affect and



interactions were not more positive. Field notes during mealtimes described staff talking with other staff and not engaging with clients, and having a room arrangement where all the individuals needing assistance were sitting with each other, concentrating staff on one side of the room. For example, one field note states, “Staff feeding many clients at once, moving quickly. Saw a client shake her head no, and staff fed her the bite anyway. Feeding over shoulder. Staff was rushing when feeding clients.” There may be ways to improve affect and interactions during mealtimes to increase levels of interaction and affect. Nijs, de Graaf, Kok, and van Staveren (2006) suggested that structuring mealtime in dementia care units around family mealtimes (explained as mealtimes structured to reflect a home-like atmosphere, with the environment and interactions similar to one an individual may see in a home setting) may decrease the decline of quality of life. They suggested that mealtimes that are done in stimulating and engaging environments are better at maintaining quality of life in persons with dementia. Another field note from the current study states, “Lunchtime staff walked around and passed out meals; a client showed interest during positive care. A client is being read to by a volunteer while eating lunch. Seems interested but has to focus on eating while listening.” This field note supports the claim that when there is more interaction occurring during mealtimes, the clients may respond with more interest and more positive affect.

### **Defining Characteristics of Quality Interactions: Creating a Quality Scale**

A second aim of this study was to define the characteristics of quality activity by analyzing field notes to create a 7-point quality scale. During the review of the field notes and data analysis, I identified the following themes: environment, staff ratio, staff

interaction/communication, engagement, and individual interests. High quality activities included: environments adding to comfort and engagement of clients, staff ratios that increased interaction and availability of assistance, staff interactions that were warm and considerate of the individual, engaging to the person with dementia, and adaptable to the individuals' preferences and abilities.

Room temperature, room cleanliness, and volume of background music or movies was frequently referenced in the field note section. These environmental factors and many others played a role in the quality of activities on the dementia care unit.

Researchers have stated the room setup and decorations may have a possible impact on improving dementia care (Mazzei, Gillan, & Cloutier, 2014). The setup of the activity, for example seating arrangement and where activity is occurring, plays a large role as well. During one activity, the field notes describe an activity that had clients on an outside patio, circled around an activity with colored balloons popping on the ground. The proximity to the activity caused clients anxiety, and the setup of the group didn't allow for clients to leave early, because they would be tracking through the mess.

However, other field notes described scenarios where the environment added to the quality of activity: "Seating was good for clients to interact; those near the front are participating." Understanding that the temperature, cleanliness, seating arrangements, and other environmental factors plays an important role in the quality of activities may help staff to take these factors into consideration when planning an activity.

Field notes on staff/client ratios pointed to how these ratios can both add to or take away from the effectiveness of activities. When ratios were low, for example, 3 staff to 27 clients, the field notes stated, "low staff to client ratio, not enough one-on-one

interaction.” In another example, “Because of the low staff-client ratio (this activity was in the great room), when memory care clients tried to leave the room staff yelled across the room for them to come back. The low number of staff caused them to do ‘crowd control’ with clients trying to leave, rather than asking them what they needed and helping them resolve the concern.” In other words, it seems that no matter how adequately trained a staff is, there is only so much interaction that can occur with ratios that low. When the ratios are high, it seemed that the clients having the greatest interaction were the higher functioning clients. Of note, there were also discussion of times when ratios were low, but staff did what they could to include other clients “Ratio was low with only 2 staff members, but they were very engaging and tried to engage all the clients.” This is why staff ratio alone, cannot determine the effectiveness of an activity. Ultimately, even in low staff/client scenarios, the engagement of the clients with the staff and with the activity, can foster positive affect in the client.

While the number of staff at an activity is a critical component, having staff interactions with clients be characterized as warm, respectful, and considerate is essential as well. The interactions during activities are seen as an important part of QoL based on Brod et al. (1999), and important to a quality activity as seen in the results of this study described above. When staff was positively interacting with clients, observers took notes stating, “Staff aware of each client, engaged clients, complimented them, made sure they were comfortable.” However, not all interactions observed had the warm or considerate component. One example of an interaction lacking the warmth, respect, and consideration was, “Staff laughed at clients. They also talked loudly to each other across the room, excluding clients. Staff didn't engage and cue, or acknowledge all clients. Lots of clients

were handed scarves and instruments w/ no verbal explanation. No choices given.”

Although warmth, respect, and consideration may not be part of the physical care that staff is trained to provide, it is important to have these characteristics present in staff to client interactions.

Two areas where staff members can make a conscious effort to improve activities and interactions with clients is both through engagement opportunities, and recognizing individual interests and making accommodations based on preferences and abilities of the individual. A study done by Gitlin and colleagues (2009) showed that when activities are individually tailored, caregivers see a decrease in behavioral symptoms. With the staff ratio on dementia care units it may be difficult to have individually tailored activities, however staff members can facilitate in making activities more engaging based on individual interests and abilities. One example of this in the field notes states “Staff was engaged with presenter and pulled clients into verbal interactions. All of the clients participated with questions or jokes.” Although the results showed that presentations had fewer positive affective responses and fewer positive staff interactions, this is an example of a time where the staff recognized the need for interaction and engaged clients. Being aware of the engagement level of clients facilitates in adjusting activities to individual interests and abilities as well. When staff recognized clients were bored or unable to participate, many times staff took steps to adapt the activity to make clients feel involved: “Staff acknowledged requests by clients to go outside rather than staying at the activity. Staff took them outside individually for walks.”

Overall the five themes I identified in the analysis of field notes indicate areas where activities can be evaluated, and hopefully, improved. The five areas listed above

have been integrated into a single scale (the Quality Activity for Persons with Dementia Scale) developed in this study. This scale and its subscales require further testing across multiple days, and multiple facilities, but should it yield positive psychometric properties, it may help establish a standard for activities on dementia care units, and eventually help provide feedback for ways to improve quality of activities.

### **Limitations**

The goal of the broader Quality of Life in Memory Care Settings Study is to gain a better understanding of dementia care, and provide guidelines and examples of quality within many different domains, only one of which is activities. Because the broader study did not utilize a research design that was specific only to assessment of activities, there were some limitations existent in the current design and analyses. The first is related to the number of observations collected on each activity type. Ideally a comparative study would have collected equal numbers of observation in each activity type for better comparison. However, in the current study, there is a wide range of observed minutes by activity. Music therapy was observed for 1,550 minutes, while arts and crafts was observed for 30 minutes. It is possible that the fairly low levels of interactions and affect observed during less observed categories, like arts and crafts, are not generalizable, and if researchers had been able to observe more within these activities, the results may have yielded different conclusions.

Similarly, the nature of the observations allowed us to observe clients who had consented and were present at activities or in the common areas. Some clients passed away throughout the months that data was being collected. These are two of the many

factors that led to data not being collected equally on all consented individuals. Some individuals contributed over 1,500 minutes of observations, and others as few as 15. An experimental research design that assigned individuals to participate equally in every activity type may have yielded more information on which activities “caused” more positive affect in clients. Using the current design we have to recognize that proportionally higher numbers of minutes contributed by certain individuals may have biased the results based on the characteristics of those individuals.

In addition, observations only occurred in one facility. It is possible that other facilities have different activities occurring, or see different levels of success within activities. At the facility observed in the current study, there were extremely low levels of negative staff interactions observed (0.8%). Perhaps the staff at the current facility has particularly well-trained staff, and that we might have seen more negative staff interactions at other facilities. We also recognize that staff are aware that they are being observed, and they may have biased their interactions to be more positive or more frequent during our periods of observation than they would have been had they not been observed.

Finally, Giebel et al. (2015) suggest that it is important to evaluate the stage of dementia when developing activities to ensure that the activities are doing all they can at preserving QoL in persons with dementia. Without HIPAA approval, we could not determine participant’s precise level of cognitive impairment, to see whether certain activities were more or less effective for individuals with differing levels of cognitive ability. While, by definition of living in the dementia unit, all residents are within at least a moderate-stage dementia or greater, including the cognitive ability in our participants

(e.g., late stage vs. moderate stage) as a comparative factor could have provided potentially helpful additional information. A common comorbidity of dementia is depression (Gutzmann & Qazi, 2015). However for this study mental health information was restricted by HIPAA regulations. This may also have helped address the issue of depression and anxiety and the impact it may have on quality of life and activities for persons with dementia.

### **Implications**

Based on the results of this study, it is recommended that dementia care units focus on training staff on appropriate interactions (what it means to have a positive interaction as opposed to negative restrictive or negative protective interaction), the importance of activities in eliciting positive affect and positive interactions, and adaptability of activities to meet clients' abilities and wants. After further examination of scale reliability and validity, the Quality Activity for Persons with Dementia Scale created from these analyses may become a tool that dementia care units (and researchers) can use to evaluate activities, and recognize areas of strengths and areas that may need improvements. By looking more at the aspects or features of these activities, we can start to see how characteristics define what is a quality activity, and make suggestions on improving activities overall, rather than suggesting different activity types as, by default being better or worse than one another. If a facility can evaluate interactions and affect during activities, they may be more sensitive to making adjustments in those activities – eliminating some that do not elicit positive affect in clients, and making adjustments to improve affect and interaction quality in those activities that they want to maintain.

The research collected throughout this study will be a great benefit to many families and individuals looking for care for loved ones. With increasing numbers of individuals developing dementia, providing families with an evaluation tool may help them select the best care facility for their loved ones. The decision to place a loved one in a dementia care unit can be a difficult decision for a caregiver (Hagen, 2001). A standardized measure of quality in dementia care activities may also be beneficial to residential care facilities not specific to dementia. In general, information about quality (in discretionary activities and beyond), will help families make informed decisions about the dementia care they chose for their loved ones.

### **Summary**

The results support prior research (Edvardsson et al., 2014) which states that participation in everyday activities is related to overall quality of life. Discretionary activities, well-being (positive affect) and positive interactions with others are all embedded within the Brod et al. (1999) definition of QoL, Participation in activities in and of itself, may not lead to significant improvements in QoL, however when these activities yield positive affect, paired with positive interactions, we are impacting three areas within Brod and colleagues QoL criteria, and therefore may be more likely to improve overall QoL. While we cannot cure Alzheimer's disease and other dementias, we can use research such as this to identify ways to maximize quality of life for those individuals living with it.



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**APPENDICES**

## APPENDIX A.

### Tables

Table 4

*Quality Activity for Persons with Dementia Scale*

Quality Activity for Persons With Dementia Scale								
Component of Quality Activity	Score 1-7							
Environment	1	2	3	4	5	6	7	
Ratio of Trained Staff to Client	1	2	3	4	5	6	7	
Staff Interaction and Communication	1	2	3	4	5	6	7	
Engagement of Clients	1	2	3	4	5	6	7	
Respect/Attention to Individual	1	2	3	4	5	6	7	
Total Score: Quality Activity for Persons with Dementia								
1	2	3	4	5	6	7		
Low Quality Activity		Moderate Quality Activity			High Quality Activity			

Table 5

*Anchors and Examples for the Item of 'Environment' for Quality Activity for Persons with Dementia Scale*

Environment	
Low (1-2)	Environment makes it difficult for clients to see or participate in the activity. Area is restricting and encloses clients within. Music too loud for conversation, or too quiet to be heard. Room temperature causing clients discomfort
Moderate (3-5)	The environment is not adding to the activity in anyway, but is not taking away from the quality. Clients are able to see some aspects of activity, but not all. Temperature fluctuates between comfort and discomfort.
High (6-7)	A quality activity is conducted in an environment that allows for clients to see and engage in the activity taking place, but also be free to leave the area or move about if they are able to, and desire to do so. If music is playing, it is at a comfortable volume not creating a distraction, and the temperature is comfortable for clients.

Environment subscore: \_\_\_\_\_

Table 6

*Anchors and Examples for the Item of 'Staff Ratio' for Quality Activity for Persons with Dementia Scale*

Staff Ratio	
Low (1-2)	Low quality activities do not have enough staff to assist clients with activities. Most clients go without interaction throughout the activity.
Moderate (3-5)	Activity has staff present, but more staff would increase the quality of activity by increasing the amount of interaction and assistance available to each client
High (6-7)	Quality activities include an appropriate number or ratio of trained staff to facilitate participation and interaction with clients.

Staff Ratio subscore: \_\_\_\_\_

Table 7

*Anchors and Examples for the Item of 'Staff Communication/Interaction' for Quality Activity for Persons with Dementia Scale*

Staff Communication/ Interaction	
Low (1-2)	Staff communication lacks warmth and consideration of the clients' autonomy. Assumes clients desire to participate, and doesn't provide options. Staff speaks negatively around clients, and excludes them from conversation, limiting the amount of social interaction a client has.
Moderate (3-5)	Staff communication has moments of warmth, and moments lacking warmth. Clients may or may not be included in conversations, and staff isn't consistently aware of keeping comments and conversations positive, but overall avoid negative statements.
High (6-7)	Staff communicates with clients using warmth, and consideration of the clients' autonomy, for example by asking permission before assuming the client wants to participate in a task. Staff does not communicate with others in a negative way in the presence of clients, and seeks to include clients in their conversations where possible.

Staff Communication/ Interaction subscore: \_\_\_\_\_



Table 8

*Anchors and Examples for the Item of 'Engagement' for Quality Activity for Persons with Dementia Scale*

Engagement	
Low (1-2)	Clients are not engaged with activity. Little to no participation, clients are sleeping or appear bored with activity.
Moderate (3-5)	Activity is engaging to some clients. There are moments where clients are engaged, and moments where they are uninterested or asleep. Does not stand out as an engaging activity.
High (6-7)	Clients seem highly engaged in activity. Clients are participating and showing positive affective responses. Staff uses the affect and interest in the clients to evaluate clients' levels of engagement.

Engagement subscore: \_\_\_\_\_

Table 9

*Anchors and Examples for the Item of 'Individual Interest' for Quality Activity for Persons with Dementia Scale*

Individual Interests	
Low (1-2)	Activity designed with specific purpose of staff, and unable to adjust to individual client preference or ability. Staff unaware of needed adjustments to increase individual clients experience in the activity.
Moderate (3-5)	Activity has some opportunity for individual adjustment. Staff attempts to understand aspects to improve the individual experience, but does not go out of their way to accommodate.
High (6-7)	Staff able to, and wiling to adjust the activities to the individual interests and abilities of the clients. Activity allows for adaptability to clients of many different cognitive and physical level have opportunity to participate. Activity provides choices and opportunity for individual expression.

Individual Interests subscore: \_\_\_\_\_