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Choice and Quality of Life in Caregivers of Individuals with Dementia

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### Abstract

The purpose of this study was to investigate the relationship and difference between choice, quality of life, and perception of level of dementia among caregivers of individuals with dementia living in the community. Implications on the field of occupational therapy were explored. This study is an extension of the Vohnout (2011) study, expanded to the population of caregivers of individuals with dementia.

One thousand surveys were distributed to caregivers of individuals with dementia living in the northwest Ohio region. The survey contained a demographic questionnaire, the Duncan Choice Index: Self-Care and Leisure (DCI) (Duncan, 1998), and the Quality of Life Rating (QOLR) (Gust, 1982). There were 292 surveys returned providing an initial response rate of 30%. Of the 292 surveys, 171 met all criteria to participate in the study. The study found a statistically significant positive correlation between the caregivers' perception of the amount of choice their daily life and their quality of life ( $r_s = .53, p < .001$ ), indicating that the more choice caregivers perceive, the higher quality of life. Significant differences were found between the three levels of dementia and the total choice perceived by caregivers ( $\chi^2 = 6.099, p < .05$ ), as well as in the total quality of life ( $\chi^2 = 8.324, p < .02$ ). The more severe the level of dementia, the lower the amount of daily choice and quality of life were rated by caregivers.

These results suggest that occupational therapy as a profession needs to advocate for caregivers of individuals with dementia to have support and strategies which enable greater choice in daily life. Additionally, occupational therapy practitioners must seek to improve the

quality of life for caregivers of individuals with dementia through providing education and planning appropriate for each level of dementia.

### Choice and Quality of Life in Caregivers of Individuals with Dementia

Researchers increasingly study the physical and emotional well-being of caregivers. Caregivers of older adults with disabilities have compromised physical health, leading to increased mortality (Schultz & Beach, 1999). In particular, caregivers of individuals with dementia have been suggested to have a greater caregiver burden than those of individuals with an otherwise specified disability (Ory et al., 1999). The number of Americans living with Alzheimer's disease is expected to increase from an estimated 5.3 million in 2008 to 13.2 million by 2050, and nearly 10 million caregivers will be unpaid lay workers, most commonly family members (Alzheimer's Association, 2009). If caregivers are not well, the ability to care for the individuals with dementia may accordingly decline. Occupational therapy may assist in providing support and strategies to the caregiver to facilitate care of the individual with dementia while protecting the health of the caregiver as well. There is limited research on the relationship between choice and quality of life for caregivers of those with dementia, and how that quality of life may vary depending on the perceived severity of the dementia. Before the current study is discussed, literature will be reviewed on choice, quality of life, and the implications upon caregivers of individuals with dementia. Further, the role of occupational therapy in offering supportive interventions that support choice and quality of life for the caregiver and the individual with dementia will be explored. The current study will then be introduced.

### **Choice in Occupational Therapy**

Founders and contributors to the field of occupational therapy have emphasized choice as an essential aspect of therapy. Voluntary movements in occupation which promoted personal

initiative on the part of the individual were advocated rather than a mechanical, isolated approach (Baldwin, 1919). Occupational therapy should not be prescribed, but rather presented as opportunities which the individual may freely choose to participate (Meyer, 1922).

Dunton (1931) believed that choices helped connect treatment to an individual's real work and leisure interests. The importance of choice in occupational therapy is reflected in numerous studies with varying populations, which strengthens the concept of choice as a key factor in daily life occupations.

The effects of choice in an art occupation were examined in 25 adolescents with psychiatric conditions living in residential treatment facilities (Schroeder & Kopp Miller, 2001). The authors hypothesized that when given an option, the participants would spend more time and apply more paint on an object than when not given an option. The study consisted of two conditions, choice or no choice, and each adolescent participated in both conditions. In the choice condition, one of five objects presented was chosen by the participant, while those in the no choice condition were given one of the five objects to paint. A significant difference was found between the two conditions. Those who were given a choice of an object applied more paint to the project, were more motivated, and produced more effort. These findings support the idea that choice in daily occupations may enhance occupational performance.

A study by Rice and Nelson (1988) involved 24 adult and adolescent males with intellectual developmental disabilities who experienced one of two conditions during the self-care occupation of ironing: choice of design in a t-shirt or no choice. There was a statistically significant difference between those who chose their t-shirts as shown by the length of time and duration which the shirts were ironed by the participants. This study provides further evidence that motivation was increased in the participants when given a choice.

In a study among 52 elderly nursing home residents, Zimmerer-Branum and Nelson (1995) studied choice between an occupationally embedded exercise and rote exercise. A statistically significant number of participants chose exercise in the form of a modified basketball game over rote exercises. Providing opportunities for choice increased the occupational performance of the participant. Implications from this study are that participants benefit when given occupational choices, especially in occupations which hold personal meaning and purpose. The impact of choice has been reviewed and found to have positive effects upon occupation. Next, the importance of quality of life will be reviewed.

### **Research on Quality of Life**

Paskulin, Vianna and Molzahn (2009) studied factors associated with quality of life in 288 older Brazilian adults. In an exploratory cross-sectional study, surveys were distributed to homes in Porto Alegre, Brazil. The survey consisted of a demographic and health data sheet, the Older American Resources and Services Scale on activities of daily living (Paskulin, Vianna & Molzahn, 2009), and the World Health Organization Quality of Life-BREF (Brazilian version) questionnaire (Paskulin, Vianna & Molzahn, 2009). The authors used an analysis of the overall quality of life as the dependent variable to conclude that perceived health status, education level, engagement in physical activity, medical conditions, age group, and use of primary health care as significant associated factors that influence overall quality of life. The results of this study bring to the attention of health professionals the issues affecting quality of life of older adults.

Community participation has also been suggested to have an influence on quality of life. Huebner, Johnson, Bennett and Schneck (2003) examined community participation and quality of life outcomes for adults with traumatic brain injury living in the community. Twenty-five adults completed follow-up surveys approximately 21 months post-brain injury. The surveys

measured quality of life, disability, community participation, and satisfaction with occupational therapy. Results supported that participation in the community related to higher quality of life. This could have implications for caregivers of an individual with dementia, since caregivers may be more isolated and have less opportunity for community participation as they did prior to assuming the caregiver role.

An evidence-based review by Letts, Edwards, Berenyi, Moros, O'Neill, O'Toole, and McGrath (2011) examined the use of occupations (activities of daily living, leisure, and social participation) to improve quality of life, health, wellness, client and caregiver satisfaction for individuals with Alzheimer's disease and related dementias. Twenty-six articles were selected based on inclusion and exclusion criteria, and were categorized as Level I (systematic reviews, meta-analyses, and randomized controlled trials), Level II (two-group, cohort or case-control studies, not randomized), Level III (one group, non-randomized, before and after, or pretest and posttest studies), and Level IV (single-case experimental design). Caregivers rated higher quality of life and satisfaction after receiving visits from trained volunteers who implemented occupations such as taking the individuals with dementia for walks, creating crafts, and engaging in conversation compared with a wait-list control group (Wishart et al., 2000).

McConaghy and Caltabiano (2005) explored quality of life factors related to caring for a person with dementia. In a cross-sectional survey design, five instruments were used to measure perceived burden, depression, coping and well-being in forty-two caregiver participants. The authors found statistically significant findings that increased levels of caregiver burden were associated with decreased psychological health. This relationship suggests that occupational therapists may have an opportunity to assess caregiver self-reports of burden, and make recommendations to maintain the psychological health of the caregiver. The factors upon quality

of life have been reviewed, and now we will examine the relationship between choice and quality of life.

### **Choice and Quality of Life**

Duncan-Myers and Huebner (2000) examined the relationship between perceived personal choices and the quality of life reported by 31 residents in a long-term care setting. Using The Duncan Choice Index: Self-Care and Leisure (Duncan, 1998) and The Quality of Life Rating (Gust, 1982), results were a significant positive correlation between the amounts of choice residents perceived and their self-reported quality of life. Implications are that providing greater opportunity for choice in every day life may be associated with improved quality of life in individuals residing in long term care facilities, and that occupational therapists may help them advocate for greater choice.

A scholarly study completed by Vohnout (2011) expanded upon the study by Duncan-Myers and Huebner (2000) by investigating the relationship between choice and quality of life in individuals residing in independent and assisted living facilities. Ninety-five participants completed the Duncan Choice Index: Self-Care and Leisure (DCI) (Duncan, 1998) and the Quality of Life Rating (Gust, 1982). Statistically significant differences revealed that participants in independent living had more choices and higher quality of life compared to those in assisted living environments. Further, a positive correlation was found between perceived amount of choice and actual quality of life reported by participants overall. The results suggest older adults residing in independent living and assisted living facilities also perceive higher quality of life when more choices are offered in daily life occupations, which reinforce the findings in Duncan-Myers and Huebner's study among older adults in long-term care facilities. In both studies, the authors echo the need for occupational therapy as a profession to serve as

advocates for greater choice opportunities in daily life of older adults. There is a need to expand this research of choice and quality of life to caregivers, particularly those of individuals with dementia. In addition, the role of occupational therapy in supporting the choice and quality of life of these caregivers will be explored.

### **Occupational Therapy, Quality of Life and Caregivers of Individuals with Dementia**

Research has shown that the strain of caregiving for an elderly person with a disability leads to increased physical and psychological problems, as well as increased mortality compared to non-caregivers (Schultz & Beach, 1999). Wives of elderly husbands who had more disabling conditions reported lower life satisfaction than wives whose husbands had less disabling conditions. The wives were called “hidden patients” because all reported having at least one chronic condition (Fengler & Goodrich, 1979). In particular, caregivers of individuals with dementia may have even higher health risks than caregivers of those with non-dementia diagnoses because individuals with dementia require more supervision, have emotional and behavioral problems, and are less likely to express gratitude for care received (Muangparisan et al., 2010).

Nationally representative data from the 1996 National Caregiver Survey (National Alliance for Caregiving and American Association for Retired Persons {NAC/AARP}, 1997) was used in a study comparing caregivers of individuals with dementia to those without dementia. Caregivers of individuals with dementia were found to spend significantly more hours a week providing care and reported greater levels of physical strain, emotional strain, and financial hardship than non-dementia caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

The severity of dementia has been studied in relationship to the level of burden on the caregiver. In a longitudinal study by Berger, Bernhardt, Weimer, Peters, Kratzsch and Frolich (2005), 42 individuals with dementia in an outpatient memory clinic along with their caregivers were evaluated over a period of two years on the severity of dementia-related symptoms in relationship to caregiver distress and depression. The caregivers were assessed on measures of caregiver burden and depression, while patients were measured on global dementia severity, functional impairment, and behavioral disturbances at baseline, 3 months, 6 months, 12 months and 24 months. Significant correlations were found between caregiver burden and dementia severity as measured by the Caregiver Burden Interview (Zarit et al., 1980) and the Global Deterioration Scale (Yesavage, et al., 1982) with the strongest correlation measured at 24 months. There was also a significant positive correlation found between caregiver burden and the patients' functional status, with the highest correlation found at 24 months. These findings support the idea that the level of severity in dementia has a direct relationship with the level of burden perceived by the caregiver, and that over time these correlations become stronger. Caregivers may increasingly experience burden, and require support during these times of worsening dementia and decreased functional status of the individual receiving care.

A systematic review of evidence of the effectiveness of educational and supportive strategies for enabling caregivers of individuals with dementia to maintain participation in that role (Thinnes & Padilla, 2011) selected 43 articles that met inclusion criteria, and found that interventions which jointly engage individuals with dementia and their caregivers in education and training in the home setting are more successful than strategies that focus solely on people with dementia. Further, the authors noted that interventions should provide caregivers with

problem solving, technical skills, support, simple home-modification strategies, and referral to community resources.

Occupational therapy has been linked with quality of life issues for caregivers, particularly those caring for individuals with dementia. Dooley and Hinojosa (2004) conducted a study of 40 persons with Alzheimer's disease living in the community along with their 40 caregivers. Using a pretest-posttest control group design, all participant pairs were assessed on the Assessment of Instrumental Function (Brinson & Marran, 1997), the Zarit Burden Interview (Zarit et al., 1980), the Affect and Activity Limitation-Alzheimer's Disease Assessment (AAL-AD) (Albert et. al., 1996), and the Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969). Those in the treatment group received a follow-up 30 minute home visit to review occupational therapy recommendations based on environmental modifications, caregiver approaches, and community-based assistance. The control group received a written report of the occupational therapy recommendations in the mail. At the posttest, caregivers in the treatment group had statistically significantly lower levels of burden after following occupational therapy recommendations. Significant results were not found in the control group, or on any other variables. The implication of this study suggests that occupational therapy recommendations are valuable in helping to decrease caregiver burden.

In another study, Gitlin, Hauck, Dennis and Winter (2005) investigated treatment effects of six occupational therapy sessions at six months and twelve months in individuals with Alzheimer's disease and their family caregivers. Using a randomized two-group design, 127 pairs of individuals with Alzheimer's disease and their caregivers were assigned to a usual care control group or intervention of six occupational therapy sessions to help families modify the environment and reduce caregiver burden. At six and twelve months, statistically significant

results were found in improvement of caregiver affect as measured on five areas: feeling calm, upset, angry, overwhelmed, and a sense of personal control. These results strengthen the idea that occupational therapy has a positive effect on caregivers of individuals with dementia.

Further research by Gitlin, Winter, Burke, Chernett, Dennis, and Hauck (2007) investigated the hypothesis that in-home skills training programs facilitated by occupational therapists for caregivers would reduce dementia-related neuropsychiatric behaviors, promote activity engagement, and enhance caregiver well-being. In a two-group, randomized controlled pilot study, sixty individuals with dementia and their family caregivers were assigned to either the treatment of eight occupational therapy sessions (called the Tailored Activity Program), or a wait list control group. After four months, caregivers were given the Zarit Burden Scale (Bedard, Molloy, Squire et al., 2001), the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977), and the Task Management Strategy Index (Gitlin, Winter, Dennis, et al., 2002). Caregivers that received the in-home skills training program were found to have significantly less perceived burden and significantly greater confidence in engaging patients in activities. These results suggest that a structured occupational therapy program is helpful in increasing the overall well-being of caregivers while caring for individuals with dementia.

Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnages, and OldeRikkert (2007) investigated the effect of occupational therapy provided in the community on quality of life, mood, and health status in individuals with dementia and their caregivers. In a randomized controlled trial, 135 pairs of individuals with dementia and their caregivers were assigned to either ten sessions of occupational therapy over five weeks or no intervention. The treatment interventions consisted of training the individuals with dementia to compensate for cognitive decline and caregivers in coping behaviors and supervision. Results found that patients and

caregivers in the treatment condition had statistically significantly better mood and health status than the control group. The caregivers also had significantly better sense of control over life. The implications of this study suggest that both individuals with dementia and their caregivers benefit significantly from occupational therapy programs in regards to both mood and health status.

In a randomized control trial using the COPE model (Care of Persons with Dementia in their Environments), occupational therapists provided a home-based intervention to 102 dyads of individuals with dementia and their caregivers in the treatment group (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). In the control group, 107 dyads received educational materials and 3 telephone calls. Caregivers in the COPE condition received up to 10 sessions over 4 months by occupational therapists in the home environment. Caregivers were trained by occupational therapists in problem-solving, communication, engaging patients in activities, and task simplification. Caregivers in the COPE condition showed statistically significant improvement in their well-being as measured by the Perceived Change Index (Gitlin, Winter, & Hauck, 2006), a 13-item instrument through which caregivers rate the change in their ability to manage dementia, emotional status, and somatic symptoms such as energy and sleep quality. This evidence suggests that occupational therapy can play an instrumental role through interventions that improve the quality of life of caregivers, offering opportunities for them to have greater choice in daily decisions.

The role of occupational therapy in quality of life and caregivers of individuals with dementia has been examined in the previous studies and found to have positive impacts upon caregivers in various areas. Next, the current study will be reviewed.

### **Current Study**

In order to expand the investigation of choice and quality of life to caregivers of individuals with dementia, the Duncan-Myers and Huebner (2000) study was expanded in this current study. Past research suggests that the severity of dementia affects the quality of life in caregivers of individuals with dementia (Donaldson, Tarrier, & Burns, 1998; Bell, Araki, & Neumann, 2001; Berger et al, 2005). However, the control that caregivers perceive to have in their lives has not been studied in relationship to the severity of dementia in the individual receiving care. This study was necessary in order to examine this relationship and find evidence that may suggest more specific support needed by these particular caregivers. Severity of dementia in the individual receiving care must be examined in light of how this may affect caregivers' daily sense of control and quality of life. In this current study, the stage of dementia as perceived by the caregiver was investigated in terms of the effect upon caregivers' choice and quality of life. Caregivers of individuals with dementia were predicted by the researchers of this study to rate higher quality of life when they perceived more personal choice in daily life. The three research questions of interest were:

- What is the relationship between caregivers' perceptions of the number of choices available in daily life and their quality of life?
- What is the relationship of choices caregivers perceive and the level of dementia in the person receiving care?
- What is the relationship between caregivers' quality of life and the level of dementia in the person receiving care?

## **Methods**

**Participants**

The participants in this study were non-paid caregivers of individuals with a diagnosis of dementia living in the community. One thousand surveys were mailed through the Alzheimer's Association of Northwest Ohio established mailing list to caregivers and family members of individuals with dementia in the northwest Ohio region. The caregivers must have provided a minimum of 8 hours of care per week to the individual with dementia.

**Study Design**

A survey research design was used for this study. The survey included a three part questionnaire.

**Instrument**

The instrument was a questionnaire consisting of three parts (see Appendix A). The first part consisted of sixteen questions eliciting demographic information on both the caregiver and the individual with dementia. Demographic information was collected on caregivers including age, gender, marital status, county of residence, educational level, and relationship to the individual with dementia. Further, data was obtained on the age and gender of the individual with dementia, current living arrangement in the community, whether he or she has received occupational therapy services in the past year, and the individual's level of dementia as perceived by the caregiver.

The second part of the questionnaire was the Duncan Choice Index: Self-Care and Leisure (DCI) developed by Duncan-Myers and Huebner (2000). The DCI consisted of 29 statements on the amount of choice regarding what, when, where, how, and with whom leisure and self-care occupations are performed. For each statement the participant indicated the frequency of choice opportunities ("I \_\_\_ have a choice in that occupation") using a 5-point scale

as follows: 1 never, 2 rarely, 3 sometimes, 4 usually, and 5 always. The scores could range from 29 to 145, with higher scores indicating greater amount of choice. The DCI also included two open-ended questions asking: (a) In which occupations would you like to have more choices? and, (b) Would you like to have more choice on when, how, or with whom you do things? One item (number twenty in the original DCI) was omitted from the DCI: “When I move (e.g., go down the hall)”. This item was designed originally for individuals residing in long-term care facilities, and was omitted in the current study because it was not likely to pertain to choice in mobility for caregivers.

The study conducted by Duncan-Myers and Huebner (2000) developed the DCI measure and determined it to have an acceptable level of reliability and internal consistency based on the Cronbach’s alpha score of .84 obtained from the study. Also, the study showed a strong correlation ( $r = .54$ ,  $p = .01$ ) of the quality of life rating with the scores on the DCI which adds support to the concurrent validity of the DCI (Duncan-Myers & Huebner, 2000). Since one item on the DCI was omitted in the current study, a Cronbach alpha score was obtained.

The third part of the questionnaire consisted of The Quality of Life Rating (QOLR) developed by Gust (1982) (as cited in Duncan-Myers and Huebner, 2000) which measures participants’ perceptions of quality of life. The QOLR consisted of 20 statements related to views on quality of life. Participants responded to the statements using a 5-point scale to rate their perception of quality of life with one meaning extremely poor, and five meaning quality is excellent. The total scores could range from 20 to 100. The higher the QOLR score, the higher the rating of quality of life. Huebner et al. (1998) identified the five distinct factors of the QOLR as self-esteem and well-being, interpersonal attachment, basic needs, recreation/leisure, and spirituality. These authors also described a correlation with measures of life satisfaction of .65,

supporting criterion-related validity, a Cronbach's alpha of .87, and a test-retest coefficient of stability of .74.

## **Procedures**

One thousand surveys containing the demographic questionnaire, Duncan Choice Index (Duncan-Myers & Huebner, 2000), and Quality of Life Rating developed by Gust (1982) (as cited in Duncan-Myers and Huebner, 2000) were randomly distributed to caregivers of individuals with dementia in the region of northwestern Ohio through an existing mailing list of the Alzheimer's Association of Northwest Ohio. Randomization was conducted by an employee of the Alzheimer's Association. A cover letter containing the written consent for participating in the research study was included with each survey. Two weeks after surveys were sent, reminder postcards were mailed to all caregivers to encourage completion of the survey.

## **Results**

### **Demographic Information**

One thousand surveys were mailed by the Alzheimer's Association of Northwest Ohio to caregivers of individuals with dementia residing in twenty-one counties of northwest Ohio. Fifteen surveys were returned undeliverable by the United States Postal Service. There were 292 surveys returned providing an initial response rate of 30%. Of the 292 surveys, 171 met all criteria to participate in the study. Of the 121 surveys that did not meet the criteria, 50 indicated less than 8 hours of care provided by the caregiver per week, 26 indicated that the individual with dementia was deceased, 22 indicated they were not caregivers, 19 omitted critical information, and 4 were returned blank without explanation. Of the 171 usable surveys, any

incomplete data were entered as missing data. The data gathered were analyzed using SPSS for Windows Statistical Software.

The following information was gathered from the demographic questionnaire portion of the survey. The ages of the caregivers ranged from 30-87 years old ( $M = 64.31$ ;  $SD = 11.44$ ). Seventy-eight percent of the caregivers were female, and 22% were male. Eighty-one percent of caregivers were married, 11% were divorced, 5% were single, and 3% were widowed. In relationship to the person with dementia, 49% of caregivers were spouses, 33% were daughters, 5% were sons, 2% were siblings, 2% were grandchildren, 1% were friends, and 8% left this question blank. Twenty-nine percent of the participants reported having a high school education, 18% had some college education, 7% had technical training, 12% had an associate's degree, 20% had a bachelor's degree, 12% had a master's degree, and 2% had a doctoral degree.

The age of the person with dementia receiving care ranged between 42-96 years old ( $M=77.69$ ;  $SD=9.40$ ). Fifty-five percent of individuals with dementia were female, 43% were male, and 2% of individuals' gender was not indicated. Sixty-six percent of the individuals received care in their own homes, 16% received care in the caregiver's home, 12% in nursing homes, 4% in assisted-living facilities, and 2% did not indicate responses to this question. Fifty-one percent of the individuals receiving care lived with their spouses, 14% with a daughter, 8% lived alone, 4% lived with a son, 2% lived with a grand-daughter, 1% lived with a daughter-in-law, and 20% left this item blank. Of the twenty-one counties represented in the survey, the highest response rates came from caregivers residing in Lucas county (32%), Wood (12%), Allen (6%), Defiance (6%), Richland (5%), and Hancock (5%).

Caregivers indicated that they had been providing care for an individual with dementia for a range 2 months to 276 months ( $M=42.66$  months;  $SD=37.95$  months). Only 15% of

caregivers received formal caregiver training. Sixty-one percent of caregivers provided more than 40 hours of care per week, 8% provided 25-40 hours of care, 14% provided 15-25 hours, 15% of caregivers provided 8-15 hours of care per week, and 2% indicated more than one range of hours for this item. Thirty-one percent of the individuals with dementia received occupational therapy services in the past.

Caregivers were asked to rate the level of dementia of the person for whom care was provided. Seventeen percent of the individuals were indicated as mild or early stage of dementia, 57% were moderate to middle stage, and 18% were severe to late stage of dementia. Eight percent of caregivers did not indicate a level of dementia on the survey. Twelve percent of caregivers indicated that they felt the person with dementia was able to do more for him or herself than he or she was currently doing, 68% believed the individual was not able to do more, and 19% of caregivers were unsure. Forty-seven percent of caregivers believed that the individual with dementia was in control of his or her behavior, 24% believed the individuals with dementia were not in control, and 23% were unsure whether the person was in control of behavior.

### **Assessment Scales**

The Duncan Choice Index: Self-Care and leisure (DCI) (Duncan-Myers & Huebner, 2000) portion of the questionnaire had a high possible score of 140. The overall mean score for amount of daily choice perceived by caregivers was 115.60 ( $SD = 20.38$ ) indicating a moderately high level of choice. The items that were marked by caregivers as having the highest and least amount of choice were analyzed by level of dementia of the individual receiving care. Caregivers of individuals rated as mild/early stage dementia rated the highest amount of choice ( $M = 121.59$ ;  $SD=22.21$ ), those caring for individuals rated as moderate/middle stage were next

highest ( $M=114.98$ ;  $SD=19.25$ ), and caregivers of individuals rated as severe/late stage of dementia scored the lowest amount of choice among all caregivers ( $M=111.94$ ;  $SD=20.38$ ).

The mean scores and standard deviations for the each of the choice items are located in Table 1 in the appendices.

| <b>Freedom of Choice</b> |  |   |  |
|--------------------------|--|---|--|
|                          | Mild/Early Dementia  | Moderate Dementia   | Late/Severe Dementia   |
| Most Choice              | <ol style="list-style-type: none"> <li>1. How I perform toilet hygiene.</li> <li>2. When I perform grooming, how I perform toilet hygiene, and when I perform oral hygiene.</li> <li>3. What I wear, how I dress.</li> </ol> | <ol style="list-style-type: none"> <li>1. What I wear.</li> <li>2. How I dress.</li> <li>3. How I perform toilet hygiene.</li> </ol>                | <ol style="list-style-type: none"> <li>1. What I wear.</li> <li>2. How I dress.</li> <li>3. How I perform toilet hygiene.</li> </ol>   |
| Least Choice             | <ol style="list-style-type: none"> <li>1. When I perform leisure.</li> <li>2. When I socialize.</li> <li>3. When I wake up in the morning.</li> </ol>  | <ol style="list-style-type: none"> <li>1. When I perform leisure.</li> <li>2. Whom I perform leisure with.</li> <li>3. When I socialize.</li> </ol> | <ol style="list-style-type: none"> <li>1. When I socialize.</li> <li>2. What leisure activities I do, where I socialize.</li> <li>3. Whom I perform leisure with.</li> </ol> |

For the DCI (Duncan-Myers & Huebner, 2000) participants had the opportunity to write down which activities he or she would like to have more choice. A total of 141 of 171 caregivers responded to the open-ended question. Socializing was the activity that was written down the most for a total of 88 times, followed by eating which was listed 13 times. Leisure and grooming were each listed 6 times.

The Quality of Life Rating (QOLR) developed by Gust (1982) (as cited in Duncan-Myers and Huebner, 2000) portion of the questionnaire had a high possible score of 100. The overall mean score of quality of life for all caregivers was 60.42 ( $SD = 17.14$ ). Mean scores and standard deviations for the each quality of life items are located in Table 2 in the appendices.

The items that were marked by caregivers as having the highest and lowest quality of life were analyzed by level of dementia of the individual receiving care.

| Quality of Life         |  |  |  |
|-------------------------|--|--|--|
|                         | Mild/Early Dementia  | Moderate Dementia  | Late/Severe Dementia   |
| Highest Quality of Life | 1. Housing/living conditions<br>2. Transportation availability<br>3. Liking myself | 1. Transportation availability<br>2. Housing/living conditions<br>3. Liking myself | 1. Transportation availability<br>2. Housing/living conditions<br>3. Liking myself |
| Lowest Quality of Life  | 1. Volunteer activities<br>2. Intimate relationships<br>3. Amount of stress        | 1. Volunteer activities<br>2. Amount of stress<br>3. Intimate relationships        | 1. Amount of stress<br>2. Intimate relationships<br>3. Hobbies                     |

### Additional Comparisons

A Spearman-rho was completed to determine if there was a correlation between the caregivers' scores for the choice and quality of life portions of the survey. The results of the Spearman-rho revealed a significantly moderate correlation ( $rs=.53, p=.001$ ). This positive correlation indicates that the higher amount of choice caregivers perceived, the higher they rated their quality of life.

A Kruskal-Wallis test was completed to determine if there was a significant difference between the caregiver's perception of the individual's level of dementia and the amount of choice which caregivers rated. A significant difference was found in the total choice perceived by caregivers and the three levels of dementia ( $\chi^2 = 6.099, p < .05$ ). Results indicated that the more severe the level of dementia, the lower amount of choice in daily life was perceived by caregivers.

A Kruskal-Wallis test was completed to determine if there was a significant difference between the caregiver's perception of the individual's level of dementia and the quality of life of the caregiver. Caregivers who rated the individual with mild/early stage of dementia perceived

the highest quality of life ( $M=66.10$ ;  $SD=16.32$ ), those who rated a moderate/middle stage of dementia perceived less quality of life ( $M=60.91$ ;  $SD=16.75$ ), and caregivers who rated the individuals as severe/late stage of dementia had the lowest quality of life ( $M=53.55$ ;  $SD=17.33$ ). Overall, a significant difference was found in the total quality of life perceived and the three levels of dementia rated by caregivers ( $\chi^2 = 8.324$ ,  $p < .02$ ).

### **Discussion**

The purpose of this study was to extend the Duncan-Myers and Huebner (2000) study to non-paid caregivers of individuals with dementia living in the community. Further, this study investigated the relationship between choice and quality of life, the level of quality of life and amount of choice perceived by caregivers in relationship to the level of dementia in the individual receiving care, and which areas caregivers have the most and least amount of choice in daily life.

This study found a statistically significant positive correlation between the caregivers' perception of the amount of choice their daily life and their quality of life, indicating that the more choice caregivers perceive, the higher quality of life. Significant differences were found between the three levels of dementia and the total choice perceived by caregivers, as well as in the total quality of life. The more severe the level of dementia, the lower the amount of daily choice and quality of life were rated by caregivers. These findings support the idea that the level of severity in dementia has a direct relationship with the level of burden perceived by the caregiver, and that over time these relationships become stronger (Berger et al., 2005).

In this study, caregivers across all levels of dementia care identified the most amount of choice in the same three areas: "what I wear," "how I dress," and "how I perform toilet hygiene". Additionally, caregivers who provide care to individuals with mild/early dementia

also perceived high choice in grooming routines overall. Caregivers identified the least amount of choice in the areas of socialization and leisure consistently across all levels of dementia. One caregiver wrote, “Even with wonderful support, I mostly feel confined, structured, restricted, controlled, and tired.” Another caregiver commented, “Caring for a husband with dementia worsening each day requires my presence and making choices is getting more difficult.” Other caregivers in this study mentioned the need for socializing apart from the individual with dementia, stating that they often must bring the individual along. One caregiver stated, “My spouse is very dependent on me and gets anxious if I am not near.” An increase in choice in the areas of socialization and leisure may positively affect the perceived quality of life in caregivers. Caregivers may not live near an adult day center, such as the center located at the Northwest Ohio Alzheimer’s Association, which provides respite care for individuals with dementia. However, relationships between the Alzheimer’s Association and universities with health-related curriculums such as gerontology, occupational therapy, social work, nursing and other fields could create opportunities for students to be trained and serve as respite caregivers as part of coursework and specialization. Communicating these opportunities for respite care to caregivers may allow for increased choice in caregivers’ social and leisure engagement.

The findings of this current study are consistent with the findings of Duncan-Myers and Huebner (2000) in that the higher amount of choice perceived by individuals, the higher they rate quality of life. In this current study, caregivers across all levels of dementia rated a moderate quality of life at 60.19 out of the highest possible score of 100, as rated on the QOLR (Gust, 1982). Across levels of dementia, caregivers consistently named the highest quality of life in three areas: “housing/living conditions,” “transportation availability,” and “liking myself.” Based on the surveys, 82% of caregivers were providing care in home settings, which may

explain why housing and transportation were rated highly for quality of life. It is noteworthy that caregivers across all levels of dementia care all rated “liking myself” as a high quality of life area, which may indicate that levels of self-esteem are intact or perhaps even increased with the role of caregiving.

The lowest quality of life items consistently rated by caregivers across all levels of dementia were “intimate relationships” and “amount of stress.” Interestingly, caregivers of those with mild/early dementia rated “amount of stress” as the third lowest quality of life, caregivers of individuals with moderate dementia rated it second lowest, and those caring for individuals with late/severe dementia rated “amount of stress” as the lowest quality of life area of all items. These findings may suggest that the stress level of caregivers steadily increases with the progression of the dementia. Caregivers of those with mild/early or moderate dementia rated “volunteer activities” as the lowest quality of life area, which suggests that caregivers who desire to participate in community volunteer opportunities are acutely not able to engage, or may not have the time, energy, or desire to volunteer. Caregivers of individuals with late/severe dementia also rated low quality of life with “hobbies,” which also highlights an area of possible support caregivers need for refreshing themselves and coping with the stress identified with caregiving.

Previous research indicates that the level of severity in dementia has a direct relationship with the level of burden perceived by the caregiver (Berger et al., 2005), which supports the results of this current study. Further, occupational therapy has been found to be effective in education and interventions for individuals with dementia and their caregivers (Dooley & Hinojosa, 2004; Gitlin, Hauck, Dennis & Winter, 2005; Graff et al., 2007; Letts et al., 2011). Previous research has shown that individuals demonstrate greater quality of occupational performance when given a choice compared to when not given a choice (Rice & Nelson, 1988;

Schroeder & Kopp Miller, 2001). Additional research has looked into the idea regarding different amounts of choice have influence on quality of life, and research shows support that increased amounts of choice have a positive influence on quality of life (e.g., Paskulin, Vianna & Molzahn, 2009; Huebner, Johnson, Bennett & Schneck, 2003). This research study, along with the Duncan-Meyers and Huebner (2000) study, expand upon the idea of choice related to quality of life with specific implications for caregivers of individuals with dementia.

The outcomes of the current study have implications for occupational therapy as a profession. Based on the survey results, 31% of caregivers reported receiving occupational therapy services in the past, yet only 15% reported receiving formal caregiver training. Occupational therapy professionals may fill a much-needed role of providing caregiver training, including practical and simple home modification tips, safety awareness, connection to resources, and strategies for meaningful engagement with the individual with dementia. Further, occupational therapists have an opportunity to collaborate with Alzheimer Association chapters to provide guidance on meaningful physical and psychosocial programming geared toward individuals with dementia and their caregivers. Occupational therapy educators may incorporate specific dementia caregiver training into curriculum coursework, as well as familiarize future therapists with effective assessment tools for caregivers. In the realm of home health care, occupational therapy has a tremendous opportunity to implement evidence-based interventions geared towards both the caregiver and the individual with dementia, as this approach has been shown more effective than treating the individual with dementia alone (Thinnes & Padilla, 2011). Occupational therapists are skilled in analyzing daily routines, and recommending changes that would maximize time, energy, and function on the part of the caregiver and the individual with dementia. Most importantly, occupational therapy professionals may become

advocates for choice and quality of life issues related to caregiving. Expanded choice for caregivers in the areas of socialization, leisure, and community participation may in turn expand the choices for the individuals with dementia. For example, if a caregiver is connected with a trained volunteer program and receives respite care in the home, the individual with dementia may have enhanced social benefits while the caregiver also has greater choices for socialization and leisure.

### **Limitations**

The first limitation of this study was the use of a survey to collect data. Survey research has many advantages such as the ability to reach a large number of respondents with a relatively minimal expenditure, to collect data on numerous variables, and the opportunity for participants to remain anonymous. However, even with these advantages survey research can be limited by participant response bias. Bias may result from participants interpreting the meaning of a question differently than intended, or response choices that do not accurately express participants' experiences or opinions.

Additional limitations could include the method of mailing surveys to this population. Caregivers may not have perceived they had time to fill out a survey. Another limitation was that the survey was ten pages in length. Participants for this survey were solicited from the twenty-four counties served by the Northwest Ohio Alzheimer's Association, and may not be representative of caregivers in other geographical areas. Also, the majority of the respondents were female, and the results may not accurately express the true opinions of male caregivers. Seventy-eight percent of caregivers were female and 22% were male, but gender differences were not significant in relation to choice and quality of life.

Lastly, the subject matter of the survey may have posed as a limitation. Although confidentiality and anonymity were assured, the participants may have hesitated to portray a negative image of caregiving, or may have focused on the negative aspects of caregiving more than the positive. Further, the way questions were worded in the demographic survey may have been confusing to participants, leading them to leave blanks on items.

### **Future Research**

More research is warranted to expand on and strengthen the results of this study and the Duncan-Meyers and Huebner (2000) study. This research study was conducted in Northwestern counties of Ohio. Additional research could be conducted on a national level in collaboration with the Alzheimer's Association to ensure adequate representation of different regions and different cultures throughout the United States. Also, since the majority of caregivers are female, future research may focus on the views and opinions of male caregivers in comparison to female caregivers on specific aspects of choice and quality of life, such as socialization needs and the impact of caregiving on intimate relationships, since those were both identified as significantly low quality of life areas for caregivers in this study.

Another possible area for future research would be the identification of ways the field of occupational therapy may support and increase choice opportunities for caregivers of individuals with dementia. Additionally future research must continue to investigate how occupational therapy may improve the quality of life of caregivers through both home-based and extended care facility education and programming. Strategies such as simplifying communication, modifying the environment for safety and function, task simplification, and activity engagement may be studied for effectiveness in improving the quality of life for the individuals with dementia as well as their caregivers. There is a pressing need for more intervention research

through well-designed studies, particularly which combination and amount of intervention is most effective, and what the long-term effects may be (Gitlin, 2012). More research is needed to demonstrate that occupational therapists have the unique skill set to help caregivers in need of support and skills training.

### **Conclusion**

This study found that there was a statistically significant positive correlation between the caregivers; perception of the amount of choice in their daily life and their reported quality of life, indicating that the more choice caregivers perceive, the higher quality of life. This study also found statistically significant differences between the three levels of dementia and the total choice perceived by caregivers, as well as in the total quality of life. The more severe the level of dementia, the lower the amount of daily choice and quality of life were rated by caregivers.

Quality of life in the areas of housing/living conditions, transportation availability, and self-esteem was the highest among all caregivers. The quality of life in the areas of volunteer activities, intimate relationships, and amount of stress was the lowest among caregivers of individuals with mild and moderate dementia, while caregivers of individuals with severe/late stage dementia reported lowest quality of life with hobbies, amount of stress, and intimate relationships. These results suggest that occupational therapy as a profession needs to advocate for caregivers of individuals with dementia to have support and strategies which enable greater choice in daily life. Additionally, occupational therapy practitioners must seek to improve the quality of life for caregivers through providing education and planning appropriately for each level of dementia.

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## Appendix A

IRB Number \_\_\_\_\_

Dear Participant:

You were selected as part of a random sample of non-paid caregivers providing care to a family member or friend with dementia. You are invited to participate in this survey regarding the amount of choice that you have on a daily basis, and how it relates to your quality of life. I am conducting this study in fulfillment of the requirements for my Doctoral degree in Occupational Therapy at the University of Toledo. The results from this study will be used for research purposes only.

The enclosed questionnaire will take approximately 15 minutes of your time. It is my intention to advance the knowledge of choice and quality of life among caregivers, particularly in the area of dementia care. This is an area that I feel is important to our field of occupational therapy, and further research is needed.

Your participation in this study is voluntary and anonymous. Your reply will be held in the strictest confidence, so please do not place your name or any other identifying information on the questionnaire. By completing this survey, you are implying your consent to participate in this study. Please return the completed questionnaire by \_\_\_\_\_ in the self-addressed stamped envelope provided. If you have any questions or concerns regarding this survey, please call Francine Ellis at (419) 699-7080 or Barbara Kopp Miller at (419) 530- 5308.

Your time and willingness to participate is greatly appreciated.

Sincerely,

Barbara Kopp Miller, Ph.D  
Principal Investigator

Francine Ellis, OTD/S  
Co-Investigator

### Caregiver Demographic Questionnaire

Please try to answer the following questions about YOURSELF when indicated, as well as questions about the person who is receiving care.

1. Your age: \_\_\_\_\_

2. Your gender: Male \_\_\_\_\_ Female \_\_\_\_\_

3. Your status: Single \_\_\_\_\_ Married \_\_\_\_\_ Divorced \_\_\_\_\_ Widowed \_\_\_\_\_

4. Please check your highest level of education:

High School \_\_\_\_\_ Some college \_\_\_\_\_ Technical training \_\_\_\_\_ Associate's degree \_\_\_\_\_

Bachelor's degree \_\_\_\_\_ Master's degree \_\_\_\_\_ Doctoral degree \_\_\_\_\_

5. What is your relationship to the person receiving care?

Spouse \_\_\_\_\_ Daughter \_\_\_\_\_ Son \_\_\_\_\_ Sibling \_\_\_\_\_ Grandchild \_\_\_\_\_ Friend \_\_\_\_\_

Other (please indicate) \_\_\_\_\_

6. Age of the person receiving care: \_\_\_\_\_

7. Gender of person receiving care: Male \_\_\_\_\_ Female \_\_\_\_\_

8. Where does the person receiving care live at this time? \_\_\_\_\_

Does he/she live with anyone? If so, whom? \_\_\_\_\_

9. What county do you (the caregiver) live in? \_\_\_\_\_

10. How many months have you been a caregiver for this person? \_\_\_\_\_

11. Have you ever received formal caregiver training? Yes \_\_\_\_\_ No \_\_\_\_\_

12. How many hours per week do you provide care for this person?

Less than 8 hours \_\_\_\_\_ 8-15 hours \_\_\_\_\_ 15-25 hours \_\_\_\_\_ 25-40 hours \_\_\_\_\_

More than 40 hours \_\_\_\_\_

13. Has the person you are caring for received occupational therapy services in the past year? Yes \_\_\_\_\_ No \_\_\_\_\_

14. How would you rate the level of dementia for the person receiving care?

Mild/Early stage \_\_\_\_\_ Moderate/Middle stage \_\_\_\_\_ Severe/Late stage \_\_\_\_\_

15. Do you feel that the person you are caring for is able to do more for him/herself than he/she is currently doing? Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure \_\_\_\_\_

16. Do you feel that the person you are caring for is in control of his/her behavior? Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure \_\_\_\_\_

Please continue to the next page.

Please circle the **AMOUNT OF CHOICE** you have in regards to each of the following activities, as if to say "I \_\_\_\_\_ have a choice in that activity." **Please try to answer every question about YOURSELF (not the person for which you are caring.)**

1. **When** I take medication.

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| 1                 | 2                  | 3                     | 4                   | 5                  |
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |

2. **When** I eat.

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| 1                 | 2                  | 3                     | 4                   | 5                  |
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |

3. **How** I eat.

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| 1                 | 2                  | 3                     | 4                   | 5                  |
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |

4. **Whom** I eat with.

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| 1                 | 2                  | 3                     | 4                   | 5                  |
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |

5. **What** I eat.

|   |   |   |   |   |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |
|-------------------|--------------------|-----------------------|---------------------|--------------------|

6. **When** I bathe.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

7. **How** I bathe.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

8. **When** I perform leisure.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

9. **Whom** I perform leisure with.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

10. **What** leisure activities I do.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

11. **When** I wake up in the morning.

|   |   |   |   |   |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

|                   |                    |                       |                     |                    |
|-------------------|--------------------|-----------------------|---------------------|--------------------|
| Never<br>a choice | Rarely<br>a choice | Sometimes<br>a choice | Usually<br>a choice | Always<br>a choice |
|-------------------|--------------------|-----------------------|---------------------|--------------------|

12. **What** time I go to bed.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

13. **When** I dress.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

14. **What** I wear.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

15. **How** I dress.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

16. **When** I socialize.

|                        |                         |                            |                          |                         |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|
| 1<br>Never<br>a choice | 2<br>Rarely<br>a choice | 3<br>Sometimes<br>a choice | 4<br>Usually<br>a choice | 5<br>Always<br>a choice |
|------------------------|-------------------------|----------------------------|--------------------------|-------------------------|

17. **Where** I socialize.

|            |             |                |              |             |
|------------|-------------|----------------|--------------|-------------|
| 1<br>Never | 2<br>Rarely | 3<br>Sometimes | 4<br>Usually | 5<br>Always |
|------------|-------------|----------------|--------------|-------------|

a choice      a choice      a choice      a choice      a choice

18. **Whom** I socialize with.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

19. **When** I use the telephone.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

20. **When** I perform grooming.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

21. **Where** I perform grooming.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

22. **How** I perform grooming.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

23. **When** I perform toilet hygiene.

|       |        |           |         |        |
|-------|--------|-----------|---------|--------|
| 1     | 2      | 3         | 4       | 5      |
| Never | Rarely | Sometimes | Usually | Always |

a choice      a choice      a choice      a choice      a choice

24. **Where** I perform toilet hygiene.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

25. **How** I perform toilet hygiene.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

26. **When** I perform oral hygiene.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

27. **Where** I perform oral hygiene.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

28. **How** I perform oral hygiene.

|          |          |           |          |          |
|----------|----------|-----------|----------|----------|
| 1        | 2        | 3         | 4        | 5        |
| Never    | Rarely   | Sometimes | Usually  | Always   |
| a choice | a choice | a choice  | a choice | a choice |

29. In which activities (e.g., eating, grooming, socializing) would you like to have more choice?

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30. Would you like to have more choice on when, how, or with whom you do things? Please explain your answer.    \_\_\_Yes    \_\_\_No

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**Please circle the number that best rates your quality of life in the following statements. Please try to answer every question about YOURSELF.**

1. My quality of life with recreation activities is

Extremely poor    1            2            3            4            5            Excellent

2. My quality of life with social relationships is

Extremely poor    1            2            3            4            5            Excellent

3. My quality of life with intimate relationships is

Extremely poor    1            2            3            4            5            Excellent

4. My quality of life with hobbies is

Extremely poor    1            2            3            4            5            Excellent

5. My quality of life with spiritual activities is

Extremely poor    1            2            3            4            5            Excellent

6. My quality of life with volunteer activities is

Extremely poor    1            2            3            4            5            Excellent

7. My quality of life with financial conditions is

Extremely poor    1            2            3            4            5            Excellent

8. My quality of life with learning activities is

Extremely poor    1            2            3            4            5            Excellent

9. My quality of life with work/career activity is

Extremely poor    1            2            3            4            5            Excellent

10. My quality of life with emotional balance is

Extremely poor    1            2            3            4            5            Excellent

11. My quality of life with transportation availability is

Extremely poor    1            2            3            4            5            Excellent

12. My quality of life with sexual adjustment is

Extremely poor    1            2            3            4            5            Excellent

13. My quality of life with family involvement is

Extremely poor    1            2            3            4            5            Excellent

14. My quality of life with physical/bodily condition is

Extremely poor    1            2            3            4            5            Excellent

15. My quality of life with liking myself is

Extremely poor    1            2            3            4            5            Excellent

16. My quality of life with housing/living conditions is

Extremely poor    1            2            3            4            5            Excellent

17. My quality of life with receiving affection is

Extremely poor    1            2            3            4            5            Excellent

18. My quality of life with control of life and future is

Extremely poor    1            2            3            4            5            Excellent

19. My quality of life with amount of stress is

Extremely poor    1            2            3            4            5            Excellent

20. My overall life quality is

Extremely poor    1            2            3            4            5            Excellent

**END OF SURVEY**

**Thank you for taking the time to complete this survey.**

Table 1

*Mean Scores of Individual Items on the Duncan Choice Index*

| Choice Item                        | Mean Score and Standard Deviation |                                |                                      |
|------------------------------------|-----------------------------------|--------------------------------|--------------------------------------|
|                                    | Early/Mild Dementia<br>Mean/(SD)  | Moderate Dementia<br>Mean/(SD) | Late/Severe<br>Dementia<br>Mean/(SD) |
| When I take medication.            | 4.46 (1.20)                       | 4.42 (1.22)                    | 4.42 (0.99)                          |
| When I eat.                        | 4.52 (0.78)                       | 4.35 (0.82)                    | 4.45 (0.77)                          |
| How I eat.                         | 4.59 (0.63)                       | 4.32 (0.88)                    | 4.10 (1.01)                          |
| Whom I eat with.                   | 4.31 (0.81)                       | 3.99 (0.98)                    | 3.61 (1.20)                          |
| What I eat.                        | 4.48 (0.63)                       | 4.34 (0.77)                    | 4.00 (0.97)                          |
| When I bathe.                      | 4.66 (0.81)                       | 4.45 (0.79)                    | 4.03 (1.33)                          |
| How I bathe.                       | 4.62 (0.94)                       | 4.52 (0.78)                    | 4.32 (1.11)                          |
| When I perform leisure.            | 3.62 (1.01)**                     | 3.34 (1.09)                    | 3.35 (1.40)                          |
| Whom I perform leisure<br>with.    | 4.07 (0.90)                       | 3.54 (1.09)                    | 3.32 (1.30)                          |
| What leisure activities I<br>do.   | 4.04 (0.88)                       | 3.58 (1.01)                    | 3.29 (1.19)                          |
| When I wake up in the<br>morning.  | 3.86 (1.06)**                     | 3.63 (1.14)                    | 3.42 (1.31)                          |
| What time I go to bed.             | 4.24 (0.95)                       | 3.91 (0.95)                    | 3.65 (1.08)                          |
| When I dress.                      | 4.28 (0.88)                       | 4.37 (0.78)                    | 4.13 (1.02)                          |
| What I wear.                       | 4.72 (0.65)*                      | 4.64 (0.69)                    | 4.65 (0.75)                          |
| How I dress.                       | 4.72 (0.65)*                      | 4.59 (0.72)                    | 4.61 (0.76)                          |
| When I socialize.                  | 3.82 (1.02)**                     | 3.39 (1.00)                    | 3.19 (1.25)                          |
| Where I socialize.                 | 4.04 (1.00)                       | 3.57 (1.06)                    | 3.29 (1.37)                          |
| Whom I socialize with.             | 4.29 (0.85)                       | 3.80 (1.04)                    | 3.61 (1.23)                          |
| When I use the telephone.          | 4.39 (0.88)                       | 4.27 (0.88)                    | 4.19 (0.98)                          |
| When I perform<br>grooming.        | 4.55 (0.74)                       | 4.40 (0.79)                    | 4.07 (0.98)                          |
| Where I perform<br>grooming.       | 4.75 (0.65)*                      | 4.47 (0.85)                    | 4.33 (0.92)                          |
| How I perform grooming.            | 4.71 (0.71)                       | 4.49 (0.73)                    | 4.26 (1.00)                          |
| When I perform toilet<br>hygiene.  | 4.68 (0.67)                       | 4.49 (0.77)                    | 4.19 (1.08)                          |
| Where I perform toilet<br>hygiene. | 4.54 (0.84)                       | 4.45 (0.90)                    | 4.29 (0.97)                          |
| How I perform toilet<br>hygiene.   | 4.75 (0.65)*                      | 4.57 (0.71)                    | 4.48 (0.87)                          |

|                               |                |                |                |
|-------------------------------|----------------|----------------|----------------|
| When I perform oral hygiene.  | 4.75 (0.65)*   | 4.46 (0.88)    | 4.39 (0.88)    |
| Where I perform oral hygiene. | 4.64 (0.83)    | 4.44 (0.93)    | 4.39 (0.88)    |
| How I perform oral hygiene.   | 4.79 (0.63)*   | 4.46 (0.91)    | 4.45 (0.89)    |
| Total                         | 121.59 (22.21) | 114.98 (19.25) | 111.94 (20.38) |

Scale: 1=Never a Choice to 5=Always a Choice

\*Notes top 3 rated items

\*\*Notes lowest 3 rated items

Table 2

*Mean Scores of Individual Items on the Quality of Life Rating*

| Quality of Life with        | Mean Score and Standard Deviation |                                |                                      |
|-----------------------------|-----------------------------------|--------------------------------|--------------------------------------|
|                             | Early/Mild Dementia<br>Mean/(SD)  | Moderate Dementia<br>Mean/(SD) | Late/Severe<br>Dementia<br>Mean/(SD) |
| Recreation activities       | 3.57 (1.00)                       | 2.81 (1.14)                    | 2.42 (1.06)                          |
| Social relationships        | 3.48 (1.21)                       | 2.95 (1.20)                    | 2.58 (1.20)                          |
| Intimate relationships      | 2.86 (1.30)**                     | 2.63 (1.40)**                  | 2.06 (1.26)**                        |
| Hobbies                     | 3.38 (1.15)                       | 2.97 (1.20)                    | 2.35 (1.08)**                        |
| Spiritual activities        | 3.36 (1.28)                       | 3.50 (1.25)                    | 2.87 (1.36)                          |
| Volunteer activities        | 2.85 (1.26)**                     | 2.19 (1.32)**                  | 2.45 (1.27)                          |
| Financial conditions        | 3.25 (1.35)                       | 3.33 (1.13)                    | 2.93 (1.25)                          |
| Learning activities         | 3.57 (1.00)                       | 3.15 (1.17)                    | 2.82 (1.16)                          |
| Work/career activity        | 3.08 (1.38)                       | 2.77 (1.33)                    | 2.50 (1.29)                          |
| Emotional balance           | 3.19 (1.11)                       | 2.94 (1.03)                    | 2.38 (0.90)                          |
| Transportation availability | 4.25 (1.27)*                      | 4.41 (0.79)*                   | 3.97 (1.09)*                         |
| Sexual adjustment           | 2.96 (1.37)                       | 2.70 (1.40)                    | 2.77 (1.34)                          |
| Family involvement          | 3.63 (1.01)                       | 3.54 (1.10)                    | 3.17 (1.31)                          |
| Physical/bodily condition   | 3.52 (1.18)                       | 3.33 (1.01)                    | 2.74 (1.09)                          |
| Liking myself               | 3.90 (1.08)*                      | 3.61 (1.12)*                   | 3.19 (1.08)*                         |
| Housing/living conditions   | 4.34 (0.94)*                      | 4.06 (0.94)*                   | 3.81 (0.98)*                         |
| Receiving affection         | 3.48 (1.30)                       | 3.43 (1.29)                    | 3.13 (1.20)                          |
| Control of life and future  | 3.17 (1.10)                       | 3.15 (1.21)                    | 2.61 (1.33)                          |
| Amount of stress            | 2.89 (1.10)**                     | 2.46 (1.01)**                  | 2.00 (1.02)**                        |
| Overall life quality        | 3.59 (0.87)                       | 3.42 (1.04)                    | 2.87 (1.12)                          |
| Total                       | 66.10 (16.32)                     | 60.91 (16.75)                  | 53.55 (17.33)                        |

Scale: 1=Extremely Poor Quality of Life to 5=Excellent Quality of Life

\*Notes top 3 rated items

\*\*Notes lowest 3 rated items