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Role Of Community Participation In Improving Quality Of Life In Clients With Dementia And Their Caregivers

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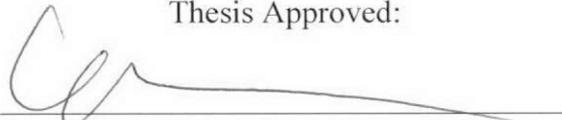
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ROLE OF COMMUNITY PARTICIPATION IN
IMPROVING QUALITY OF LIFE IN CLIENTS WITH DEMENTIA
AND THEIR CAREGIVERS

By

Mridula Dhamija, OTR

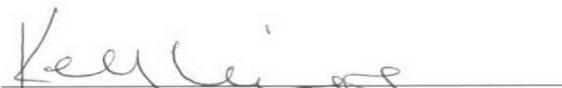
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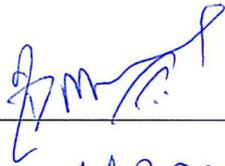


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IMPROVING QUALITY OF LIFE IN CLIENTS WITH DEMENTIA
AND THEIR CAREGIVERS

By

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in partial fulfillment of the requirements
for the degree of
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DEDICATION

This thesis is dedicated to my clients, family, and friends
especially my parents for always being my inspiration.

ACKNOWLEDGEMENTS

I also owe a special thank you to my thesis advisor and gratitude for the participants who willingly participated.

ABSTRACT

Aim: The purpose of this study was to investigate the effects on quality of life for clients with dementia and their caregivers by participating in a community program, the Memory Café.

Method: In this qualitative, cross case study, the Marwit Meser Caregiver Grief Inventory (MM-CGI) was given to caregiver. Data collection was done by interviewing the participants; there was a main question with follow- up questions as needed. All the interviews were audiotaped and transcribed followed by primary and secondary coding. Shortlisting of categories resulted in emergence of themes which were common across cases and unique to each case.

Results: Emergent themes common across cases were: couplehood, community awareness and involvement, and role of occupational therapy. There were other themes which were found to be unique to each role of client, caregiver and care-provider (occupational therapist and community outreach coordinator).

Conclusion: Community participation has a direct impact on cognitive functioning and participation in community based programs favorably affects quality of life among clients with dementia and their caregivers. Participants had positive feedback about their involvement in community based program such as Memory Café which is supported strongly by literature.

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CHAPTER 1

LITERATURE REVIEW

INTRODUCTION

Today more than forty-six million people are living with dementia worldwide which is more than the population of Spain. This number is estimated to increase to one hundred and thirty-one million by 2050. The total estimated cost of dementia worldwide is US \$818 billion, and it will become a trillion-dollar disease by 2018 (World Alzheimer Report, 2015). Five million Americans are living with Alzheimer's disease, resulting in more than \$150 billion paid by Medicare and Medicaid in 2014 for health care, long-term care and hospice of people with Alzheimer's and other dementia (Alzheimer's association, 2014). One third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia (Alzheimer's Association, 2014). Community based occupational therapy has improved daily functioning of elderly with dementia, and burden was found to be reduced on their informal caregivers for those who participated in these programs (Graff et al, 2006; Parker, Miller, & Abbey, 2008). Active social engagement has been shown to be associated with better health and health outcomes for clients with dementia and their caregivers (Berkmann & Syme, 1979; Bassuk et al., 1999; Mendes de Leon et al., 2003; Wang et al., 2002; Saczynsk et al., 2006).

LITERATURE REVIEW

Social Participation and Risk of Dementia

Wang, Karp, Winblad, and Fratiglioni (2002) showed that frequent participation in social, mental or productive activities can be associated with a lower risk of dementia in the older population and these associations are independent of age, sex, education,

cognitive functioning, presence of other chronic diseases, and physical and mental functioning. Hypothesized mechanisms for competence in social participation were: the role of mental stimulation in preservation of cognition, the person's self-concept of usefulness, and the person's competence in task completion. High levels of participation in social activities were found to prevent cognitive decline in community dwelling older adults (Wang, Karp, Winblad, & Fratiglioni, 2002). Based on their research, Fratiglioni, Borg and Winblad (2004) further concluded that an active and socially integrated lifestyle in late life protects against dementia and Alzheimer's disease. Farias, Mungas, Reed, Harvey, & Carli (2009) confirmed a significantly higher rate of conversion from mild cognitive impairment to dementia in clinically based samples of clients actively seeking evaluation and/or treatment in outpatient settings as compared to lower conversion rates in the community based cohorts.

Zunzunegui, Alvarado, Ser, and Otero (2003) examined two hypotheses: first, older men and women with poor social networks, little social integration, and engagement are at higher risk of cognitive decline irrespective of functional limitations; second, the nature of social relationships which are considered to be associated with cognitive function differ by sex in the elderly population. They concluded that older people with poor social connections and social disengagement are at higher risk of cognitive decline and/or dementia. Beland, Zunzunegui, Alvarado, Otero, and Ser (2005) further examined the conjoint trajectories of cognitive decline and social relations within the community, social ties and engagement with children, extended family and friends in a community-dwelling sample of people aged 65 and older over a time period of 7 years. Results showed that there is an association between social relations and cognitive

functions suggesting they help in maintaining higher mental function in later stages of life.

During Honolulu Asia aging study by Saczynsk et al (2006), the association of social engagement (which included maintaining social connections, and participation in social activities) and risk of dementia was examined and they concluded that there is an increasing risk of getting dementias with decreasing social engagement in late life, but there was no association found between midlife social engagement and late life dementia. Furthermore, according to Taaffe et al (2008), high levels of physical activities were associated with the reduction in the risk for incident dementia in the prospective cohort study of 2263 non-demented elderly Japanese American men. Findings from this study also suggested that men with poor physical function would benefit from enhancement of physical activity potentially leading to a protective effect or delaying the onset of dementia (Taaffe et al., 2008).

In an instrumental case study, the research found that capacities of participants for engagement in activities and emotional vitality were infrequently expressed at special care units. Diminished quality of life was attributable to dementia related impairments of the participants along with insufficient attention towards their occupational needs, capacities, and initiatives (Wood, Womack, & Hooper, 2009). According to Wood, Womack, and Hooper (2009) occupational therapists were not a part of the treatment team observed in their study. Occupational therapists could mentor frontline caregivers, along with strategy teaching and modeling, for implementing and designing activity situations that would optimize the interests, capacities, and participation of residents with dementia. Pynnonen (2012) concluded that participation in collective and productive

social activities have been correlated to decreased risk for mortality. In institutions such as long term care centres, the association was strong at the beginning of the study and not at follow-up.

To identify dimensions associated with physical and mental health, Golden, Conroy, and Lawlor (2009), conducted a research study that showed family support and social engagement to be uncorrelated. They concluded participation in social events and contact with friends and neighbors are elements of social engagement and the active ingredient of social support networks. Research done in the Irish Republic by Conroy, Golden, Jeffares, Neill, and McGee (2010), examined associations between cognitive impairment, loneliness, and boredom-proneness. The research revealed that loneliness and boredom proneness were closely related with decreased cognitive functions and had common underlying mechanism: failure to select and maintain attention on particular features of social environment (loneliness) or non-social environment (boredom-proneness) (Conroy, Golden, Jeffares, Neill, & McGee, 2010). Therefore, there is a strong correlation between community participation and cognitive functioning.

Leisure Activity Participation and Risk of Dementia

Wang et al (2013) proved that participation in leisure activities was related to a decreased risk of subsequent cognitive decline and was maintained over an average of 2.4 years in a population of Chinese people aged 65 years and above. Different types of activities protected against cognitive decline on different cognitive domains; for example, physical activity was associated with memory and language whereas social activity was found to be associated with global cognition. Their study concluded that participation in at least a single activity was related to maintained or improved cognitive function

irrespective of the gender. Across a 15-year perspective study, Sorman, Sundstrom, Ronnlund, Adolfsson, and Nilsson (2014) provided additional evidence relating the short term effects of engagement in leisure activities to decreased risk of developing dementia. Dube and Choyal (2012) examined the role of leisure in promoting healthy ageing among the elderly and cited the importance of appropriate leisure programs. Leisure programs can improve the quality of life among the elderly, in terms of social, creative, emotional and psychological well-being.

Impact of Activity Engagement on QOL

Quality of life (QOL) has been identified as central goal in the treatment of dementia by individuals with dementia, their families and their care providers. An evidence based literature review that examined evidence-based psychological treatments (EBTs) for behavioral disturbances in older adults with dementia, by Logsdon, McCurry, and Teri (2007). They have shown that psychosocial interventions (behavior therapy, environmental modifications, and caregiver training and education) can increase pleasant events, occupational therapy programs can promote participation in meaningful activities, physical activities can improve mood and decrease behavioral disturbances, and cognitive stimulation can improve memory and problem solving. Strong evidence exists that OT interventions help to maintain functioning of community dwelling clients with dementia and decrease caregiver burden which improves QOL of people with dementia within the community (Logsdon, McCurry, & Teri). Another evidence based review undertaken by Letts et al., (2011) looked for evidence establishing the effect of ADLs, IADLs, leisure and social participation on the following outcomes: quality of life, health and wellness, and client and caregiver satisfaction for people with AD and related dementias. Tailored

and activity based leisure interventions were found to impact caregiver satisfaction and well-being of dementia clients positively. Social interventions had short term positive effects on clients who were still engaged in verbal social interactions (Letts et al.). Strong evidence exists of effectiveness for modification of activity demands in occupational therapy to enable people with AD to participate in self-care and leisure occupations (Padilla, 2011). Additional systematic review of 28 studies revealed an increasing evidential base for different activity modifications to foster client engagement in activities. Activity modification showed potential to reduce behavioral and psychological symptoms resulting in enhanced quality of life in persons with dementia (Trahan, Kuo, Carlson, & Gitlin, 2014). Therefore, activity engagement positively affects cognitive functioning and impacts quality of life.

Caregiver Role to Promote Activity Engagement

MacRae (2011) examined how reactions of other people to and treatment of people living with dementia can influence how clients experience the condition. Findings revealed the significance of social context by showing the diminishing of negative effect from supportive relationships and positive social interactions. Research uncovered an important role played by family in enabling clients with dementia to become involved socially. Encouragement by family helped clients in creating meaningful life and identity sustenance (MacRae, 2011). Caregivers could play an important role in engaging clients with dementia in meaningful activities, feeling less burdened and more satisfied as activity participation is a representation of wellness for clients with dementia (Tsunaka, Chung, & Jenny, 2012). An online cross sectional survey by Dwyer, Moyle, Gembeck, and Leo (2013) included measures of suicidality, self-efficacy, physical health,

hopelessness, depression, optimism, anxiety, caregiver burden, and other aspects of life. They found that out of 120 family caretakers, 26 percent had contemplated suicide more than once in previous year, half of these never told this to anyone, and 30 percent said they were likely to attempt suicide in the future. They concluded a significant number of people might contemplate suicide while caring for a family member with dementia. Poorer mental health and lower self-efficacy for community support service use were the most important reasons considered for caretakers who had contemplated suicide (Dwyer, Moyle, Gembeck, & Leo, 2013). Hence, caregivers play an important role in improving participation of clients in community activities.

Dementia Care and Occupational Therapy

A case study by L. Graff et al (2006) provided details about the role of occupational therapy in improving communication, daily performance skills, quality of life, and sense of competence in a client with dementia and his/her primary caregiver. Occupational therapy intervention included an amalgamation of education, feasible goal setting, physical environmental adaptations, compensatory and supervision skills training, functional cognition change on client behavior, and improving caregiving roles. Occupational therapy proved to be of great value to both client and caregiver (L. Graff et al.). A novel occupational therapy program aimed at physical, cognitive, psychological, functional and behavioral domains showed improvements in sleep quality, physical performance, and greater energy for ADLs. Psychological components such as enhanced life appreciation and decreased fear and depression were also noted as being effective in delaying or preventing decline in quality of life in elderly with dementia (Kumar et al., 2014).

Research by Dooley and Hinojosa (2004) supported the unique importance of occupational therapy in progressive health conditions such as AD in effective prevention of unnecessary decline and maintenance of quality of life for both client and caregiver. A single blind randomized control trial by Graff et al (2006) showed that community based occupational therapy improved daily functioning of clients with dementia, despite limited learning abilities, which decreased caregiver burden. They used a community based occupational therapy program consisting of cognitive and behavioral intervention programs to train community dwelling clients for the use of compensatory aids for cognitive decline and coping behaviors, and supervision to caregivers that showed an improvement in their mood, health status and quality of life which was still significantly present at 12 month follow up (Graff et al., 2007). Hence, occupational therapy/therapists has a unique role to play in activity/environmental modification which maintains the functional levels of the clients and help them in improving their community participation.

Community Based Dementia Care

Social support systems and policy developers should place more emphasis on leisure activities for promoting process of healthy aging (Dube & Choyal, 2012). Charles et al (2005) assessed the effectiveness of four community based dementia care networks examining the relationship between types of administrative and service delivery exchanges among agencies. They further examined members' perception of the effectiveness of the different types of service delivery. This research clearly showed that using of multiple methods of service delivery had a positive impact on health and dementia care of elderly (Charles et al., 2005). Community based health care

professionals can be trained successfully in order to implement behavioral intervention with family caregivers of people with AD (Teri, McCurry, Logsdon, & Gibbons, 2005) which will improve dementia care. Policies and practices related to the active engagement (paid work, formal voluntary work, political involvement, community events participation, and social activism) of older people in the community life were compared in Sweden and Australia. Leonard and Johansson (2008) concluded that major issues were reduction of services for older population who only need small assistance and services for rural areas common in both countries. Some other issues were also found such as limited social activism and absence of age discrimination legislation (Leonard & Johansson). The evolution of Community Based Participatory Research (CBPR) has improved delivery of health services for people with dementia and their caregivers and is most likely to lead to sustained improvements in delivery of health services (Morgan et al., 2014). There is a great need of increase in participation of community based health care professionals to improve dementia care.

Holistic Intervention for Caregivers

Caregiver Options for Practical Experience (C.O.P.E.), an intervention program by occupational therapists, was proved beneficial for caregivers as it increased their awareness about remaining strengths of client with dementia. Recommendations helped caregivers reduce disturbed behaviors which decreased barriers in daily functioning and facilitated environment engagement for better living of both client and caregiver (Miller & Butin, 2000). A systematic review by Parker, Mills, and Abbey (2008), examined effectiveness of caregiver interventions (education, skills training and needed support to continue caregiving) which directly affect interactions and relationships between

caregiver and client, and assist caregiver to provide support for community dwelling clients. The evidence found about effectiveness of different interventions (multicomponent, psycho educational and support) was assessed on the outcome categories of depression, burden and health. Caregiver depression appeared to be the most important outcome measure to assess effectiveness of interventions (Parker, Miller, & Abbey, 2008). In Canada, research featured the profound effects of frontotemporal dementias (FTD) on spouses and children. Intervention programs (internet based video conferencing support group for spouses, website support for children and their parents and adult day program for patients) started by clinicians with the encouragement of family members through community engagement had positive impacts on clients and their caregivers (Schnall et al., 2013). There is a need for provision of community based holistic intervention programs to improve dementia care.

Alzheimer's/ Memory Cafe

Research was undertaken by Capus (2005) in the United Kingdom to understand the importance of Alzheimer's café for the people with dementia and their caregivers as well as concerned health professionals. Alzheimer's cafe proved beneficial by allowing caregivers to discuss their concerns with other caregivers which normalized their emotions, giving different social network to isolated families, and supporting clients in terms of living with dementia. In conclusion, Alzheimer's café provided non-stressful, non-clinical, unique, and unstructured environment for dementia clients and their care providers to meet as equals and have better insights, and understandings and work towards solutions together (Capus, 2005). Kumpers, Mur, Maarse, and Raak (2005) compared dementia care in England and Netherlands. Major shortcomings found were

weaknesses of generic services in supporting people with dementia and their caregivers, and failure to achieve integrative care. Alzheimer's café plays a significant role in the provision of educational, mental health, and emotional support for all those who are affected by dementia and Alzheimer's café setting is particularly useful as it can reach more people (Morrissey, 2006). In Australia, Alzheimer's café provided social and educational service, social inclusion and peer support. These were found to be the key benefits of the cafes and were successful in achieving all the goals of the service model by promoting social inclusion, preventing social isolation, and improving social and emotional well-being of people living with dementia, their caregivers and service providers (Dow, Haralambous, Hempton, Hunt, & Calleja, 2011).

Technology- Boon for people with Dementia and Caregivers

According to Lauriks et al (2007), support services and regular care insufficiently meet some of the needs (needs for personalized information, need for support in regard to symptoms of dementia, need for social contact and company and need for health monitoring and safety of the clients) of persons with dementia and their caregivers. Information and Communication Technology (ICT) has been showed to contribute to meet above mentioned unmet needs as websites offer tips and support for caregivers, but are not really attuned to individual clients. Instrumental ICT support has not been given much importance but there is an evidence that it could help coping behavioral and psychological changes in clients with dementia. Technical solutions like video conferencing and telephone has increased positive effects on clients and their caregivers, GPS technology has also been found to enhance feelings of safety, security and decreased levels of fear and anxiety among caregivers (Lauriks et al., 2007). Community mobility

represents connectedness to others, to goods and services, and to the occupations of everyday life as per Marottoli et al. (2000). Classen (2010) found a link between driving cessation and social isolation, depression, and early nursing home admission. Driving cessation was reported to be associated with declines in general health, physical, social and cognitive functions, and with increased risk of admissions to long term care facilities and mortality (Driving Cessation Report, 2015). Furthermore, a pilot study by Pot, Willemse, and Horjus (2012) focused on the effectiveness, feasibility and acceptability of Global Positioning System (GPS) by clients with dementia and their caregivers. People with dementia using GPS experienced more freedom when not accompanied by caretakers, reported being outside more than before, and had less conflicts with their caretakers. Caregivers of these clients felt less worried especially those who could reach their relatives using telephone. Research showed use of GPS to be promising in early stages of dementia for both clients and their caregivers (Pot, Willemse, & Horjus, 2012).

CHAPTER 2

JOURNAL MANUSCRIPT DRAFT

Abstract

Aim: The purpose of this study was to investigate the effects on quality of life for clients with dementia and their caregivers by participating in a community program, the Memory Café.

Method: In this qualitative, cross case study, the Marwit Meser Caregiver Grief Inventory (MM-CGI) was given to caregiver. Data collection was done by interviewing the participants; there was a main question with follow-up questions as needed. All the interviews were audiotaped and transcribed followed by primary and secondary coding. Shortlisting of categories resulted in emergence of themes which were common across cases and unique to each case.

Results: Emergent themes common across cases were: couplehood, community awareness and involvement, and role of occupational therapy. There were other themes which were found to be unique to each role of client, caregiver and care-provider (occupational therapist and community outreach coordinator).

Conclusion: Community participation has a direct impact on cognitive functioning and participation in community based programs favorably affects quality of life among clients with dementia and their caregivers. Participants had positive feedback about their involvement in community based program such as Memory Café which is supported strongly by literature.

Key words: community based programs; Alzheimer's/ Memory Café; dementia; caregivers; care-providers; social participation.

INTRODUCTION

Today more than forty-six million people are living with dementia worldwide which is more than the population of Spain. This number is estimated to increase to one hundred and thirty-one million by 2050. The total estimated cost of dementia worldwide is US \$818 billion, and it will become a trillion-dollar disease by 2018 (World Alzheimer Report, 2015). Five million Americans are living with Alzheimer's disease; Medicare and Medicaid paid \$150 billion in 2014 for health care, long-term care and hospice of people with Alzheimer's and other dementia (Alzheimer's Association, 2014). One third of all seniors who die in a given year have been diagnosed with Alzheimer's or another dementia (Alzheimer's Association, 2014).

Social Participation and Risk of Dementia

Wang, Karp, Winblad, and Fratiglioni (2002) showed that frequent participation in social, mental, or productive activities can be associated with a lower risk of dementia in older population. High levels of participation in social activities were found to prevent cognitive decline in community dwelling elderly (Wang, Karp, Winblad, & Fratiglioni, 2002). Based on their research, Fratiglioni, Borg and Winblad (2004) concluded that an active and socially integrated lifestyle in late life protects against dementia and Alzheimer's disease. Farias, Mungas, Reed, Harvey, and Carli (2009) confirmed a significantly higher rate of conversion from mild cognitive impairment to dementia in clients actively seeking evaluation and/or treatment in outpatient settings as compared to lower conversion rates in the community. Hence, involvement in various activities and participation in the community lowers risk of dementia.

Zunzunegui, Alvarado, Ser, and Otero (2003) concluded that older people with poor social connections and social disengagement are at higher risk of cognitive decline and/or dementia. Beland, Zunzunegui, Alvarado, Otero, and Ser (2005) showed that there is an association between social relations and cognitive functions suggesting that social relations help in maintaining higher mental function in later stages of life. During the Honolulu Asia aging study by Saczynsk et al (2006), the association of social engagement (which included maintaining social connections and participation in social activities) and risk of dementia was examined and they concluded that there is an increasing risk of getting dementias with decreasing social engagement in late life. According to Taaffe et al (2008), high levels of physical activities were associated with the reduction in the risk for incident dementia. The research revealed that loneliness and boredom proneness were closely related with decreased cognitive functions and had a common underlying mechanism: failure to select and maintain attention on particular features of social environment (loneliness) or non-social environment (boredom-proneness) (Conroy, Golden, Jeffares, Neill, & McGee, 2010). Therefore, there is a strong correlation between community participation and cognitive functioning.

Impact of Activity Engagement on QOL and Risk of Dementia

Wang et al (2013) proved that participation in leisure activities was related to a decreased risk of subsequent cognitive decline. Different types of activities protected against cognitive decline on different cognitive domains; for example, physical activity was associated with memory and language whereas social activity was found to be associated with global cognition. Letts et al. (2011) showed tailored and activity based leisure interventions were found to impact caregiver satisfaction and well-being of

dementia clients positively. Social interventions had short term positive effects on clients who were still engaged in verbal social interactions (Letts et al., 2011). Strong evidence exists of effectiveness by modification of activity demands in occupational therapy to enable people with AD to participate in self-care and leisure occupations (Padilla, 2011). Additional systematic review added that activity modification showed potential to reduce behavioral and psychological symptoms resulting in enhanced quality of life in persons with dementia (Trahan, Kuo, Carlson, & Gitlin, 2014). Therefore, activity engagement positively affects cognitive functioning and impacts quality of life.

Caregiver Role to Promote Activity Engagement

Parker, Mills, and Abbey (2008), examined effectiveness of caregiver interventions (education, skills training and needed support to continue caregiving) which directly affected interactions and relationships between caregiver and client as well as assist caregivers to provide support for community dwelling clients. Research uncovered an important role played by family in enabling dementia clients to involve socially and encouragement by family helped clients in creating meaningful life and maintaining identity (MacRae, 2011). Caregivers could play an important role in engaging dementia clients in meaningful activities, feeling less burdened and satisfied as activity participation is a representation of “wellness” for clients with dementia (Tsunaka, Chung, & Jenny, 2012). Hence, caregivers play an important role in improving participation of clients in community activities.

Dementia Care and Occupational Therapy

Research by Dooley and Hinojosa (2004) supported the unique importance of occupational therapy in progressive health conditions such as AD in prevention of

unnecessary decline and maintenance of quality of life based on person environment fit model which was proved to be effective for both client and caregiver. A case study by Graff et al (2006) provided details about the role of occupational therapy in improving communication, daily performance skills, quality of life and sense of competence in dementia client and his/her primary caregiver. They further used a community occupational therapy program that consisted of cognitive and behavioral intervention programs to train community dwelling clients for the use of compensatory aids for cognitive decline and coping behaviors, and supervision to caregivers that showed an improved their mood, health status and quality of life (Graff et al., 2007). Hence, occupational therapy/therapists has a unique role to play ranging from activity/environmental modification which maintains the functional levels of the clients and help them in improving their community participation.

Community Based Dementia Care

Community based health care professionals can be trained successfully in order to implement behavioral intervention with family caregivers of people with AD (Teri, McCurry, Logsdon, & Gibbons, 2005) which will improve dementia care. Social support system and policy developers should emphasize more on leisure activities for promoting process of healthy aging (Dube & Choyal, 2012). Community Based Participatory Research (CBPR) works for the improvement in delivery of health services for people with dementia and their caregivers has evolved and is most likely leading to sustained improvements in delivery of health services (Morgan et al., 2014). There is a great need of increase in participation of community based health care professionals to improve dementia care.

Holistic Intervention for Caregivers

Driving cessation was reported to be associated with declines in general health, physical, social and cognitive functions, and with increased risk of admissions to long term care facilities and mortality (Classes, 2010; Driving Cessation Report, 2015). Global Positioning System technology has also been found to enhance feelings of safety, security and decreased levels of fear and anxiety among caregivers (Lauriks et al., 2007). Parker, Mills, and Abbey (2008), found evidence about effectiveness of different interventions (multicomponent, psycho educational and support) could be assessed on the outcome categories of depression, burden and health. Research showed use of GPS to be promising in early stages of dementia for both clients and their caregivers (Pot, Willemse, & Horjus, 2012). In Canada, intervention programs (internet based video conferencing support group for spouses, website support for children and their parents and adult day program for patients) started by clinicians with the encouragement of family members through community engagement had positive impacts on clients and their caregivers (Schnall et al., 2013). There is a need for provision of community based holistic intervention programs to improvise dementia care.

Alzheimer's/ Memory Cafe

Research was undertaken by Capus (2005) in United Kingdom to understand the importance of Alzheimer's café for the people with dementia and their caregivers, and concerned health professionals. Alzheimer's cafe proved beneficial by allowing caregivers to discuss their concerns with other caregivers which normalized their emotions, giving different social network to isolated families, and supporting clients in terms of living with dementia. In conclusion, Alzheimer's café provided a non-stressful,

non-clinical, unique, and unstructured environment for dementia clients and their care providers to meet as equals, have better insights and understandings, and work towards solutions together (Capus, 2005). Kumpers, Mur, Maarse, and Raak (2005) compared dementia care in England and Netherlands. Major shortcomings found were weaknesses of generic services in supporting people with dementia and their caregivers, and failure to achieve integrative care. Alzheimer's café plays a significant role in the provision of educational, mental health, and emotional support for all those who are affected by dementia, and the Alzheimer's café setting is particularly useful as it can reach more people (Morrissey, 2006). In Australia, Alzheimer's café provided social and educational service, social inclusion, and peer support. These were found to be the key benefits of the cafes and were successful in achieving all the goals of the service model by promoting social inclusion, preventing social isolation, and improving social and emotional well-being of people living with dementia, their caregivers and service providers (Dow, Haralambous, Hempton, Hunt, & Calleja, 2011). There is a need to increase community based programs such as Memory Café because it not only provides a positive environment for informal conversations but also maintains functioning of a client.

Background

An Alzheimer's café is a place where people with memory problems and other symptoms of dementia often meet along with their family, caregivers and friends. The first ever Alzheimer's café was started in the Netherlands in 1997 by Dr. Bere Miesen, a geriatric psychiatrist who developed and implemented this idea where there could be open communication, supportive and encouraging interactions between caregivers and

care providers in playful, joyous and entertaining atmosphere. European model of Netherlands or UK focuses on education about disease progression, socialization and support for caregivers whereas the American model of Canada and United States emphasis is emphasized on informal social conversations, friendships are facilitated with provided informal support and focus areas are arts, entertainment, music or crafts.

Previous research studies were found were mostly from the Netherlands and United Kingdom as Memory café is a relatively new concept in the United States of America. In these prior studies, no importance was given to the viewpoint of the clients with dementia. There was no participation of clients and only caregivers were interviewed about their experiences in the found data.

Purpose of study

The purposes of this study were to: (1) describe effects of participation in community based programs like Memory Café on quality of life for clients with dementia and their caregivers; (2) explore meanings, experiences and methods of achieving increased community participation for clients with dementia and their caregivers; and (3) develop program implications; for example GPS use and its effects, reimbursement for professionals who are implementing such programs, involving healthcare professionals other than occupational therapists; (4) to make an addition to the limited research literature published in the United States.

Study Design

This study is a qualitative study using an in-depth interview approach, (Polit & Beck, 2004) and cross case analysis (Miles, Huberman & Saldana, 2013). Data collection was done by interviewing the participants by asking a main question with

follow up questions as needed using the Polit and Beck approach. There was a different set of follow up questions for the client with dementia, his caregiver and care provider. Interviews were recorded and transcribed verbatim after which coding was done and categories were shortlisted.

To ensure trustworthiness, first the caregiver's stress and grief levels were assessed by using a quantitative assessment tool called Marwit-Meuser Caregiver Grief Inventory. The MM-CGI, was developed and pilot tested on two samples of dementia caregivers: eighty-seven caregivers during development phase and one hundred sixty-six for pilot testing. Total grief level is summed up by adding items of personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation. Scores are then plotted on the grid which is a grief profile and grief levels could be high, average or low (Marwit & Meuser, 2001).

Participants

Purposeful recruitment was done for this qualitative study through a local Memory Café, program running at a University in southeast, USA for clients with dementia and their caregivers. Interested individuals contacted the lead investigator by phone/email to be screened and briefed on the study, and to schedule an initial meeting. The following inclusion criteria were selected: (a) Community dwelling participants of Memory Café; (b) Clients with dementia and their caregiver with age range 55 years and above; (c) diagnosed with any type of dementia in medical records and stable with current medications; and (d) health care provider with experience working with Memory Café. (Table 1)

Procedure

IRB approval was obtained from the university. Data collection took place over a single session per participant in the participants' location of choice. Each interview was audiotaped. The client with dementia was accompanied by two caregivers so that one caregiver could supervise the client while the primary caregiver was interviewed. The lead author collected all data. At the beginning of the session, the study's purpose was again thoroughly reviewed, the consent form was signed, and the MM-CGI was administered to the primary caregiver. During the second part of the session, qualitative interviewing process was initiated and concluded. Each participant was asked "What are your experiences with the Memory Café" with follow-up questions as needed. A different set of follow up questions was used each for client, caregiver and care providers. The client was given answer options and a rating scale to accommodate his cognitive level. Guiding questions revolved around how participation in Memory Café affected community participation and quality of life, role of occupational therapy, and about use of technology like GPS. (See Table 2 for sample questions).

Data Analysis

All audiotaped sessions were transcribed verbatim and inductively analyzed by the investigator. The investigator completed an initial analysis of the data collected by first reading the entire interview. Then, the transcription was examined line- by- line and important key statements were identified and reflective remarks were included in the margins. In particular, the interviews were examined for statements related to community participation and Memory café. Next, key statements and reflective remarks were reviewed from each interview and discussed by the investigator and thesis advisor.

Case by case analysis was conducted, resulting in initial codes for each participant: 17 codes for the client with dementia, 48 codes for the caregiver, 39 codes for one care-provider (occupational therapist) and 33 codes for the other care-provider (outreach coordinator). After primary coding, secondary coding was done. Secondary coding resulted in categories across the cases which were: increased involvement in activity and leisure for the clients; decreased anxiety, stress and isolation among clients and their caregivers; decreased depression and frustration among caregivers; meeting new people lead to exchange of idea which encourages support from the family (other than caregiver); caregivers learned new ways to support the client; improved quality of life for the client with dementia and their caregivers; increased connections within different families; quality time spent by client with dementia and their spouse which helped maintaining couplehood; Memory Café was an enjoyable, stress free environment where worry free socialization takes place; need for volunteers, funding and more participants (clients with caregivers and care providers); community need to be aware of such programs. After categories were identified, some were common across all cases while others were unique to each case

Emergent themes across the cases after final analysis were: (1) Couplehood, (2) Community awareness and involvement, (3) and Role of occupational therapy. Themes unique to the client were: Preferred activities with a more physical component and Business meetings were boring. Themes unique to the caregiver were: Care giving is a never ending learning process because it is always changing and Other families need to be involved, it is an important part of taking care of the person with dementia. Themes unique to the care-providers were: OT helps in facilitating event venue (community) and

client/caregiver needs, Informational session for caregivers, Use of technology, and Maintain/improve client functioning. (See Table 3)

Trustworthiness

Prior to data collection, the investigator and thesis advisor carefully examined their own assumptions and biases regarding clients with dementia, especially about current participants of Memory Café. Author requested an expert give feedback on how to best write questions to be used during an interview for the client as appropriate to his cognitive level. As the occupational therapist, who has been running local Memory Café, had a very positive outlook towards all the aspects of the program hence, another participant care-provider, who is currently employed with the Alzheimer's Association as Community Outreach Coordinator and has an experience of attending Memory Cafes at different locations, was interviewed to double check the results. The investigator had experience interviewing and working for clients with dementia and their caregivers previously. An experienced researcher was involved with author throughout during the process of development of categories and themes. The MM-CGI was given to the caregiver to assess her grief levels and she was found to be in average range which means neither in the need for formal intervention to enhance coping and nor in the state of denial.

Results

Couplehood

Couplehood supported development of new memories among clients with dementia and their spouse; decreased isolation and increased socialization; supported more socially appropriate behavior and increased participation in activities by clients

with dementia in a stress free environment being at Memory Café events; increased conversations among clients with dementia with their caregivers and different families; and support from other families helped caregivers in learning new strategies at a comfortable and happy place like Memory Café. Sandra (occupational therapist) said, “Well, I think first of all one of the things that we really need to do is to make sure that we keep couples together and that we have reinforcements for their couplehood.” Caregiver validated by saying, “Memory Café gives us (couple) a common thing with others (clients and caregivers) that have dementia.

Community Awareness and Involvement

Every participant had a viewpoint that there is a great need of community awareness at involvement not only at the level of participation as a caregiver/ care provider with a client but also at the level of volunteering by students and medical professionals. There is poor funding for running such community based programs and reimbursements are not there which hampers the participation by entry level occupational therapists. Volunteering by occupational therapy students and mother medical professions should be encouraged with reimbursements for the better functioning of community based programs like Memory cafe. According to the Alzheimer’s Association, there are five million Americans living with dementia (Alzheimer’s Association, 2014); it is imperative that there be acceptance of this disease, of clients with dementia and their families. Communities need to understand the progression and impact of dementia on the clients and their families in order to support them in the best possible manner. Mrs. H (caregiver) mentioned during an interview,

It might be that we could try to find some people in the community, and I just thought of this, ... [people] that maybe could do like OT's husband did one time, he brought artifacts that they could discover but I also think there are other things in the community that if we talk to some of the people they might be able to come up with something to help us. I don't know whether the library might be able to bring books that might interest them if it was nothing even but picture books.

Role of Occupational Therapy

Occupational therapists have an integral and unique role at the community level as they have the right training and better skills as a care provider to work with clients with dementia as mentioned by community outreach coordinator “Occupational therapists have the training to help families with dementia adapt their environment, modify tasks, and educate families so that persons with dementia can maintain their independence and level of functioning for as long as possible.” Occupational therapists can help families by adaptation of home and community environment and task modification and can educate caregivers at different stages during the progression of the disease. The wife of a client with dementia (caregiver) said,

Because I think the occupational therapy group has been taught to take care of the patient and I think that's what we're dealing with is patients... I think you all have been taught how to deal with this situation and you have more patience than I do.

Themes Unique to Participant Roles

There were themes that were found during the research that were unique to each role of care providers (OT and Community Outreach Coordinator), caregiver (wife), and client with dementia (husband). According to *care providers*, OT helps in facilitating

event in the community by meeting needs of client and/or caregiver. Also, OT can provide informational sessions for caregivers which could make transition from one stage to another smooth during the progression of the disease. Use of technology like global positioning systems, iPads etc. can help in maintaining client functioning. As per *caregiver*, caregiving for the clients with dementia is important aspect because of the progressive nature of the disease, therefore, caregiving is never ending learning process because symptoms of the disease are always changing. She also feels that other families need to be involved in community based programs such as Memory Café as it helps in taking care of client with dementia in a better manner. *Client* preferred activities with more physical components and business meetings were boring to him possibly because he was supposed to listen to the speaker for at least the initial first half of the event.

Discussion

Positive impressions of a community based program Memory Café was found. The Community Outreach Coordinator (care-provider) who has been participating in two different Memory Cafes said,

Memory Cafés, they're designed so that caregivers have a way, have an outlet to do something with their loved one with dementia. And so it's a low stress kind of environment. We don't talk about memory problems. We try to do as much socialization as we can with folks. Life's not over and I think Memory Café is a way to continue that journey for folks.

Occupational therapist (care-provider) who runs this program had wonderful experiences and clearly mentioned, "My experiences with the Memory Café have been very, very positive. I found that clients required fewer cues and that there was less anxiety and a

more relaxed atmosphere at the Memory Café than there was at the respite program.” Caregiver said, “I like Memory Café, especially the fact that it gets together those that have lost or are having trouble with their memory and it gives them someone to communicate with without feeling a stress problem, but I also like the fact that families also are involved in that and you get to talk to other families.” Client with dementia himself rated found Memory café positive and rated it nine out of ten on the scale of ten.

The caregiver played an important role in engaging her husband with dementia in meaningful activities, felt less burdened and more satisfied as activity participation as a result of participation in Memory Café. These results are similar to those found by Tsunaka, Chung, and Jenny (2012) that caregivers can help in better participation of clients with dementia in community based programs such as Memory Cafe. Caregiver and care-providers all supported that an occupational therapist can modify activity demands which has been previously found to enable people with AD to participate in leisure occupations (Padilla, 2011, Dooley &Hinojosa, 2004). Caregiver and care-providers all substantiated the concept that Memory Café plays a significant role in the provision of educational, mental health, and emotional support for all those who are affected by dementia and that more community-based programs are needed (Morrissey, 2006). Therefore, community based programs such as Memory Café not only increase participation of clients and their caregivers in the community but also gives them an informal platform to discuss their worries and get the right kind of support. All participants validated that the Memory Café was a happy, enjoyable, and stress-free place where the caregiver and the client could participate together in different activities and work towards solutions together with the care-provider in an informal environment which

is supported in the literature (Capus, 2005). It can be concluded that Memory Café provides a platform to clients and caregivers to engage better at community level with different families and care-providers.

A limitation of the study was a small sample size from a single Memory Café in a specific geographic region. In addition, a lack of ethnic diversity among the participants makes it difficult to find significant relationships from the data to transfer to other populations. Larger sample sizes from different Memory Cafes would have ensured a more representative distribution of the population and be considered a better representation of groups of people to whom results could be generalized or transferred. Lastly, time was constrained as the available period to investigate the research problem and to measure change or stability over time was less than a year.

Implications for Health Care

The results of this study implied that there is a need to have more community based programs like Memory Café where clients with their caregivers and the general population should be encouraged to participate so as to increase quality of life in clients and their caregivers as well as more acceptance of dementia in society. Medical healthcare professionals in addition to occupational therapists should be trained to initiate and implement or contribute to such programs in their respective local communities. Three of the four participants mentioned the need for funding for initiation and implementation of community based programs and reimbursements for the involved professionals. Use of technology like GPS provides freedom to clients with dementia for better mobility in the community and participate in community based programs such as Memory café (Pot, Willemse, & Horjus, 2012). Preferences of a client, for example,

“business meetings were boring” should be kept in mind while preparing the program design because even minimal contribution of the client with dementia should be of utmost importance. For informational sessions, caregivers’ issues at hand should be resolved by giving it topmost priority and then proceeding with usual plan. Hence, more community based programs can make dementia care better and more beneficial for participants.

Table 1

Examples of follow up questions

	Examples of follow up questions as needed
Client with Dementia	<ol style="list-style-type: none"> 1. What do you like about the Memory Café? 2. What is your favorite activity at Memory Café? Aquatics, Bowling, Eating out, Playing miniature golf, Musical concerts, Business meetings with a theme (international tea) 3. What other community activities do you like? 4. Rate your experiences with Memory Café on the scale of ten.
Care-provider – Occupational Therapist	<ol style="list-style-type: none"> 1. How important are community based programs such as Memory Café and why? 2. Do you think we need to have more such community based programs? 3. How do you think such community based programs enhance quality of life for clients with dementia and their caregivers? 4. How do you think occupational therapists play an integral role in the initiation and implementation of community based programs like Memory café?
Care-provider – Community Outreach Coordinator	<ol style="list-style-type: none"> 1. What would you suggest to help the Memory Café be better equipped? 2. How could the larger community involve other healthcare professionals in the implementation of community based programs? 3. How do you think such community based programs enhance quality of life for clients with dementia and their caregivers? 4. Do you think that occupational therapists should play an integral role in initiation and implementation of community based programs like Memory café? Why or why not? If yes, are they given opportunities to do so?
Caregiver	<ol style="list-style-type: none"> 1. What are your reasons for currently being actively involved in Memory Café? What were your goals/reasons for joining Memory café? Are those goals being met? 2. How do you think Memory Café has improved the level of community participation for you and your family member with dementia? 3. How has Memory Café enhanced quality of life for you and your family member? 4. How have your caregiving stress levels changed since you started participating in Memory Café?

Table 2

Description of participants

<u>Participant</u>	<u>Age</u>	<u>Occupation</u>	<u>Number of years working with dementia</u>	<u>Number of years with dementia</u>
Sandra Norway	N/A	Occupational Therapist- Care Provider	20 years	N/A
Cindy Smith	N/A	Community Outreach Coordinator- Care Provider	15 years	N/A
Mrs. Hawkins	75 y.o.	Caregiver	N/A	N/A
Mr. Hawkins	74 y.o.	Care Recipient	N/A	8

Table 3

Data Analysis

<p>Primary Coding</p>	<ul style="list-style-type: none"> • 17 codes for the client with dementia • 48 codes for the caregiver • 39 codes for one care-provider (occupational therapist) • 33 codes for the other care-provider (community outreach coordinator).
<p>Categories after Secondary Coding</p>	<ul style="list-style-type: none"> • Increased involvement in activity and leisure for the clients • Decreased anxiety, stress and isolation among clients and their caregivers • Decreased depression and frustration among caregivers; meeting new people lead to exchange of idea which encourages support from the family (other than caregiver) caregivers learned new ways to support the client • Improved quality of life for the client with dementia and their caregivers • Increased connections within different families; quality time spent by client with dementia and their spouse which helped maintaining couplehood • Memory Café was an enjoyable, stress free environment where worry free socialization takes place • Need for volunteers, funding and more participants (clients with caregivers and care providers) • Community need to be aware of such programs.
<p>Emergent themes across the cases after final analysis</p>	<ul style="list-style-type: none"> • Couplehood • Community awareness and involvement • Role of occupational therapy
<p>Unique themes</p>	<p>Client</p> <ul style="list-style-type: none"> • Preferred activities with a more physical component • Business meetings were boring. <p>Caregiver</p> <ul style="list-style-type: none"> • Care giving is never ending learning process because it is always changing. • Other families need to be involved, it is important part of taking care of the person with dementia. <p>Care-provider</p> <ul style="list-style-type: none"> • OT helps in facilitating event venue(community) and client/caregiver needs • Informational session for caregivers • Use of technology • Maintain/improve client functioning.

Table 4

Cross Case Analysis Quotes

<p>Couplehood</p>	<p><u>Care Providers</u>- “I found that they (clients) required fewer cues and that there was less anxiety and a more relaxed atmosphere at the Memory Café than there was at the respite program. When they (clients) were with their spouse I felt that they behave in a more adult socially appropriate manner, rather than when they were separated from their spouse and in a room among people that they weren’t as familiar with.”</p> <p><u>Caregiver</u>- “Memory Café gives us a common thing with others that have dementia.”</p>
<p>Community Awareness and Involvement</p>	<p><u>Care Provider</u>- “Memory Café can have informational sessions and that during these sessions you can very easily involve physical therapists to come in and talk about the benefits of physical therapy, can have a role for a pharmacist to come in and give an informational session and a nurse, etc., or you could even have a neurologist present”</p> <p><u>Caregiver</u>- “I think I am very disappointed that we don't have more from the group that. I would like to know how to encourage them, you know, to participate because I think they're missing out on something.”</p>
<p>Role of Occupational Therapy</p>	<p><u>Care Provider</u>- “But I think the word plan is that an occupational therapist is, again, able to foresee some of the pitfalls and some of the problems and solve them before the site is utilized in order to maximize the enjoyment and reduce the stress of both the caregiver and the client.”</p> <p><u>Caregiver</u>- “I think you (OT) all have been taught how to deal with this situation and you have more patience than I do.”</p>

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APPENDIX A

Informed Consent in Eastern Kentucky University Format

Consent to Participate in Research Study

Role of community participation in improving quality of life of life in dementia clients and their caregivers

Why am I being asked to participate in this research?

You are being invited to take part in research study about the effectiveness of participation in community based program such as Memory Café in improving quality of life. You are being invited to participate in this research because you are a caregiver/care-provider to client with dementia and you meet criterion necessary for effective research. If you take part in this study, you will be one of about 13 people to do so.

Who is doing the study?

The person doing this study is Mridula Dhamija, OTS at Eastern Kentucky University. Dr. MaryEllen Thompson is guiding her in this research. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

By doing this study, we hope to learn effectiveness of community based programs such as Memory cafe in improving quality of life in dementia clients and their caregivers. Although, some literature does exist, more is needed to solidify potential of such programs to help increase the quality of life for dementia clients and their caregivers. We hope to, from this study, be able to incorporate community participation into the numerous treatment interventions that we currently have for loss of quality of life for dementia clients and their caregivers.

Where is the study going to take place and how long will it last?

The interviews will take place on the Eastern Kentucky University campus, either in the Crabbe library or the Dizney building. Interviews may also be conducted over the Skype application' email messages, phone conversations done at the lead investigators home or private room in the Dizney building, and text messages. Phone conversations will be done over the speaker phone and will be voice recorded and transcribed.

What will I asked to do?

If you are a caregiver, you will be asked to complete the MM Caregiver Grief Inventory and a semi-structured interview. If you are a care-provider you will be asked to complete a semi structured interview.

Are there any reasons why I should not take part in this study?

You should not participate if the person you provide care for is not 55 years of age and older, has not participated or is currently participating in the Memory Café, has cognitive impairments other than dementia or is unstable with present medications.

What are the possible risks and discomforts?

There are no potential risks to participants of the study. You may, however, experience a previously unknown risk or side effect.

Will I benefit from taking part in this study?

There is no guarantee that you will get any benefit from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not take part to take part in the study, there are no other choices.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in this study? You

will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what information us. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my taking part in this research end early?

If you decide to take part in this study, you will still have the right to decide at any time that you no longer want to participate. You will not be treated differently, if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to do activities they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Mridula Dhamija, OTS at 859-582-4742 immediately. It is important for you to know that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. The cost will be your responsibility. Also, Eastern Kentucky University will not pay for your wages you may lose if you are harmed by this study.

Usually, medical costs that result from research related harm cannot be included as regular medical costs. Therefore, the costs related to dementia care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you accept this invitation to take part in this study, please ask any questions that come to your mind now. Later, if have any questions about the study you can contact the investigator, Mridula Dhamija, OTS at 859-582-4742. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study Name of person providing information to subject

IRB Approval 06 -216 <hr/> THE FORMAL 6/30/15 - 1/9/16

Appendix B

MM-CGI

Appendix B
Marwit—Meuser Caregiver Grief Inventory

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1—5 to the right using the answer key below (for example, 5 = strongly agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed at the end.

ANSWER KEY					
1 = Strongly Disagree // 2= Disagree // 3=Somewhat Agree // 4 = Agree // 5=Strongly Agree					
1	I've had to give up a great deal to be a caregiver.	2	3	4 5	
2	I miss so many of the activities we used to share	1	2	3 4 5	
3	I feel I am losing my freedom.	3	4	5	
4	My physical health has declined from the stress of being a caregiver.	3	4	5	
5	I have nobody to communicate with.	2	3	4 5	
6	I don't know what is happening. I feel confused and unsure.	3	4	5	
7	I carry a lot of stress as a caregiver.	3	4	5	
8	I receive enough emotional support from others.	3	4	5	Cr
9	I have this empty, sick feeling knowing that my loved one is "gone."	3	4	5	
10	I feel anxious and scared	3	4	5	
11	My personal life has changed a great deal.	3	4	5	
12	I spend a lot of time worrying about the bad things to come.	3	4	5	
13	Dementia is like a double loss . . . I've lost the closeness with my loved one and connectedness with m famil	2	3	4 5	
14	I feel terrific sadness	3	4	5	
15	This situation is totally unacceptable in my heart.	2	3	4 5	
16	My friends simply don't understand what I'm going through.	3	4	5	

17	I feel this constant sense of responsibility, and it just never leaves.					
18	I long for what was, what we had and shared in the past.	2	3	4	5	
	I could deal with other serious disabilities better than with this.		3	4	5	
20	I can't feel free in this situation.		3	4	5	
21	I'm having trouble sleeping.	2	3	4	5	
22	I'm at peace with myself and my situation in life.		3	4	5	Cr
23	It's a life phase, and I know we'll get through it.	2	3	4	5	Cr
24	My extended family has no idea what I go through in caring for him/her.	2	3	4	5	
25	I feel so frustrated that I often tune him/her out.	1	2	3	4	5
26	I am always worrying	2	3	4	5	
27	I'm angry at the disease for robbing me of so much.		3	4	5	
28	This is requiring more emotional energy and determination than I ever expected.		3	4	5	
29	I will be tied up with this for who knows how long.		3	4	5	
30	It hurts to put her/him to bed at night and realize that she/he is "gone."		3	4	5	
31	I feel very sad about what this disease has done.	2	3	4	5	
32	I feel severe depression.	2	3	4	5	

ANSWER KEY							
1 = strongly Disagree // 2= Disagree // 3= Somewhat Agree // 4 = Agree//5 = Strongly Agree							
33	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
34	The people closest to me do not understand what I'm going through	1	2	3	4	5	C
35	His/her death will bring me renewed personal freedom to live my life.		2	3	4	5	
36	I feel powerless.	1	2	3	4	5	
37	It's frightening because you know doctors can't cure this disease, so things only et worse.	1	2	3	4	5	
38	I've lost other people close to me, but the losses I'm experiencing now are much more troubling	1	2	3	4	5	
39	Independence is what I've lost . . . I don't have the freedom to go and do what I want.	1	2	3	4	5	
40	I've had to make some drastic changes in my life as a result of becoming a caregiver.	1	2	3	4	5	
41	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	
42	I'm stuck in this caregiving world, and there's nothing I can do about it.	1	2	3	4	5	
43	I can't contain my sadness about all that's happening	1	2	3	4	5	
44	What upsets me most is what I've had to give up.	1	2	3	4	5	
45	I'm managing pretty well overall.	1	2	3	4	5	Cr
46	I think I'm denying the full implications of this for my life.	1	2	3	4	5	C
47	I get excellent support from members of my family.	1	2	3	4	5	Cr
48	I've had a hard time accepting what is happening.	1	2	3	4	5	
49	The demands on me are growing faster than I ever expected.	1	2	3	4	5	
50	I wish this was all a dream and I could wake up back in my old life.	1	2	3	4	5	

FAIR USE OF THE MM-CGI: The inventory was developed and pilot tested on two samples of dementia caregivers: 87 caregivers (45 adult children, 42 spouses) in the development phase and 166 (83 of each type) for pilot testing. Funding support came from Alzheimer's Association Grant 1999-PRG-1730. A three factor solution materialized (Kaiser-Meyer-Olkin = .889), and these factors are listed below. The authors consider this instrument to be part of the public domain. The authors would appreciate hearing feedback on how the scale is used. Researchers who wish to administer the inventory and/or modify it as part of a formal study are asked to notify the authors of their plans (meuser@abraxas.wustl.edu).

References:

Meuser, T. M , & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41, 658—770

Self-Scoring Procedure: Add the numbers you circled to derive the following subscale and total grief scores. Use the letters to the right of each score to guide you. C Items with r afterwards must first be reverse scored (1 -+5, 2+4, 3+3, 4+2, 5+1) before adding to calculate your scores.

Personal Sacrifice Burden (A Items) = _____
 (18 items, ___ 54 3, SD = 14.1, 93, split-half = 91)

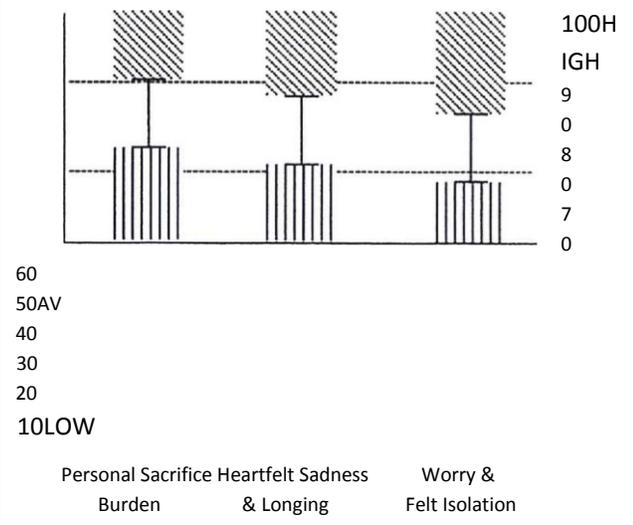
Heartfelt Sadness and Longing (B Items) = _____
 (15 items, M: 48 2, SD= 11.1, a = 90, split-half = 86)

Worry and Felt Isolation (C Items) = _____
 (17 items, ___ 40 6, SD = 11.9, 91, split-half = .91)

Total Grief Level (Sum A + B + C) = _____
 (50 items, 144 0, SD = 31.6, a = .96, split-half= 87)

Plot your scores using the grid to the right. Make an "X" in the shaded section nearest to your numeric score for each subscale. This is your grief profile. Discuss this profile with your support group leader or counselor.

MM-CGI Personal Grief Profile



What do these scores mean?

Scores in the top hash-marked area are higher than average based validation sample statistics (1 SD above the mean). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores in the bottom section (1 SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief. Average scores in the center of each column indicate common reactions. These are general guides for discussion and support only; more research is needed on more specific interpretation issues

Source: Meuser, T. M , & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41, 658—770

Appendix C
Interview Questions

Questionnaire

For clients with dementia

1. Tell me about what you do at the Memory Café

Follow up questions as needed

5. What do you like about the Memory Café?
6. What is your favorite activity at Memory Café?

Aquatics

Bowling

Eating out

Playing miniature golf

Musical concerts

Business meetings with a theme (international tea)

Other

7. What other community activities do you like?
8. What activities would you like to suggest for Memory Café?
9. What is the most interesting part of being at Memory Café?
10. How has Memory Cafe improved your level of community participation?
11. How has Memory Café enhanced your quality of life?

“Quality of life” is your general well-being. Your health, comfort, happiness relationship with others, feelings.

12. What activities did you do out in the community before you had dementia?
13. What activities did you do out in the community now? Do you do more activities or less activities in the community now than you did before?

For Caregivers

1. Tell me about your experiences with the Memory Café

Follow up questions as needed

5. What are your reasons for currently being actively involved in Memory Café? What were your goals/reasons for joining Memory café? Are those goals being met?
6. How do you think Memory Café has improved the level of community participation for you and your family member with dementia?
 - a. What was the level of community participation for you and family member with dementia before he/she was diagnosed with dementia?
 - b. Could you please explain how Dementia affected the level of community participation for you and your family member with dementia?
7. How has Memory Café enhanced quality of life for you and your family member?
8. How have your caregiving stress levels changed since you started participating in Memory Café?
9. Can you give any suggestions to make Memory Café better?
10. Why would you recommend community based programs like Memory Cafe to other caregivers?
11. How has community participation in the Memory Cafe helped you to be a better caregiver?
12. Would you like to be involved in more community based programs like Memory Café?
13. How do you think occupational therapy has a role to play in initiation and implementation of such programs?

For Occupational Therapists

1. Tell me about your experiences with the Memory Café.

Follow up questions as needed

5. How important are community based programs such as Memory Café and why?
6. Do you think we need to have more such community based programs?
7. How do you think such community based programs enhance quality of life for clients with dementia and their caregivers?
8. How do you think occupational therapists play an integral role in the initiation and implementation of community based programs like Memory café?
9. What roles could be played by occupational therapists in these settings?
 - a. Do we have adequate knowledge, skills and opportunities to do that?

10. Should other health care professionals be involved in implementation of community based programs like Memory café? Why or why not?
11. Do you teach use of technology that would be helpful to caregivers and clients with dementia? If not, would you want to do that?
12. Do you think technology can also help in better involvement for clients with dementia and their caregivers in community participation?
13. How comfortable are you about using technology with clients who have Dementia?

For an Attendee from Alzheimer's Association

1. Tell me about your experiences with the Memory Café.

Follow up questions as needed

5. Why do you think community based programs like Memory Café are important?
6. Do you think we need to have more such community based programs? Why or why not?
7. What would you suggest to help the Memory Café be better equipped?
8. How could the larger community involve other healthcare professionals in the implementation of community based programs?
9. How do you think such community based programs enhance quality of life for clients with dementia and their caregivers?
10. Do you think that occupational therapists should play an integral role in initiation and implementation of community based programs like Memory café? Why or why not? If yes, are they given opportunities to do so