

The Lived Experience Of Young-onset Dementia

2011

Debra A. Hunt
University of Central Florida

Find similar works at: <http://stars.library.ucf.edu/etd>

University of Central Florida Libraries <http://library.ucf.edu>

 Part of the [Nursing Commons](#)

STARS Citation

Hunt, Debra A., "The Lived Experience Of Young-onset Dementia" (2011). *Electronic Theses and Dissertations*. 2053.
<http://stars.library.ucf.edu/etd/2053>

This Doctoral Dissertation (Open Access) is brought to you for free and open access by STARS. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of STARS. For more information, please contact lee.dotson@ucf.edu.

THE LIVED EXPERIENCE OF YOUNG-ONSET DEMENTIA

by

DEBRA A. HUNT

BSN, Southern Adventist University, 1996

MSN, University of Central Florida, 1998

A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the College of Nursing
at the University of Central Florida
Orlando, Florida

Spring Term
2011

Major Professor: Karen Aroian

© 2011 Debra A. Hunt

ABSTRACT

The lived experiences of dementia in older persons have been well studied, but the unique experiences of persons between ages 35 and 65 years who are living with young-onset dementia have not been closely examined. The purpose of the research was to explore the experiences of middle-aged individuals living with young-onset dementia.

Van Manen's (1990) approach to interpretive phenomenological inquiry was used to answer the research question. Purposive sampling was used to recruit 9 people between 42 to 61 years of age who had received a formal diagnosis of mild or early-stage dementia. Participants were prescreened for the ability to reflect on their illness and the Short Portable Mental Status Questionnaire (SPMSQ) was used to verify the participant's eligibility. Semi-structured, conversational interviews were used to gather the data. Consistent with van Manen's method of phenomenological reflection, theme analysis using the selective approach was used to grasp the essential meanings of the experience. Each participant was interviewed a minimum of two times.

Six themes were extracted from 19 conversational interviews with persons living with young-onset dementia: feeling frustrated, fear of slipping away, loss of personhood, life interrupted, finding a sense of security in the familiar, and wanting one's voice to be heard. These themes are interpretations of the human experience of living with dementia and are not intended to be generalizations or theoretical concepts.

The experiences described in this study raise awareness about young-onset dementia and help health care practitioners and society-at-large develop a better understanding of what it is like to live with the disease. The misperception that people suffering from dementia do not have insight and the underestimation of their abilities is a great source of frustration for these people.

Study findings also suggest that middle-age people with dementia want to be involved in meaningful, productive activities. Their resounding plea is to have their personhood embraced instead of negated.

This dissertation is dedicated to my family. To my husband Alan, thank you for your love, support, and guidance. Without your encouragement, my successes would not have been possible. You are the reason I am here today. To my children, Jeff, Adam, and Ashley, thank you for your love and support. And finally, to the people who participated in my study. Thank you for sharing your experiences, hopes, and dreams for a better tomorrow for people who are living with dementia.

ACKNOWLEDGMENTS

First and foremost, my gratitude goes to my advisor, mentor, and committee chair, Dr. Karen Aroian, who shared her passion for research and supported me through countless hours of advisement and guidance in my pursuit of a doctorate. I am inspired by her scholarship and hope to follow her example by mentoring those who follow me.

I would like thank my committee members, Dr. Jean Kijek for encouraging me to pursue a doctoral degree and her never wavering support; Dr. Angeline Bushy for her valuable insights on vulnerable populations and the phenomenological method; and Dr. Denise Gammonley for sharing her expertise and perspectives on an aging society.

To my colleagues and friends, Dr. Victoria Loerzel and Dr. Betsy Guimond, thank you for always 'being there' for me. Your friendship and support will never be forgotten.

Lastly, thank you to the Florida Nurses Foundation and the Greater Florida Chapter of the Lupus Foundation of America for their financial support in the form of grants.

TABLE OF CONTENTS

LIST OF TABLES	x
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: YOUNG-ONSET DEMENTIA: A REVIEW OF THE LITERATURE.....	3
Abstract	3
Introduction.....	3
Distinctions between Young-Onset and Older-Onset Dementia	4
Psychosocial Issues.....	5
Developmental Issues	5
Work Role.....	7
Family Roles and Relationships.....	8
Difficulty Obtaining a Diagnosis	9
Lack of Resources.....	10
Implications for Nursing	11
References.....	12
CHAPTER 3: THE LIVED EXPERIENCE OF YOUNG-ONSET DEMENTIA	16
Abstract	16
Introduction.....	16
Methods.....	18
Design	18
Sample.....	19
Demographics	20
Data Collection	20

Data Analysis	21
Interpretation and Findings	22
Feeling Frustrated	22
Fear of Slipping Away	24
Loss of Personhood.....	26
Life Interrupted	27
Finding a Sense of Security in the Familiar	27
Wanting the Voices of People with Dementia to be Heard	28
Discussion.....	30
Limitations	32
Implications for Practice and Policy	32
Direction for Future Research.....	33
Conclusions.....	33
References.....	34
 CHAPTER 4: CHALLENGES TO EXPLORING THE EXPERIENCES OF PEOPLE WITH	
 DEMENTIA.....	
Abstract.....	38
Introduction.....	38
Investigating the Lived Experience of Young-Onset Dementia.....	40
Capacity to Give Informed Consent	41
People with Dementia as Informants	43
Discussion.....	45
Conclusion	46

References.....	47
APPENDIX A: DISSERTATION PROPOSAL.....	51
APPENDIX B: IRB APPROVAL	81
APPENDIX C: INFORMED CONSENT.....	83
APPENDIX D: CERTIFICATE OF COMPLETION OF CONTINUING EDUCATION FOR PROTECTION OF HUMAN PARTIPICANTS IN RESEARCH.....	85
APPENDIX E: INSTRUMENTS AND INTERVIEW GUIDELINES	88
APPENDIX F: CURRICULUM VITAE.....	95

LIST OF TABLES

Table 1: Causes and Characteristics of Young-Onset Dementia	5
---	---

CHAPTER 1: INTRODUCTION

Dementia is an umbrella term for progressive neurodegenerative disorders characterized by changes in cognition, personality, social functioning, and language. The term *young-onset dementia* (YOD) refers to persons who first experience signs and symptoms of dementia prior to age 65 (American Psychiatric Association, 1994). It is estimated that there are more than ½ million person under age 65 living in the United States with young-onset dementia (Alzheimer's Association, 2010). The prevalence of young-onset dementia is expected to increase as Baby Boomers age. Throughout this study, the term young-onset dementia will refer to persons who are between age 36 and 65.

Evidence suggests that middle aged people with dementia may have different experiences than their older counterparts. Developmental tasks in middle age include productive work, caring for a family, and maintenance of social relationships. In addition, middle-age people may be more aware than their senior counterparts that something is wrong. Despite the increasing numbers of middle-age people affected by young-onset dementia, less research attention has been paid to persons under 65. The majority of research regarding the experience of living with dementia has focused on older adults, the neuropathology of the illness, or care giver burden. The overall purpose of this research was to explore the experience of living with young-onset dementia from the perspective of affected individuals.

The goal of this research was to add to the body of knowledge concerning the experience of living with young-onset dementia. The research proposal in Appendix A includes extensive details of the overall purpose of this study, specific aims, research design, methods, and data analysis. An interpretive phenomenological method was used to explore the lived experience of young-onset dementia.

This dissertation followed the University of Central Florida non-traditional dissertation model and is comprised of three manuscripts that focus on middle age people who are living with a young-onset dementia. The first manuscript, entitled *Young onset dementia: A review of the literature* focuses on the state of the science related to middle-age people, 35-64, with young-onset dementia. The second manuscript, entitled, *The lived experience of young-onset dementia*, describes the experience of living with dementia from the perspective of persons living with the disease. The third manuscript, entitled, *Challenges to conducting research with people with dementia*, focuses on the challenges encountered by the researcher during the proposal phase of the research study. These three papers were written in the order in which they appear in the subsequent chapters.

CHAPTER 2: YOUNG-ONSET DEMENTIA: A REVIEW OF THE LITERATURE

Abstract

It is estimated more than ½-million people in the United States are living with young-onset dementia and another ½-million with mild cognitive impairment, a precursor of dementia. Relatively little has been written about the psychosocial needs of these people but there is information that can be extrapolated from literature about dementia in older persons and the developmental tasks and roles of middle age. This paper synthesizes these items of literature and provides information to assist psychiatric nurses and other health care professionals to better understand persons living with young-onset dementia.

Keywords: young-onset dementia, lived experience, developmental roles, loss

Introduction

It is estimated there are more than ½-million persons under age 65 living in the United States with young-onset dementia (Alzheimer's Association, 2006). Another ½-million people ages 55 to 64 years have mild cognitive impairment, which can be a precursor to dementia (McMurtray, Clark, Christine, & Mendez, 2006). The prevalence of young-onset dementia is expected to increase as Baby Boomers age. Deterioration in everyday functional ability is a critical aspect of dementia. Dementia causes impairments in planning, organizing, and decision making. The resultant anxiety and depression may lead to mood and personality changes. It is unlikely health care providers will know how to care for middle-aged people with dementia without a better understanding of the impact of dementia on this population.

Although there is some literature about persons with young-onset dementia, most of the information about this clinical population is limited to caregiver burden or the neuropathology of the disease process (Arai, Matsumoto, Ikeda, & Arai, 2007; Armstrong, 2003; Kaiser & Panegyres, 2007). Little has been documented about the psychosocial needs and experiences of this population. As a result, nurses are not equipped to provide the best possible care to younger people with dementia, nor are nurses prepared to assist in the training of lay caregivers. (Harris & Keady, 2004).

This purpose of this review is to extrapolate information from the literature concerning young-onset dementia, developmental tasks in middle age, and the impact of chronic illness in middle age and provide information to assist psychiatric nurses and other health care professionals to better understand persons living with young-onset dementia. The paper begins with a discussion of the fundamental distinctions between young-onset and older-onset dementia. It continues with psychosocial issues related to young-onset dementia, including developmental tasks, work roles, and loss issues, and concludes with implications for nursing. Knowledge gained from this review will help psychiatric nurses and other health care providers understand persons living with dementia by sensitizing them to the unique needs of middle-aged people with dementia.

Distinctions between Young-Onset and Older-Onset Dementia

Regardless of age at onset, deterioration in everyday functional ability is a critical aspect of dementia. Dementia causes impairments in planning, organizing, and decision making. However, the causes of young-onset dementia are different from those of late-onset dementia (Licht, McMurtray, Saul, & Mendez, 2007) and seem to play a role in the pace and extent to

which functional abilities decline. In younger onset dementia, presentation of cognitive impairment is more likely to occur in other areas besides memory (Koedam, et al., 2010). The causes and characteristics of young-onset dementia are summarized in Table 1.

Table 1: Causes and Characteristics of Young-Onset Dementia

Causes of Young-Onset Dementia	Characteristics
Frontotemporal dementia (FTD) (a)	<ul style="list-style-type: none"> • Typically affects persons between 45 & 65 but may occur in 20's • Psychiatric symptoms • Behavioral and speech disorders • Familial in 20-40% of cases
Alzheimer's dementia (a)	<ul style="list-style-type: none"> • Early symptoms, in 1/3 of cases, include apraxia and visio-spatial dysfunction • Psychiatric symptoms • Decreased interest in social activities • Frequently familial
Vascular dementia (a)	<ul style="list-style-type: none"> • Related to disease of small vessels, small percentage related to genetic arterioapthies • Gait disturbances, psychiatric symptoms
Autoimmune / Inflammatory dementia (b,c)	<ul style="list-style-type: none"> • Memory loss, frontal executive dysfunction • Personality changes • May be reversible if diagnosed early
<p>a. (Sampson, Warren, & Rossor, 2004) b. (Berlit, 2007) c. (Stoquart et al., 2010)</p>	

Psychosocial Issues

Developmental Issues

Developmental reasons explain why the experiences of persons with young-onset dementia should be different from those of the elderly with dementia. Erik Erikson (1980), the first theorist to assert that significant development occurs in adulthood, defined *generativity* as

the developmental task of middle-aged adults. Generativity involves productivity: work, caring for a family, and social relationships of middle age. Cognitive functions and psychosocial variables such as self-confidence and self-mastery peak during middle adulthood (Harden, 2005). Dementia, even in the very early stages, can erode confidence in mastery of expected roles.

Younger persons with dementia may be more aware that something is wrong because they and others (e.g., spouses, children, and employers) have higher expectations of their abilities and capacities. Their abilities and capacities are more often on display in the occupational and social spheres; younger persons with dementia tend to have more responsibilities in terms of employment and family commitment. Decisions made concerning work and social roles of the younger person with dementia can have considerable effects on others.

It is to be expected that the declines naturally associated with aging mean losses will outnumber gains eventually. Cognitive losses associated with young-onset dementia are premature and shift the proportion of gains to losses to a less positive balance (Baltes, 1997). Although there is little in the literature concerning losses associated with dementia in middle-aged persons (Armstrong, 2003; Harris & Keady, 2004), a number of studies describe the psychosocial effects and meaning of illness in persons with other various chronic illnesses and physical maladies (Bulsara et al., 2004; Harden, 2005; Wardini & de la Rosa, 2005). Steverink, Westerhof, Bode, and Dittmann-Kohli (2001) reported older adults perceived less stress related to chronic illness because longevity seems to prepare people for loss in later life. Studies of chronic illness in middle-aged adults portray role and developmental influences that contrast their experiences with older, chronically ill adults.

For example, younger female cancer survivors reported higher levels of negative impact on their life compared to older cancer survivors. This disparity may be related to secondary role

strains, such as outside employment, child rearing, and social obligations that continued over time (Nijboer et al., 2000). A study by Söderberg, Lundman, and Norberg (1999) noted the loss of credibility and dignity experienced by middle-aged women living with fibromyalgia. The women reported feeling they were not taken seriously because they did not look sick. Another factor associated with the women's perceptions of loss of credibility was the lack of knowledge about fibromyalgia and health care providers' negative attitudes, related to their numerous physical complaints, of many health care providers from whom the women sought treatment.

Work Role

Unlike their older counterparts, persons with young-onset dementia may be in mid-career when symptoms emerge. For persons in the fourth and fifth decades of life, work is usually a primary function and an important part of self-identity.

It may be in the work environment where symptoms of cognitive decline are first publicly noticed. Some of the earliest signs of dementia include difficulty with word finding, decreased ability to multitask, and impairment in planning, organizing, and decision making. The inability to express thoughts, especially complex ideas, makes workplace conversation more difficult. Behavior changes such as emotional outbursts may occur (Harris & Keady, 2004). Even for the affected person who manages to maintain acceptable social skills, the progressive inability to perform usual job-related tasks may lead to premature loss of income, difficulty obtaining medical benefits, and loss of full retirement benefits. All of these losses can cause significant financial burden to the affected person and his or her family.

Little is known, from the perspective of persons living with young-onset dementia, about the experience. However, these individuals face numerous psychological stressors including

uncertainty of diagnosis, coping with a chronic illness, and grief associated with what will be, ultimately, a fatal disease (Henderson, Packman, & Packman, 2009). The role of middle-aged breadwinner may change unexpectedly when loss of judgment and the inability to plan cannot be ignored, forcing premature retirement.

Family Roles and Relationships

Dementia also forces individuals to assume dependent roles within their families. If the affected person is the primary caregiver this role change may result in feelings of helplessness and frustration. Unlike their older counterparts, persons with young-onset dementia may be caring for both school-aged children and aging parents (Armstrong, 2003; Harris & Keady, 2004). As cognitive impairment declines, younger persons with dementia can no longer parent their children or maintain their mantle of leadership. Role reversal is common: The majority of those with young-onset dementia are cared for in the home by their families, and multiple generations may be recipients of care administered by the youngest generation in the household.

The family dynamic changes when the head of household, whether mother or father, is diagnosed with young-onset dementia. There is fear and uncertainty associated with suspected hereditary dementia. The parent living with young-onset dementia may experience guilt that his or her children may eventually develop an inherited form of dementia.

Young-onset dementia can disrupt the typical transitional stages of the family life cycle. The fifth and longest stage of the family life cycle involves launching children and regeneration of the marital dyad (McGoldrick & Carter, 2003). When a parent has dementia, the children may find it difficult to leave home, preventing the family from moving on to the next stage. Because caring for someone with dementia requires the caregiver to spend increasing amounts of time

with the affected individual, the disease reduces the caregiver's opportunities for social interaction outside of the home.

Social isolation is a concern for people with dementia, regardless of their age (Harris & Keady, 2004). For the person with young-onset dementia, this isolation may be compounded by the notion of dementia being a disease of old age. Progressive disability and behavioral changes may discourage friends and family members from visiting, resulting in further isolating the sufferer and caregiver.

Difficulty Obtaining a Diagnosis

Part of the experience of middle-aged persons with young-onset dementia involves difficulty in obtaining a diagnosis. Behavior and personality disorders may be misdiagnosed as psychiatric in origin. Middle-aged persons with cognitive deficits are often not diagnosed with dementia until 2-3 years after the onset of symptoms, resulting in delayed treatment and emotional stress for them and their caregivers (Harris & Keady, 2004). Because a diagnosis of dementia in middle age is not expected, those with young-onset dementia may labor to find a health care provider who can identify the cause of their cognitive impairment. Alzheimer's disease presents a particular challenge because neurological examination is often unremarkable in the early stages (Harvey, Skelton-Robinson, & Rossor, 2003).

Misdiagnosis is common. In the younger adult, early symptoms of memory impairment may be mistaken as stress-related or depression. Changes in behavior and personality disorders may also be misdiagnosed as psychiatric in origin. In an autobiographical account about his journey to a diagnosis of young-onset Alzheimer's disease, Taylor (2007) talked about the fear associated with being aware that 'something was wrong' with his memory. He goes on to lament

about his frustration with health care providers who seemed to trivialize his concern about cognitive changes, chalking them up to depression or stress.

A definitive diagnosis of dementia can pose a dilemma for both clinicians and patients. Some clinicians hesitate to relay the diagnosis to a middle-aged person, citing a concern that receiving a diagnosis of dementia may overwhelm the person and trigger depression or even suicide (Carpenter et al., 2008). This concern has some merit. Because recent memory is lost before long-term memory, the affected person may be aware of the deterioration experienced to date as well as the long-term prognosis for dementia. The diagnosis has been known to cause fear and uncertainty for the future but some studies have indicated that a confirmed diagnosis of young-onset dementia brings the relief of knowing the cause of cognitive changes (Carpenter et al., 2008; Jha, Tabet, & Orrell, 2001).

Lack of Resources

The most obvious distinction between young-onset and senior-onset dementia is age and its associated physical and psychosocial needs. Those few studies that included the younger person's perspective reported that persons with young-onset dementia were frustrated by the lack of age-specific resources. For example, younger persons with dementia who attended day care programs designed for older adults reported feeling out of place and described the day care providers as inhibiting their physical activity and independence (Beattie, Daker-White, Gilliard, & Means, 2004). Most dementia care settings are designed for older adults and not equipped to meet the needs and interests of younger persons with dementia. Younger persons with dementia are more likely to be physically healthy than older adults with dementia and may require alternative approaches to providing care (Beattie et al., 2004).

In summary, Regardless of etiology, psychosocial losses have an impact on younger adults coping with chronic illness. Given the limited knowledge surrounding the experience of young-onset dementia, the belief that persons with young-onset dementia are unable to reflect and elaborate on their illness may be grossly exaggerated. Losses associated with young-onset dementia threaten the generativity of middle-aged adults because of the multiple roles they play in the professional and personal lives of others. For the person with young-onset dementia, the ability to care for one's self and others and to contribute to society is impaired as cognitive function declines. This interruption in usual roles associated with middle age may result in feelings of unimportance. Like persons with other chronic illnesses, persons with young-onset dementia need to adapt or modify their prior roles to accommodate the illness as well as social expectations (Lewis & Lubkin, 2002). The accommodation process may produce role strain, including anxiety, depression, grief, hostility, and apathy.

Implications for Nursing

A diagnosis of young-onset dementia should be considered for people with early memory loss, emotional lability, and decreased interest in usual activities. Early diagnosis and intervention may improve the quality of life for younger persons with dementia. Individuals with young-onset dementia will likely need help coping with work-related losses and mourning the loss of ability to care for self and family members. Although many of the needs of persons living with young-onset dementia can be extrapolated from the literature about developmental tasks of middle-age and expected role issues, research directly exploring the experience of living with young-onset dementia, is needed to help psychiatric nurses and other health care providers

gain a more thorough understanding of the life experiences, needs, and concerns of middle-aged people living with dementia.

References

Alzheimer's Association (2006). *Early onset dementia: A national challenge, a future crisis*.

Retrieved from: www.alz.org.

Arai, A., Matsumoto, T, Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22, 1255-1261. doi: 10.1002/gps.1935

Armstrong, M. (2003, August 1). The needs of people with young-onset dementia and their carers. *Nursing Times.net*. Retrieved from <http://www.nursingtimes.net/nursing-practice-clinical-research/the-needs-of-people-with-young-onset-dementia-and-their-carers/199806.article>

Baltes, P. B. (1997). On the incomplete architecture of human ontogeny: Selection, optimization, and compensation as foundation of developmental theory. *American Psychologist*, 52, 366-380. doi: 10.1037/0003-066X.52.4.366

Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). "How can they tell?" A qualitative study of the views of younger people about their dementia and dementia care services. *Health & Social Care in the Community*, 12, 359-368. doi: 10.1111/j.1365-2524.2004.00505.x

Berlit, P. (2007). Neuropsychiatric disease in collagen vascular diseases and vasculitis. *Journal of Neurology*, 254 (Suppl. 2), II87-II89. doi: 10.1007/s00415-007-2021-6

- Bulsara, C., Ward, A., & Joske, D. (2004). Haematological cancer patients: Achieving a sense of empowerment by use of strategies to control illness. *Journal of Clinical Nursing, 13*, 251-258. doi: 10.1046/j.1365-2702.2003.00886.x
- Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., . . . Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatrics Society, 56*, 405-412. doi: 10.1111/j.1532-5415.2007.01600.x
- Erikson, E. H. (1980). Generativity versus stagnation. In *Identity and the life cycle* (rev. ed., pp. 103-104). New York, NY: Norton.
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: A review of the literature. *Cancer Nursing, 28*, 85-98. doi: 10.1097/00002820-200503000-00002
- Harris, P. B., & Keady, J. (2004). Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly, 5*, 111-122. Retrieved from <http://journals.lww.com/actjournalonline/pages/default.aspx>
- Harvey, R. J., Skelton-Robinson, M., & Rossor, M. N. (2003). The prevalence and causes of dementia in people under age of 65 years. *Journal of Neurology, Neurosurgery & Psychiatry, 74*, 1206-1209. doi: 10.1136/jnnp.74.9.1206
- Henderson, S. L., Packman, W., & Packman, S. (2009). Psychosocial aspects of patients with Niemann-Pick disease, type B. *American Journal of Medical Genetics Part A, 149A*, 2430-2436. doi: 10.1002/ajmg.a.33077

- Jha, A., Tabet, N. & Orrell, M. (2001). To tell or not to tell—Comparison of older patients' reaction to their diagnosis of dementia and depression. *International Journal of Geriatric Psychology, 16*, 879-885. doi: 10.1002/gps.412
- Kaiser, S., & Panegyres, P. K. (2007). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Dementias, 21*, 398-402. doi: 10.1177/1533317506293259
- Koedam, E.L., Lauffer, V., van der Vlies, A.E., van der Flier, W.M., Scheltens, P., Pijnenburg, Y.A. (2010). Early-versus late-onset Alzheimer's disease: more than age alone. *Journal of Alzheimer's Disease, 19* (4): 1401-8.
- Lewis, P. R., & Lubkin, I. M. (2002). Illness roles. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and interventions* (5th ed., pp. 25-52). Sudbury, MA: Jones & Bartlett.
- Licht, E. A., McMurtray, A. M., Saul, R. E., & Mendez, M. F. (2007). Cognitive differences between early- and late-onset Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 22*, 218-222. doi: 10.1177/1533317506299156
- McGoldrick, M., & Carter, B. (2003). The family life cycle. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed., pp. 375-398). New York, NY: Guilford Press.
- McMurtray, A., Clark, D. G., Christine, D., & Mendez, M. F. (2006). Early-onset dementia: Frequency and causes compared to late-onset dementia. *Dementia and Geriatric Cognitive Disorders, 21*, 59-64. doi: 10.1159/000089546

- Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & van de Bos, G. A. M. (2000). Patterns of caregiver experiences among partners of cancer patients. *The Gerontologist, 40*, 738-746. doi: 10.1093/geront/40.6.738
- Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal, 80*, 125-139. doi: 10.1136/pgmj.2003.011171
- Söderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research, 9*, 575-587. doi: 10.1177/104973299129122090
- Steverink, N., Westerhof, G. J., Bode, C., & Dittmann-Kohli, F. (2001). The personal experience of aging, individual resources, and subjective well-being. *Journals of Gerontology: Series B, Psychological Sciences & Social Sciences, 56*, 364-373. doi: 10.1093/geronb/56.6.P364
- Stoquart-El Sankari, S., Périn, B., Lehmann, P., Gondry-Jouet, C. & Godefroy, O. (2010). Cognitive forms of multiple sclerosis: Report of a dementia case. *Clinical Neurology and Neurosurgery, 112*, 258-260. doi: 10.1016/j.clineuro.2009.11.018
- Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.
- Wardini, Y., & de la Rosa, P. (2005). The effects of adapted logotherapy on the self-esteem of mid-life women with life-threatening illnesses: Findings from a study in Indonesia. *Asian Journal of Nursing Studies, 8*(3), 39-49.

CHAPTER 3: THE LIVED EXPERIENCE OF YOUNG-ONSET DEMENTIA

Abstract

Young-onset dementia refers to occurrence of dementia before age 65 and covers a spectrum of neurodegenerative disorders that can overwhelm affected individuals, their caregivers, and health care resources. Although the number of middle-aged persons with young-onset dementia is expected to rise as Baby Boomers age, this population is understudied and not well understood. Missing is their perspective of living with the disease. This phenomenological study explored the lived experience of dementia in middle-aged persons. Nineteen conversational interviews were conducted with 9 persons, ages 42 to 61, who had received a formal diagnosis of dementia. Using van Manen's phenomenological interpretive approach, the following themes describing the experiences of living with dementia were extracted from interview transcripts: feeling frustrated, fear of slipping away, loss of personhood, life interrupted, finding a sense of security in the familiar, and wanting one's voice to be heard. These themes are interpretations of the human experience of living with young-onset dementia and are not intended to be generalizations or theoretical concepts.

Keywords: young-onset, dementia, lived experience, phenomenology

Introduction

Dementia is an umbrella term for progressive neurodegenerative disorders characterized by changes in cognition, personality, social functioning, and language. *Young-onset dementia* (YOD) is described as any form of dementia that occurs prior to age 65 (Maslow, 2006). It is estimated that more than a half million people in the United States live with YOD (Maslow,

2006) and another half million people live with mild cognitive impairment, which can be a precursor of dementia (McMurtray, Clark, Christine, & Mendez, 2006). Prevalence of YOD is expected to increase as Baby Boomers age, taxing an overburdened health care system to accommodate this population.

People with young-onset dementia are treated like older adults with dementia, without special consideration of how their needs and life circumstances are shaped by their developmental stage (Beattie, Daker-White, Gilliard, & Means, 2004). Although there is some literature concerning persons with young-onset dementia, most of it is limited to caregiver burden or the neuropathology of the disease process (Arai, Matsumoto, Ikeda, & Arai, 2007; Armstrong, 2003; Kaiser & Panegyres, 2007). Little documentation is available on the psychosocial needs and experiences of this population. As a result, health care providers are not prepared to provide the best possible care to younger adults with dementia (Harris & Keady, 2004).

Regardless of age at onset, deterioration in everyday functional ability is a fundamental aspect of dementia. Dementia causes impairments in planning, organizing, and decision making. However, there are good reasons to believe that the experience of living with dementia will be different when its onset occurs in middle-aged persons.

Developmental tasks in middle age include productive work, caring for a family, and maintenance of social relationships. Cognitive function and self-confidence also peak during middle age (Harden, 2005). Dementia, even in the very early stages, can erode confidence in mastery of expected roles. Although cognitive and physical changes associated with aging lead to an expected imbalance between losses and gains, cognitive losses associated with young-onset dementia are premature and shift the proportion of gains to losses to a less positive balance

(Baltes, 1997). In addition, middle-aged persons with dementia may be more aware than their senior counterparts that something is wrong: middle-aged persons and their spouses, children, and employers have higher expectations, and middle-aged persons' abilities and capacities are more often on display in the occupational and social spheres.

Although little is known about the experience of living with young-onset dementia from the perspective of persons living with a dementia syndrome, these individuals are known to face numerous psychological stressors including uncertainty of diagnosis. For example, dementia in middle-age persons can be difficult to diagnose because changes in personality and behavior, as well as mild memory loss, are similar to those of other conditions. Thus, young-onset dementia is often misdiagnosed as depression, stress, or mood disorder (Armstrong, 2003; Beattie et. al., 2004). Precious time to plan treatment and prepare for future needs is lost. Additional stressors include awareness of having a chronic, progressive illness, and the grief associated with what will ultimately be a fatal disease (Henderson, Packman, & Packman, 2009).

The purpose of this study was to explore the experience of living with dementia from the perspective of middle-aged people. My initial interest in this topic was piqued after I discovered an autobiographical account of young-onset dementia (Taylor, 2007). I communicated with the author and learned that there are people with young-onset dementia who long to be heard.

Methods

Design

Van Manen's (1990) approach to phenomenological inquiry and data analysis was used in this study. Phenomenology is compatible with the philosophy put forth by leaders in the field

about how to care for people with dementia: They need to be understood in their full humanity, as unique persons in their lifeworld (Kitwood, 1997; Sterin, 2002; Touhy, 2004).

Sample

The sample included eight women and one man, all with young-onset dementia who met the following inclusion criteria: they had received a formal diagnosis of mild or early-stage dementia, were between the ages of 35 to 64, were able to understand and speak English, and had demonstrated the ability for self-reflection. Geographical location was not a criterion for inclusion or exclusion; participants could live anywhere in the United States. Type of dementia was not a criterion because the goal was to facilitate understanding the experience across a range of dementia subtypes. Study participants were recruited until no new themes emerged.

Recruitment included posting informational flyers in health care offices and online dementia support forums. In addition, the Association for Frontotemporal Dementias mailed study flyers and letters of support to members who were known to meet inclusion criteria.

Potential study participants contacted the PI via e-mail or telephone and were prescreened for the ability to self-reflect on their illness. This screening was conducted as a two-part process. First, each person was asked to explain why he or she was interested in participating in this study. Persons who were able to respond by coherently explaining their reasons for wanting to participate were then administered the Short Portable Mental Status Questionnaire ([SPMSQ] Pfeiffer, 1975) to screen further for cognitive functioning.

The SPMSQ is a brief, 10-item test of cognitive functioning that is simple to administer via telephone. Items on the SPMSQ address orientation, remote memory, and capacity for calculation. Although telephone administration of the SPMSQ can result in misclassification

25% of the time, the potential for misclassification was offset by having more than one method of screening (i.e., asking potential participants why they were interested in participating in the study). The SPMSQ has good test-retest reliability ($r = 0.82$ to 0.83) (Pfeiffer, 1975). High correlations have been found between SPMSQ scores and clinical diagnosis (Roccaforte, Burke, Bayer, & Wengel., 1994). The SPMSQ takes less than 5 minutes to administer. Scoring includes counting errors. Unanswered items are treated as errors. Individuals who scored less than four errors on the SPMSQ, indicating mild or early dementia, were scheduled for the first of two interviews.

Demographics

All nine participants were Caucasian and college graduates. Two participants were single, two reported being in long-term cohabitating relationships, and five were married. Two participants reported having received a diagnosis of Alzheimer's dementia, five reported a diagnosis of frontotemporal dementia, one reported Lewy body dementia, and one reported dementia related to head trauma.

Data Collection

After obtaining institutional review board approval and individual participants' informed consent, data were collected through 19 in-depth conversational interviews. Each study participant was interviewed twice, with the exception of one person who was interviewed a third time to accommodate her desire to share additional information. Second interviews were conducted within two weeks of the first interview. Of the 19 interviews, 17 were conducted via telephone and two were conducted face-to-face at the home of one participant. During the first

interview, participants were asked to describe their experiences of living with dementia. The interview began with, “Please tell me about your experience with discovering that you have young-onset dementia.” Additional questions included, “How did you feel when you were told that you have dementia?” and “How has living with dementia affected your life and your relationships?”

The interviews were conducted in a conversational style between the PI and interviewee. When needed, clarifying questions were asked, such as, “How did this make you feel?” and “Can you elaborate on that a bit more?” The second interview was conducted as a follow-up after preliminary analysis of the first interview. During the follow-up interview, the participants were presented with the themes the researcher had extracted from their first interview and asked to reflect on them. This procedure provided participants with the opportunity to become more active collaborators in the research (van Manen, 1990). The 19 conversations, each of which lasted 45-90 minutes, were recorded on a digital audio recorder and subsequently transcribed verbatim. In addition to the audio recordings, the researcher kept notes, writing about changes in the participant’s tone of voice, interruptions in the conversation, and extended periods of silence.

Data Analysis

Using van Manen’s (1990) analytical strategy, the PI listened carefully to each audio recording of the conversations. Using a selective approach, the transcript was read several times and statements or phrases that were particularly revealing of the experience being described were identified and highlighted. The highlighted statements and phrases became objects of reflection between the researcher and participant in the follow-up interpretive conversation. During these follow-up conversations, the researcher read the themes extracted from the participants’

statements and asked, “Is this really what the experience means to you?” or “Is this really what it is like to live with dementia?” In this way, the researcher and the participant collaborated in the interpretation of the conversational interviews.

Interpretation and Findings

The conversations with persons living with young-onset dementia illuminated the struggle to “live” in a society that stigmatizes dementia. Participants shared their experiences through unique stories that bring us closer to understanding what it is like to be a middle-aged person living with dementia. Six major themes emerged from the conversations: feeling frustrated, fear of slipping away, loss of personhood, life interrupted, finding a sense of security in the familiar, and wanting one’s voice to be heard. To maintain participants’ privacy while facilitating presentation of these themes, henceforth in this document, participants will be referred to by a first-name pseudonym.

Feeling Frustrated

Every participant spoke about feeling frustrated. Their frustrations pertained to difficulty getting others to consider that they were genuinely suffering from dementia and their declining abilities once their cognitive ability began to falter.

A major source of frustration was getting others to consider dementia as a possibility or cause for the individual’s inability to continue managing his or her life. These others included doctors, peers, and family members. Doctors often mistook early signs and symptoms of young-onset dementia as indicative of a psychological disorder. Liz described how a doctor interpreted her problem of “getting lost at a job I have been at for 15 years” and her husband’s opinion that

her “personality had changed.” She elaborated, “The doctor told me I was just depressed”. Felicia recounted a similar experience. She stated, “He [my doctor] told me I needed to see a shrink.” Her frustration was apparent by her subsequent statement, “I knew something was wrong but I’m not crazy.” Participants also reported feeling frustrated from multiple referrals or “being passed from doctor to doctor” while trying to determine what was wrong.

Adding to their frustration, was being told by doctors to “watch and wait,” to see if trials of psychotropic medications would improve their symptoms. Experimental trials of psychotropic medications were a source of particular frustration because they seldom improved the symptoms that prompted the initial health care encounter. In some cases, the medication trials caused additional unpleasant symptoms. Deanna reported, “I was told that I had depression and was started on Prozac. The medication made me feel terrible. I wandered around the house all night and felt all jittery. I couldn’t sleep. . . . It didn’t help my memory at all.” Felicia added, also referring to a trial of medication for a supposed psychiatric disorder, “I kept telling the doctor that the medication was making me so tired. . . . I think my memory got worse.”

Comments from family and friends who insisted that a diagnosis of dementia was not possible added to feelings of frustration. Participants offered examples of people interpreting their efforts to maintain an active and meaningful life as proof that middle-aged persons cannot possibly be experiencing dementia. Liz reported a particularly hostile interpretation of her active community involvement by her sister: “My sister said, ‘You still do so much for everybody . . . You don’t have dementia, you’re just crazy. . . . You’re just trying to get attention.’” Carol said, “When I tell people that I have FTD [frontotemporal dementia], they don’t know what to say. Usually it’s, ‘Oh you can’t have dementia, you are too young. You look so normal, are you sure?’”

Another source of frustration was when the person was no longer able to work. All participants were forced to leave their jobs. It was particularly frustrating for participants when their work performance was declining and their dementia was undiagnosed. Joe, a computer engineer, said, “Nobody knew what was wrong. I was fired.” He elaborated on the frustration of trying to improve his performance before knowing that the problem was declining functional ability. He stated, “I tried to do better. . . . I just couldn’t improve; I couldn’t learn new things.” This must have been particularly frustrating for Joe, given that he was an accomplished engineer.

Participants also talked about their frustration of not being able to perform minimal skills once they replaced their prior work with more menial jobs. Liz, who had worked as a unit clerk in a community hospital before she was diagnosed, spoke of her brief experience working in a fast-food chain. “I worked with an older lady who tried to help me. . . . I would get mixed up.” She continued, her voice rising with emotion, “I needed a *babysitter* to help me flip burgers!”

Frustration also ensued from declining ability to socialize with people in a meaningful way. Karen talked about her difficulty with keeping up with conversations in social settings. “I just sit there with my wine and smile. . . . I laugh when everyone else laughs. . . . That’s how I manage.” Unlike Karen, most participants chose to withdraw rather than continue to feel frustrated by social situations. Participants reported feeling frustrated by friends treating them differently once their diagnosis was made public. They felt that they were being watched, and that friends and peers were waiting for increasing evidence of cognitive decline.

Fear of Slipping Away

Persons with young-onset dementia recognized the changes occurring in their cognitive and functional abilities. Ginny exemplified this awareness: “I’m lonely most of the time. There

is this peacock in my neighborhood . . . he calls out every morning. He calls and calls and no one calls back. That's what I feel like, a stupid peacock.”

Awareness of cognitive and functional decline was described as slipping away, either slowly or by drowning. Slipping away was associated with fear. Karen, referring to her declining ability to socialize with friends, described fear that reached panic proportions: “As the current gets stronger, you try to keep your head above water. . . . You're fighting like hell, just to stay above the water. . . . That's what it's like.” Deanna, a cancer survivor, pronounced that, compared to dementia, cancer was easy. She elaborated, “I'd take cancer over dementia any day. If you don't beat cancer, you die pretty quick, but this [dementia] is awful. . . . You feel yourself slipping away, a little bit, every day.” Gina declared, “I don't want to die, but the thing I dread the most is the in-between stage, when I'm a zombie. I have some days like that now . . . I can tell it's getting worse.” The possibility of retaining some sense of awareness, after the ability to speak erodes, was particularly frightening. Karen said, “It's scary. . . I won't be able to communicate . . . nobody will know if I'm still here.”

Liz talked about the fear she experienced when she first realized her cognitive ability was failing, before she was actually diagnosed with young-onset dementia. “I realized that something was wrong when I didn't recognize the family dog. It was kind of scary . . . you know . . . that was my dog and I didn't know who he was.” She turned to her 7-year-old son and asked, “What is that . . . out there in the yard?” She sensed that she should know why the animal was in her yard. She reported trying to turn the incident into a joke, laughing and telling her son “I know that...he's such a good dog.” Inside, she was confused and afraid; panicking about not being able to recognize the family dog and why this was happening to her.

Loss of Personhood

Personhood is a social standing or status that is bestowed by others and implies recognizing and respecting an individual as a unique being with value and purpose (Kitwood, 1997). Participants reported feeling that they had come to be defined by their dementia and were no longer seen by others as whole individuals with purpose and value. Not being valued as a person elicited strong emotional responses from participants. These concerns were reflected above when describing Karen's fear that "nobody will know if I'm still here" and Ginny's portraying herself as "a stupid peacock." Felicia was more explicit about the loss of personhood. She declared, "We are still here . . . we need and deserve to be treated like we have some value. I feel like an emotional plant, but I'm not a plant. I'm a person."

The loss of personhood stems from the participants' perception of others' belief that those with dementia can no longer contribute in a meaningful way. Sara, a former social worker, surrendered her license and closed her practice because she knew that she could not maintain her private counseling practice. After surrendering her license, she found some satisfaction in volunteering at a local dementia support group. However, her satisfaction was tempered by frequent reminders, by leaders of the group, that she was no longer a social worker. She elaborated, "I know I can't practice anymore, but I can help people who are living with dementia. I can help their caregivers too. The Association lets me hang around as long as there is a group leader with me. . . . It's kind of demeaning . . . what do they think I'm going to do?" Similarly, Liz expressed feeling belittled by her experience with hospital administrators at her former place of work. "They told me that I couldn't stay at the hospital because I was a liability . . . all my years on the job didn't matter . . . I was a liability."

Life Interrupted

Repeatedly, participants spoke of the cruelty of dementia, elaborating on how declining ability affected their everyday lives, hopes, and dreams. Carol was grieving about the effects of her dementia on her family: “This disease sucks. My partner has to work so damn hard. . . . My kids have been forced to grow up too fast. . . . They never know what they might come home to.”

Participants also spoke of how young-onset dementia robs people of the sense of accomplishment that they worked years to achieve. Retirement plans are abandoned, life savings are depleted, and relationships are strained. Joe lamented, “My wife and I were ready to retire to our cabin on the lake. We can’t do that now. . . . My wife has to keep working . . . because of me.”

As illustrated in many of the quotes above about loneliness and difficulty in social situations, participants also discussed how dementia forced them into a reclusive life, devoid of social interaction with former friends, peers, and siblings. Interestingly, participants asserted that their interrupted social life was due to others’ fear of becoming a victim of dementia.

Finding a Sense of Security in the Familiar

The feeling of security that comes from bonding with another person in a trusting relationship has been well studied. Bowlby (1979) asserted that bonding is instinctive in nature and provides a kind of safety net. Although participants described many examples of losing their social life, most reported comfort from their closest or most intimate relationships. When Liz talked about her husband, the tone of her voice changed. She said, “My husband knows I mess up. . . . He checks to be sure that I haven’t put the ice cream in the microwave or the laundry in the freezer. We laugh about it. . . . Actually, it’s not that funny, but he never makes me feel like

a fool.” In contrast with how participants felt that they were being judged in social situations, being with an intimate family member provided respite from the pressure to perform. Felicia talked about the comfort she gets from her husband: “My husband is very patient and doesn’t push me if I can’t find the right words. He accepts it for what it is . . . we try to enjoy every day we have.”

People with dementia are continually finding themselves in unfamiliar situations, activating their need for safety and security (Miesen, 1992). Much like the feelings of comfort from intimate relationships, participants spoke of feeling safe in their homes. Joe described his experiences outside the home as an assault on the senses. “Sometimes when I go out, there are so many noises and smells . . . I get upset. When I get home I feel calmer, safe . . . almost.”

Wanting the Voices of People with Dementia to be Heard

Every participant in the study voiced a willingness to help others living with dementia and worked hard to achieve this goal by insisting that people listen to them and acknowledge their capabilities. As evidenced above, they had an awareness of their limitations. More notable is the fact that they had great insight and ability to reflect on their illness. This capability was easily evidenced when they were participating in this study. Yet others, particularly health care professionals, were described as doubting their ability, treating them as lacking insight and ability.

Karen personified the determination to be heard. She played an integral role in the development and production of a documentary about young-onset dementia. She and her partner contributed more than \$50,000 to the production of the film. Karen gave an example of her motivation for the project, saying, “Maybe when the doctors see this film, they will start to listen

to us.” Karen also conducted a survey, through an online support group, of early signs and symptoms of dementia to assist health care providers to diagnose young-onset dementia earlier and reduce delays in treatment. She explained, “We have experienced a lot of symptoms that the doctors chose to ignore. If enough people report the same thing and we can get some doctors to read the report, maybe they will figure this thing out.” She added, “The experts say that we lack enough insight. We have enough insight to realize that they don’t know much about this disease. We can help educate them. They just need to listen.”

Writing provided a good vehicle for participants to make their voices heard. Writing was described by most participants as positive and therapeutic. Liz found ways to compensate for her cognitive difficulty by communicating on-line. She said, “When I’m online, the thoughts seem to come easier . . . I can see what I’m saying and fix my mistakes.” Felicia elaborated on this idea, saying, “Even on a bad day, if my husband opens [Microsoft] Word for me, I can write. . . . [I] might not make sense when I speak, but I can make sense when I write.” Another participant, Gina, was in the midst of writing a book. She laughed when she told me, “Sometimes, I write the same thing, over and over, but it’s coming along and actually makes sense. Writing helps me stay grounded.” She added, “I’m living proof that people with dementia can function for a long time. She and other participants also believed that their positive experiences with writing should be incorporated into rehabilitation programs for other people who have young-onset dementia. Gina elaborated, “If I could find someone to listen (about the benefits of writing), maybe we could start to put the pieces together and find ways for people with dementia to maintain their cognitive function.”

Discussion

This study focused on middle-aged people living with young-onset dementia. Participants' self reports demonstrated that people with mild dementia possess great insight and awareness about the experience of living with young-onset dementia. Each participant struggled to live in a society that stigmatizes dementia. They described frustration, fear and feeling diminished or devalued as a person. These negative feelings stemmed from the losses that ensued from their cognitive and functional decline, which interrupted their careers, social lives, family roles, and future plans. They were aware that further cognitive and functional decline was forthcoming and would result in more devaluation by others. Findings about these aspects of their lived experience are notable in that health professionals were identified as causing much of their frustration and feelings of devaluation. Additional findings pertain to how the participants found security and respite in the familiar by limiting their social interactions with former friends and neighbors and taking respite in the familiarity of home and intimate relationships with spouses. The only exception to withdrawing from life at large was their remarkable effort to make their voices heard to advocate for more understanding of the experience of living with young-onset dementia. In fact, participants saw this study as an important first step to acknowledging their ability to provide insight into a disease that robs middle-aged adults of the ability to remain valuable members of society.

Many of these findings are consistent with the literature. Participant's perceptions that health care providers trivialized and misattributed their concerns have also been documented by other researchers. The earliest signs of young-onset dementia are often misinterpreted as psychological disorders (Harris & Keady, 2004; Henderson et al., 2009), resulting in delayed diagnosis and appropriate treatment. Other people suffering from somewhat ambiguous

syndromes have described similar frustrations. For example, women living with fibromyalgia report that they are not taken seriously because they do not look sick (Söderberg, Lundman, & Norberg, 1999).

Loss of personhood was reported by all participants in the study. Interactions with health care providers were consistently described as both frustrating and demeaning. Individuals in other devalued groups, such as people with chronic pain or mental illness or victims of domestic violence have reported similar experiences, proclaiming that they had become defined by their illness (Morrow, 2007; Van Den Tillaart, Kurtz, & Cash, 2009). Like other stigmatized or devalued groups, people living with dementia are often rendered voiceless (Van Den Tillaart et al., 2009). However, persons with dementia have a limited amount of time in which to make their voices heard because of the progressive cognitive losses. This may have contributed to why participants in this study went to great effort to make their voices heard. The fact that they were suffering from a disease during middle-age, a time of high productivity, may have also contributed to their zeal to remain valuable members of society.

The participants' awareness of their cognitive decline and the fear and uncertainty it caused for the future was demonstrated in a recent study. Clare, Rowlands, Bruce, Surr, and Downs (2008) explored awareness in people with moderate to severe dementia and found strong evidence that the capacity for awareness is retained late into the disease process. This finding challenges how participants described being treated by society at large and by health care providers, specifically how others expected them to lack insight and awareness and, as a result, diminished their personhood.

Preliminary evidence from a study being conducted on the effects of cognitive rehabilitation in dementia suggests that interventions, such as writing and other mentally

challenging activities, have the potential to enhance well-being and maintain involvement in everyday life (Clare, 2011). Consistent with this finding, participants in the current study also described writing as a way to maintain cognitive function and were of the opinion that writing should be included in formal cognitive rehabilitation programs.

Limitations

A limitation of this study was that the sample was primarily women, people with high education, and people who were previously employed. The fact that they were highly articulate and easily reflected on their experiences of living with young-onset dementia may be the result of how the sample was recruited (i.e., by advertising and relying upon participants to initiate study participation). However, documentation that people with severe dementia retain awareness suggests that less educated participants would also have been able to reflect on and communicate their experiences. However, educational level likely influenced the kind of activities the participants used to make their voices heard (e.g. conducting a survey, making a documentary, writing a book). Although the experience of young-onset dementia might have been different if more men participated, none of the themes that emerged from the study appear to be gender specific.

Implications for Practice and Policy

Findings from this study have a number of implications specific to persons with young-onset dementia. Health care practitioners need to listen to reports of cognitive and behavioral changes and not discount these symptoms because of the person's young age. Health care providers and society at large also need to be educated or reminded about the cognitive abilities

of people with dementia. Health care providers' misperception that people suffering from dementia do not have insight and their underestimation of their abilities is a great source of distress for middle-age people with dementia. Study findings also suggest that middle-aged people with dementia want to be involved in productive, meaningful activities. Health care practitioners and policy makers need to capitalize on their ability and desire; not only involving middle-age people with dementia in their own health care but also listening to their recommendations about how to improve life for other people suffering from dementia.

Direction for Future Research

Findings from this study highlight a number of issues that warrant further investigation. Future research on young-onset dementia needs to include persons with varying levels of education and more equal representation of men. Further research is also needed to investigate recommendations made by participants about the value of writing as a means of forestalling cognitive decline and determine if writing is a viable alternative form of communication when verbal ability is lost. Given that some participants expressed concern over how dementia affects their children, another important area for future research is the exploration, from the perspective of a dependent child, of the experience of having a parent with dementia,.

Conclusions

The experiences described in this study raise awareness about young-onset dementia and help health care practitioners and society at large develop a better understanding of what it is like for them to live with the disease. Their resounding plea is to have their personhood embraced instead of negated. Doing so will lessen their frustration and allow their voices to be heard,

which may in turn ease their fears about “slipping away”. Doing so may also improve the quality of life for others who are afflicted with young-onset dementia.

References

- Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22(12), 1255-1261. doi: 10.1002/gps.1935
- Armstrong, M. (2003, August 1). The needs of people with young-onset dementia and their carers. *Nursing Times.net*. Retrieved from <http://www.nursingtimes.net/>
- Baltes, P. B. (1997). On the incomplete architecture of human ontogeny: Selection, optimization, and compensation as foundation of developmental theory. *American Psychologist*, 52(4), 366-380. doi: 10.1037/0003-066X.52.4.366
- Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). “How can they tell?” A qualitative study of the views of younger people about their dementia and dementia care services. *Health & Social Care in the Community*, 12(4), 359-368. doi: 10.1111/j.1365-2524.2004.00505.x
- Bowlby, J. (1979). *The making and breaking of affectional bonds*. New York, NY: Routledge.
- Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., . . . Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer’s disease and mild cognitive impairment. *Journal of the American Geriatrics Society*, 56(3), 405-412. doi: 10.1111/j.1532-5415.2007.01600.x

- Clare, L. (2002). Developing awareness about awareness in early stage dementia. The role of psychosocial factors. *Dementia, 1*(3), 295-312. doi: 10.1177/147130120200100303
- Clare, L. (2011). Cognitive rehabilitation and people with dementia. In J. H. Stone & M. Blouin, (Eds.), *International Encyclopedia of Rehabilitation*. Retrieved from <http://cirrie.buffalo.edu/encyclopedia/en/>
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). "I don't do like I used to do": A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. *Social Science and Medicine, 66*(11), 2366-2377.
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: A review of the literature. *Cancer Nursing, 28*(2), 85-98. doi: 10.1097/00002820-200503000-00002
- Harris, P.B., & Keady, J. (2009). Family matters. Editorial. *Dementia, 8*:5-8. doi: 10.1177/1471301208099042
- Harris, P. B., & Keady, J. (2004). Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly, 5*(2), 111-122. Retrieved from <http://journals.lww.com/actjournalonline/>
- Henderson, S. L., Packman, W., & Packman, S. (2009). Psychosocial aspects of patients with Niemann-Pick disease, type B. *American Journal of Medical Genetics Part A, 149A*(11), 2430-2436. doi: 10.1002/ajmg.a.33077
- Kaiser, S., & Panegyres, P. K. (2007). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Dementias, 21*(6), 398-402. doi: 10.1177/1533317506293259

- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.
- Maslow, K. (2006). *Early onset dementia: A national challenge, a future crisis*. Retrieved from the Alzheimer's Association website: <http://www.alz.org>
- McMurtray, A., Clark, D. G., Christine, D., & Mendez, M. F. (2006). Early-onset dementia: Frequency and causes compared to late-onset dementia. *Dementia and Geriatric Disorders*, 21(2), 59-64. doi: 10.1159/000089546
- Miesen, B. (1992). Attachment theory and dementia. In G. M. M. Jones & B. M. L. Miesen (Eds.), *Care-giving in dementia* (Vol. 1, pp. 38-56). London, England: Routledge.
- Morrow, M. (2007). Women's voices matter: creating women centered mental health policy. In M. Morrow, O. Hankivsky, & C. Varcoe (Eds.), *Women's health in Canada: Critical perspectives on theory and policy* (pp. 355-379). Toronto, ON, Canada: University of Toronto Press.
- Pfeiffer, E. (1975). A Short Portable Mental Status Questionnaire for the assessment of organic brain deficit in elderly persons. *Journal of the American Geriatrics Society*, 23(10), 433-441. Retrieved from <http://www.americangeriatrics.org/publications/>
- Roccaforte, W. H., Burke, W. J., Bayer, B. L., & Wengel, S. P. (1994). Reliability and validity of the Short Portable Mental Status Questionnaire administered by telephone. *Journal of Geriatric Psychiatry and Neurology*, 7(1), 33-38. Retrieved from <http://jgp.sagepub.com/>
- Söderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity: The meaning of women's experience of living with fibromyalgia. *Qualitative Health Research*, 9(5), 575-587. doi: 10.1177/104973299129122090

- Sterin, G. J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia: International Journal of Social Research Practice*, 1(1), 7-10. doi: 10.1177/147130120200100103
- Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.
- Touhy, T. A. (2004). Dementia, personhood, and nursing: Learning from a nursing situation. *Nursing Science Quarterly*, 17(1), 43-49. doi: 10.1177/0894318403260639
- Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. In P. Smith (Series Ed.), *The philosophy of education*. Albany: State University of New York Press.
- Van Den Tillaart, S., Kurtz, D., & Cash, P. (2009). Powerlessness, marginalized identity, and silencing of health concerns: Voiced realities of women living with a mental health diagnosis. *International Journal of Mental Health Nursing*, 18(3), 153-163. doi: 10.1111/j.1447-0349.2009.00599.x

CHAPTER 4: CHALLENGES TO EXPLORING THE EXPERIENCES OF PEOPLE WITH DEMENTIA

Abstract

Persons with dementia are one of the most excluded groups in Western society and their experiences have rarely been studied. In most studies of dementia conducted to date, researchers interested in their experiences have relied on proxy accounts rather than listening to those living with dementia. In part, that may be explained by the challenges of conducting research with persons with dementia. This article describes the challenges of studying the lived experiences of persons with young-onset dementia, including concerns about the capacity of persons with dementia to give informed consent and their ability to be good informants about their subjective experience. The paper concludes that these concerns, shared by IRB, grant reviewers, dementia associations and health care practitioners, alike, are unwarranted.

Keywords: dementia, capacity, consent, informant

Introduction

Persons with dementia are one of the most excluded groups in Western society (Dewing, 2002; Wilkinson, 2002) and their perspective is conspicuously underrepresented in the research literature. A key concern in research with people with dementia is their capacity to give consent (Cubit, 2010). Capacity refers to a person's ability to understand information relevant to making an informed, voluntary decision (NIH, 2009). Although there are no dementia specific protocols for obtaining informed consent, researchers studying this population generally recognize three fundamental requirements: participants should be fully informed of the risks and benefits of

participation, their right to withdraw, at any time, without consequence, and confidentiality procedures (Hellström, Nolan, Nordenfelt, & Lundh, 2007).

Deterioration in everyday functional ability is a fundamental aspect of dementia. People with dementia are thus a vulnerable population because their decision-making abilities are compromised. However, dementia is not always associated with a lack of capacity for informed consent (Beck & Shue, 2003). Dewing (2002) notes that current approaches to determining consent place too much emphasis on cognitive ability, resulting in an exclusionary approach that in essence is a 'one size fits all model'. Further, Pratt (2002) contends that there is no way of judging whether anyone, with or without dementia, is 100% informed; therefore, the goal should be to try to ensure 'maximally informed consent'. The National Bioethics Advisory Commission (2001) recognizing this inconsistency, has offered recommendations for research protocols, including a method to determine the capacity of potential participants and a plan to reassess cognitive capacity during participation in a study (Beuscher & Grando, 2009).

Concern has also been expressed about the ability of persons with dementia to be good informants. Characteristically, good informants possess insight and awareness and the motivation to disclose. However, it is widely believed that once diagnosed, a person with the dementia is permanently rendered incapable of insight and coherent thought (Beattie, 2009). Thus the assumption is that persons with dementia lack the capacity to reflect on and share their experiences. Consequently, in lieu of firsthand reports, researchers have relied on proxy accounts from family members to examine the experience of living with dementia.

Yet there is evidence that people with dementia are able to inform researchers of their feelings and needs, even when the dementia affects how well they communicate those feelings and needs (Bourgeois, 2002). For example, qualitative studies have revealed that people with

dementia are not only aware of their cognitive decline (Downs, 2005) but can also describe how they cope with the stress of living with dementia (Phinney, Wallhagen, & Sands, 2002; Snyder, 2003). Fellows (1998) suggested that the decision making skills that have served these individuals for their entire lives, may persist at some level. It has also been suggested that current approaches, which restrict contact with the person with dementia until after proxy consent has been obtained, amount to exclusionary ethics (Post, 1995).

This article describes the challenges in undertaking a study of the experiences of persons with young-onset dementia. The layers of protection typical of studies involving human subjects were multiplied for this population. Concerns related to the capacity of people with dementia to consent and their ability to be good informants were shared by several gatekeepers including the Institutional Review Board (IRB), grant reviewers, health care practitioners, and dementia associations. The paper describes how challenges were overcome and concludes with optimism about further research on the subjective experiences of this vulnerable population.

Investigating the Lived Experience of Young-Onset Dementia

The study of the lived experience of young-onset dementia (YOD) included nine people, ages 42-61, who had been diagnosed with YOD and were in the early stages of the disease. Potential participants were screened for their appropriateness for the study using a two part process. First, they were unobtrusively asked to explain their reasons for wanting to participate. Then, using the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975), the degree of their impairment was estimated. Persons who scored less than four errors on the SPMSQ were enrolled in the study. Data were collected by engaging participants in conversational interviews, focusing on the experience of living with dementia. Each person was

interviewed twice, with the exception of one participant, who, at her request was interviewed a third time. During the first interview, participants were asked to describe their experiences of living with dementia. The interview process began with a simple question: “Please tell me about your experience with discovering that you have young-onset dementia.” More probing questions included, “How did you feel when you were told that you have dementia?” and “How has living with dementia affected your life and your relationships?” The second interview was conducted within 2 weeks of first interview and its purpose was for the interviewer and participant to reflect on themes identified from the first interview. During the second interview, the interviewer read themes extracted from the first interview and asked the participant to elaborate on the themes. For example, “Can you tell me a bit more about that experience?” and “Is this what the experience means to you?” All participants spoke freely and shared their experiences in great detail. The interviews, each of which lasted 45-90 minutes, were recorded on a digital audio recorder and subsequently transcribed verbatim.

Capacity to Give Informed Consent

Concerns about the capacity of people with dementia to provide informed consent are widely shared, but there is little in the way of practical guidance for dealing with this issue (Bartlett & Martin, 2002; Hellström, Nolan, Nordenfelt, & Lundh, 2007). Consistent with these concerns, the IRB of the university in which the study was conducted, was initially apprehensive about whether participants could be fully informed. They suggested that it might be more appropriate for a family member with power of attorney to provide consent on behalf of the person with dementia. In response to their concerns, the researcher cited the literature indicating that the level of competence of people with dementia is variable and should be determined in

relation to the nature of the decision to be made (Shah & Dickenson, 1999). For example, among people with dementia, ability to comprehend is far greater when focused on feelings than when focused on facts (Pratt & Wilkinson, 2001). Thus incompetence in one area of life does not necessarily imply incompetence in others (Holm, 2001).

Qualitative research does not involve a single event but rather, is an ongoing engagement between the researcher and the participant (Kayser-Jones & Koenig, 1994). Thus, consent is an on-going process. This is particularly salient in research with persons with dementia as their cognitive abilities may fluctuate. Since this study was qualitative, the IRB members also expressed concern about whether the participants would remember, from one meeting to the next the nature of the study and the fact that they had consented to participate. The researcher explained that participants' capacity to play an active part in the interview would be assessed at the beginning of each encounter.

The university IRB adheres to strict standards for the protection of human subjects, and is accredited by the Association for the Accreditation of Human Research Programs, the gold standard for ethical human research. On the basis of the information provided by the researcher, the IRB decided that the proposed study included appropriate safeguards to protect the participants and posed minimal risk. The study was deemed exempt and the investigator was granted permission to proceed.

Several grant proposals were submitted to obtain funding for this study and the comments of reviewers reflected concerns similar to those expressed by the IRB. One reviewer was surprised that the university's IRB would permit informed consent to be obtained from a person with dementia, and suggested that the IRB members were remiss in their duties in exempting the study from review. Unfortunately, communication with grant reviewers is one way and the

researcher was thus not able to provide rebuttal to this. However, since this was a dissertation proposal, not reliant on funding, the study proceeded.

People with Dementia as Informants

Gatekeepers were also skeptical about the ability of persons with dementia to be ‘good informants’. As noted above, for people with dementia, the ability to comprehend and communicate is greater when focused on feelings than when focused on facts (Pratt & Wilkinson, 2001; Holm, 2001). This characteristic lends itself to the qualitative method of inquiry, in which the researcher aims to obtain authentic insights into the participant’s experiences (Burns & Grove, 2003). Phenomenology, the method used in this study of young-onset dementia, seeks to capture the ‘lived-experience’ of study participants. Unlike other research methodologies, phenomenology requires the researcher to develop a trusting relationship with the informant, actually forming a partnership in the inquiry. In the study of YOD, trusting relationships were formed between the researcher and the participants, which led to open and honest discussions about the experience of living with dementia.

Interestingly, several health care practitioners who were contacted for permission to place recruitment flyers in their offices indicated that there were no patients with YOD in their practice. These views probably came from the fact that many people with early dementia have preserved functional abilities and are able to compensate for some cognitive losses. Yet during the interview the study participants revealed that a major source of their frustration came from the assumption of health care practitioners that middle-aged people were unlikely to have dementia.

Several dementia associations were also contacted to enlist their support in recruiting participants. A representative of one association suggested that posting a study flyer on their website would be intrusive. The researcher was informed that the association's members expected privacy and people who are not affected by dementia were not welcome. One support group member who was determined to have his voice heard contacted the association, urging them to post the study information. Subsequently, a single, one-time post was permitted, which resulted in recruitment of two participants. This member's effort was consistent with other participants' report that the organizations created for the purpose of helping them might actually inhibit their ability to maintain independence and have their voices heard (Hunt, 2011).

This kind of protective paternalism over people with YOD was not demonstrated by all dementia associations. The Association for Frontotemporal Dementias, for example, affirmed that many of its younger members had voiced concern about the scarcity of resources and opportunities for them to share their experiences. This association assisted in study recruitment by mailing study flyers and a letter of support to members who were known to meet inclusion criteria. Fourteen letters were sent and four people responded.

Persons with dementia have largely been excluded from research because of perceived challenges to their ability to communicate and understand (Corner & Bond, 2004). Some reviewers of proposals to fund this study suggested the use of additional quantitative screening tools to assess cognition. Other reviewers suggested including caregivers as informants. Otherwise, they reasoned, the study findings were likely to be invalid because persons with dementia would be unable to remember conversations from one encounter to the next. Conversations with people living with dementia revealed their frustration at the assumptions of others that they lack the ability to reflect on their lives and remember a conversation. And during

the prescreening process, participants noted that some of the tools typically used to screen for cognitive decline are not valid. Some participants mentioned memorizing parts of the Mini Mental State Exam ([MMSE] Folstein, Folstein, & McHugh, 1975). Others described their experiences with cognitive screening as demeaning and expressed frustration at health care providers' reliance on quantitative tools.

Participants' complaints about screening is consistent with the literature which has noted a growing consensus that cognitive tests such as the MMSE may not accurately capture the abilities of persons with dementia (Hellström, Nolan, Nordenfelt, & Lundh, 2007; Pratt, 2002). This sentiment was reinforced by study participants who said that if others would take the time to talk with and really listen to them, their true ability would be revealed. Participants demonstrated this ability when they were able to provide cues when a question needed clarification or they had concern that the researcher might not understand their answers. For example, one person simply stated, "I don't understand what you're asking." Another person asked, "Am I making sense to you?" Several participants affirmed their awareness, informing the researcher that there were days when the ability to form cohesive thoughts was lost and requesting they be given a 'second chance' if an interview had been scheduled for one of those 'bad days'.

Discussion

Despite gatekeepers' concerns, the participants in the study of young-onset dementia described the experience as positive and enjoyable. Several participants described the experience as therapeutic and expressed gratitude that someone was taking the time to listen to them. They made remarkable efforts to be heard and to advocate for a deeper understanding of the experience of living with YOD. Several participants noted that they saw this study as an

important first step to acknowledging their ability to provide insight into a disease that robs middle-aged adults of their personhood and the ability to remain valuable members of society.

Many of the researcher's experiences with gatekeepers, when designing and conducting this study, were echoed by participants. For example, they reported feeling invisible in social situations because former friends no longer sought out their company. They reported being dismissed by healthcare practitioners after failing a cognitive screening test. Like other stigmatized or devalued groups, people living with dementia are often rendered voiceless (Van Den Tillaart, Kuryz, & Cash, 2009). The resounding plea from persons with dementia is to have their personhood embraced instead of negated.

This researcher's experiences with study participants, whose abilities challenged the concerns of the gatekeepers, suggest that other researchers should not assume that people with dementia lack the capacity to participate in the consent process. Nor should we doubt their ability to be good informants, thus denying them an opportunity to make a meaningful contribution (Barlett & Martin, 2002). Reliance on the traditional competence-based, quantitative approach to consent systematically excludes the voices of persons with dementia. There is growing evidence that such 'tests' bear no relationship to the ability of people with dementia to talk about their experiences and they may make it impossible to establish a trusting relationship between the researcher and participant (Hellström, 2007; Pratt, 2002). If we are to understand the subjective experience of dementia, we need to listen to the people who are living with the disease.

Conclusion

This paper provides an overview of what researchers interested in the experiences of people living with dementia are likely to encounter and provides evidence that people with

dementia have the capacity to provide informed consent and be good informants. The procedures used to conduct this study reflect attention to practical guidance in how to include these people especially in the informed consent process (Barlett & Martin, 2002; Dewing, 2002). In particular, it is important to draw on the strengths of people with dementia rather than emphasizing their weaknesses (Hellström, 2007).

Concerns expressed by gatekeepers in this study proved to be unwarranted. Persons living with dementia are asking to have their voices heard. By excluding them from research on the experience of dementia, we deprive them of the opportunity to feel useful by making a meaningful contribution to research and we lose the opportunity to understand their experience from their perspective. Participants in this study demonstrated a remarkable level of awareness and insight and not only were they good informants, they were excellent informants!

References

- Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp. 47-61). London, England. Jessica Kingsley.
- Beattie, E. (2009). Research participation of individuals with dementia. *Research in Gerontological Nursing*, 2 (2), 94-102.
- Beck, C., & Shue, V. (2003). Surrogate decision-making and related issues. *Alzheimer's Disease & Associated Disorders*, 17(Suppl. 1), S12-S16. Retrieved from <http://journals.lww.com/alzheimerjournal/>

- Beuscher, L., & Grando, V.T., (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontology Nursing*, 2(1), 6-11. doi: 10.3928/19404921-20090101-04
- Bourgeois, M. S. (2002). "Where is my wife and when am I going home?" The challenge of communicating with persons with dementia. *Alzheimer's Care Today*, 3, 132-144. Retrieved from <http://journals.lww.com/actjournalonline/>
- Burns, N., & Grove, S. (2003). *Understanding Nursing Research*, 3rd. ed. (pp.357-377). Philadelphia, PA. Saunders.
- Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18, 143-155. doi: 10.1016/j.jaging.2004.01.007
- Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse*, 34 (2), 230-236.
- Dewing, J. (2002). From ritual to relationship: A person-centered approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1, 157-171. doi: 10.1177/147130120200100204
- Downs, M. (2005). Awareness in dementia: In the eye of the beholder. *Aging & Mental Health*, 9, 381-383. doi: 10.1080/13607860500215212
- Fellows, L. (1998). Competency and consent in dementia. *Journal of the American Geriatric Society*. 46, 922-926.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198. doi: 10.1016/0022-3956(75)90026-6

- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*, 608-619. doi: 10.1177/0969733007080206
- Holm, S. (2001). Autonomy, authenticity, or best interest: everyday decision making and persons with dementia. *Medicine, Health Care and Philosophy, 4*: 153-159.
- Hunt, D. (2011). The lived experience of young-onset dementia. *Journal of Psychosocial Nursing. In Press*
- Kayser-Jones, J., & Koenig, B. A. (1994). Ethical issues. In J. F. Gubrium & A. Sankar (Eds.), *Qualitative methods in aging research* (pp. 15-32). Thousand Oaks, CA: Sage.
- National Bioethics Advisory Commission. (2001). *Ethical and policy issues in research involving human participants*. Bethesda, MD: Author. Retrieved from <http://bioethics.georgetown.edu/nbac/human/oversumm.pdf>...
- National Institutes of Health. (2009). *Research involving individuals with questionable capacity to consent: points to consider*. Bethesda, MD: Author. Retrieved from <http://grants.nih.gov/grants/policy/questionablecapacity.htm>
- Pfeiffer, E. (1975). A Short Portable Mental Status Questionnaire for the assessment of organic brain deficit in elderly persons. *Journal of the American Geriatrics Society, 23*, 433-441. Retrieved from <http://www.americangeriatrics.org/publications/>
- Phinney, A., Wallhagen, M., & Sands, L. P. (2002). Exploring the meaning of symptom awareness and unawareness in dementia. *Journal of Neuroscience Nursing, 34*, 79-90. doi: 10.1097/01376517-200204000-00007
- Post, S.G. (1995). Alzheimer's disease and the 'then' self. *Kennedy Institute for Ethics Journal, 5*, 307-321.

- Pratt, R. (2002). "Nobody's ever asked how I felt." In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp. 165-182). London, England: Jessica Kingsley.
- Pratt, R., & Wilkinson, H. (2001). *No diagnosis has to be your whole life: The effect of being told the diagnosis of dementia from the perspective of the person with dementia*. London, England: Mental Health Foundation.
- Shah, A. & Dickenson, D. (1999). The capacity to make decisions in dementia: Some contemporary issues (Editorial). *International Journal of Geriatric Psychiatry*, 14, 803-806. doi: 10.1002/(SICI)1099-1166(199910)14:10<803::AID-GPS23>3.3.CO;2-Q
- Snyder, L. (2003). Satisfactions and challenges in spiritual faith and practice for persons with dementia. *Dementia*, 2, 299-313. doi: 10.1177/14713012030023002
- Van Den Tillaart, S., Kuryz, D., & Cash, P. (2009). Powerlessness, marginalized identity, and silencing of health concerns: Voiced realities of women living with a mental health diagnosis. *International Journal of Mental Health Nursing*, 18(3), 153-163. doi: 10.1111/j.1447-0349.2009.00599.x
- Wilkinson, H. (2002). Including people with dementia in research: Methods and motivations. In H. Wilkinson (Ed), *The perspectives of people with dementia: Research methods and motivations* (pp. 9-25). London, England: Jessica Kingsley.

APPENDIX A: DISSERTATION PROPOSAL

THE LIVED EXPERIENCE OF YOUNG-ONSET DEMENTIA

by

DEBRA A. HUNT

B.S. Southern College of Seventh Day Adventists, 1996

M.S. University of Central Florida, 1998

Major Professor: Karen Aroian

Abstract

Specific Aims: The lived experiences of dementia in older persons have been well studied, but the unique experiences of persons between ages 35 and 65 years who are living with young-onset dementia have not been closely examined. This study is intended to examine the experiences of middle-aged individuals living with young-onset dementia.

Background and Significance: It is estimated that more than ½-million people in the United States live with young-onset dementia and another ½-million with mild cognitive impairment, a precursor of dementia. Prevalence of young-onset dementia is expected to increase as Baby Boomers age, taxing an overburdened health care system to accommodate this population using an approach established for the older adult. This approach does not address the specific needs of individuals with young-onset dementia and often results in loss of self-esteem and social isolation.

Purpose: The purpose of this study is to explore the lived experience of middle-aged adults between 35 and 65 years who are living with young-onset dementia.

Research Design and Methods: Hermeneutic phenomenology, compatible with the philosophy put forth by leaders in the field about how to care for people with dementia—specifically that they need to be understood in their full humanity, as unique persons—will be used to explore the meaning of living with young-onset dementia. Semistructured interviews will be used to gather data. Purposive sampling will be used to recruit 8-12 people between 35 and 65 years of age who are living with mild dementia. Additional participants will be recruited until no further

themes are made (data saturation is achieved). Consistent with van Manen's method of phenomenological reflection, theme analysis using the selective approach will be conducted to grasp the essential meanings of the experience.

Relevance to Healthcare: Knowledge gained from this study will help health care professionals understand and communicate with persons living with young-onset dementia by sensitizing them to the unique needs of middle-aged persons with dementia. This information will assist in identifying resources that specifically address the needs of middle-aged persons with dementia.

Purpose of the Study

This hermeneutic phenomenological study will explore the lived experience of middle-aged adults with young-onset dementia. The term *young onset dementia* refers to persons who first experience the signs and symptoms of dementia prior to age 65 (American Psychiatric Association, 1994). Consistent with this definition, throughout this proposal, young-onset dementia will refer to persons who are between the ages of 35 and 65.

Background and Significance

Dementia is a chronic, progressive, debilitating brain disorder that affects a person's ability to carry out activities of daily life. It is characterized by an insidious onset of cognitive and/or behavioral symptoms that constitute a departure from an individual's customary way of thinking and/or behaving. Changes can occur in memory, reasoning, judgment, language, and personality (Mesulam, 2000; Wickland & Weintraub, 2005).

While dementia is not an uncommon diagnosis in persons over 65, the prevalence of young-onset dementia may be far greater than is generally acknowledged. Harvey, Skelton-Robinson, and Rossor (2003) investigated the epidemiology and clinical symptoms of young-onset dementia in the United Kingdom and found the prevalence of dementia in persons between 30 and 64 years of age was 54 per 100,000 (95% CI). In the United States, it has been proposed that more than one-half million of the 5.2 million adults living with dementia are under 65 years of age (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Another one-half million people ages 55 to 64 years have mild cognitive impairment, which can be a precursor to dementia (Knopman, Petersen, Cha, Edland, & Rocca, 2006; McMurtray, Clark, Christine, & Mendez, 2006). In addition, it is estimated that 6-10% of older adults with Alzheimer's disease may have

experienced unrecognized symptoms of dementia prior to age 65 (Alzheimer's Association, 2003), which means that they, technically, were living with young-onset dementia.

Atypical Dementia in Middle-Aged Persons

Middle-aged persons are at increased risk for developing an atypical dementia, such as frontotemporal dementia, HIV-related dementia, alcohol encephalopathy, Downs syndrome-related dementia, and dementia related to traumatic injury (Harris & Keady, 2004; Harvey et al., 2003). In a study conducted at a large veterans' memory clinic, head trauma, alcohol abuse, and HIV infection were the most common causes of dementia in middle-aged clinic patients (Licht, McMurtray, Saul, & Mendez, 2006). From age 35 onward, the prevalence of dementia in patients with head trauma, alcohol abuse, and HIV infection doubles with each 5-year increase in age. These findings are consistent with the results from three other studies that indicated that the frequency of dementia from conditions that are more common among young to middle-aged adults increases between the ages of 45 and 65 (Bottino et al., 2008; Hofman et al., 1991; Nandi et al., 2008). As the Baby Boomer population ages, findings suggest that the prevalence of young-onset dementia will increase, presenting an overburdened health care system with unique challenges.

Literature Review

Most of the research about young-onset dementia has been limited to neuropathology of the disease process or, to a lesser extent, caregiver burden (Arai, Matsumoto, Ikeda, & Arai, 2007; Armstrong, 2003; Kaiser & Panegyres, 2007). Unlike the literature on dementia in older adults, which addresses the personal experience of living with dementia (Harman & Clare, 2006; Phinney & Chesla, 2003), few studies explore young-onset dementia from the perspective of an affected person between the ages of 35 and 65. Even the few studies that purported to include

the perspective of the younger person with dementia reported only briefly on the younger person's perspective and focused much more on the caregiver's experiences (Armstrong, 2003; Harris & Keady, 2004; Lough & Garfoot, 2007; Williams, Cameron, & Dearden, 2001).

Those few studies that included the younger persons' perspective reported that persons with young-onset dementia were frustrated by the lack of age-specific resources. Most dementia care settings, for example, are designed for older adults and not equipped to meet the needs and interests of younger persons with dementia. Younger persons with dementia are more likely to be physically healthy than older adults with dementia and may require alternative approaches when providing care (Beattie, Daker-White, Gilliard, & Means, 2004). More specifically, younger persons with dementia who attended day care programs designed for older adults reported feeling out of place and described the day care providers as inhibiting their physical activity and independence (Beattie et al., 2004).

Part of the experience for middle-aged persons with young-onset dementia pertains to difficulty in obtaining a diagnosis. Middle-aged persons with cognitive deficits are often not diagnosed with dementia until 2-3 years after the onset of symptoms, resulting in delayed treatment and significant emotional distress for them and their caregivers (Harris & Keady, 2004). Behavior and personality disorders may be misdiagnosed as psychiatric in origin. An accurate diagnosis is often delayed while the person is needlessly treated for a psychiatric disorder. Some clinicians have been hesitant to relay a diagnosis of dementia to a middle-aged person, citing a concern that receiving a diagnosis of dementia may overwhelm the person and trigger depression or even suicide (Carpenter et al., 2008; Vassilas & Donaldson, 1998). This concern has some merit. Because recent memory is lost before long-term memory, affected persons may be aware of the deterioration experienced to date as well as the long-term prognosis

for patients with dementia. Thus, the diagnosis has been known to cause fear and uncertainty for the future. Other studies however, have indicated that a confirmed diagnosis of early-onset dementia can result in relief in knowing the cause of cognitive changes (Carpenter et al., 2008; Husband, 1999; Jha, Tabett, & Orell, 2001).

Dementia Subtypes and Burden in Middle-Aged Persons

The burden of a dementing illness in the middle-aged person will be different from that experienced by older adult with dementia. The causes of young-onset dementia are different from those of late-onset dementia (Licht et al., 2007) and seem to play a role in how quickly and to what degree functional abilities decline. One type of dementia, frontotemporal, typically affects persons between the ages of 45 and 60, and is a clinical syndrome of behavioral disorders associated with frontotemporal cerebral atrophy (Gustafson, 1993). Frontotemporal dementia is indicated by an insidious onset of selective loss of cognitive abilities, behavioral disturbances, personality changes, and loss of empathy. The person with frontotemporal dementia may behave in a socially inappropriate manner, demonstrate sexual disinhibition, and become emotionally labile. Loss of judgment and the inability to plan can force premature retirement (Sampson, Warren, & Rossor, 2004).

Vascular dementia, another cause of young onset dementia (Harvey et al., 1998), may be related to diseases of the small vessels or, less frequently, genetic arteriopathies (Nandi et al., 2008; Sampson et al., 2004). The affected person may display psychiatric symptoms, gait disturbances, and urinary incontinence. These symptoms can cause embarrassment and lead to social isolation. They may also affect employment and other roles typical for middle-aged adults.

Alzheimer's disease in the person under 65 years of age is frequently familial, the result of a gene mutation (Sampson et al., 2004). In Alzheimer's disease, the most frequent early sign is mild memory impairment, which, in the younger adult, may be mistaken as depression or, more commonly, considered to be stress-related. Neurological examination is often normal in the early stages of Alzheimer's disease (Harvey et al., 2003), which further complicates the diagnostic process.

Young Onset Dementia and Developmental and Role Issues for Middle-Aged Adults

Developmental reasons exist that explain why the experiences of young-onset dementia should be different from those of the elderly with dementia. Erik Erikson (1980), the first theorist to assert that significant development occurs in adulthood, defined *generativity* as the developmental task of middle-aged adults. Generativity involves productive work, caring for a family, and significant social relationships. In contrast, psychosocial development encompasses gains and losses throughout the life span. It is to be expected that with age-related decline, the losses will outnumber the gains. In other words, losses are considered somewhat normative for older adults because they are attributed to the aging process. Cognitive losses associated with young-onset dementia are premature and shift the proportion of gains to losses to a less positive balance (Baltes, 1997).

These losses threaten the generativity of middle-aged adults because they affect the multiple roles typically held by this population. Middle-aged adults assume multiple roles in their professional and personal lives. Middle adulthood is a time of high activity and productivity in which people set and achieve goals and view themselves as being in the prime of life (Harden, 2005).

Younger persons with dementia may be more aware that something is wrong because they and others (e.g., spouses, children, and employers) have higher expectations of their abilities and capacities. Their abilities and capacities are more often on display in the occupational and social spheres; younger persons with dementia tend to have more responsibilities in terms of employment and family commitment. Subsequently, decisions made concerning work and social roles of the younger person with dementia can have considerable effects on others. If the affected individual is a primary caregiver, roles change dramatically; the person with dementia is forced to assume a dependent role within the family. This role change may result in feelings of helplessness and frustration.

Work Role. Unlike their older counterparts, persons with young-onset dementia may be in midcareer when symptoms emerge. For persons in the fourth and fifth decades of life, work is usually a primary function and an important part of self-identity. It may be in the work environment where symptoms of cognitive decline are first publicly noticed. Some of the earliest signs of dementia include difficulty with word finding, decreased ability to multitask, and impairment in planning, organizing, and decision making. The inability to express thoughts, especially complex ideas, makes workplace conversation more difficult. Behavior changes such as emotional outbursts may occur (Harris & Keady, 2004). Even for the affected person who manages to maintain acceptable social skills, the progressive inability to perform usual job-related tasks may lead to premature loss of income, difficulty obtaining medical benefits, and loss of full retirement benefits. All of these losses can cause significant financial burden to the affected person and his or her family.

Family Roles. Unlike their older counterparts, persons with young-onset dementia may have children at home and may be caring for aging parents (Armstrong, 2003; Harris & Keady,

2004). Russo, Vitaliano, Brewer, Katon, and Becker (1995) discussed the fear and uncertainty associated with suspected hereditary dementia. The parent living with young-onset dementia may experience significant guilt with the knowledge that his or her children may eventually develop an inherited form of dementia. As cognitive impairment declines, younger persons with dementia can no longer parent their children and lose family leadership responsibilities. Role reversal is common: the majority of young-onset dementia sufferers are cared for in the community by their families and receive minimal services (Baldwin, 1994; Newens, Forster, & Kay, 1995).

Young-onset dementia can disrupt the typical transitional stages of the family life cycle. The fifth and longest stage of the family life cycle involves launching children and regeneration of the marital dyad (McGoldrick & Carter, 2003). When a parent has dementia, the children may find it difficult to leave home, thereby preventing the family from moving on to the next stage. Because caring for someone with dementia requires the caregiver to spend increasing amounts of time with the affected individual, the disease reduces the caregiver's opportunities for social interaction outside of the home. Progressive disability and behavioral changes may discourage friends and family members from visiting, resulting in further isolating the affected person and the caregiver.

Chronic Illness and Loss. An extensive search of the literature yielded only a few articles that presented a thorough discussion of loss associated with dementia in the middle-aged person (Armstrong, 2003; Harris & Keady, 2004). Many studies discussed the psychosocial effects and meaning of chronic illness in persons with various physical maladies (Bulsara, Ward, & Joske, 2004; Burnie, 2000; Giddings, Roy, & Predeger, 2006; Harden, 2005; Wardini & de la Rosa, 2005). Steverink, Westerhof, Bode, and Dittman-Kohli (2001) reported that older adults

perceived less stress related to chronic illness because longevity seems to prepare the person for loss later in life.

Studies of chronic illness in middle-age adults portray role and developmental influences that contrast their experience with older, chronically ill adults. For example, younger female cancer survivors reported higher levels of negative impact on their life compared to older cancer survivors. This disparity may be related to secondary role strains such as outside employment, child rearing, and social obligations that continued over time (Nijboer et al., 2000). A study by Söderberg, Lundman, and Norberg (1999) discussed the loss of credibility and dignity experienced by middle-aged women living with fibromyalgia. The women reported feeling that they were not taken seriously because they did not look sick. Another factor associated with the women's perceptions of loss was the lack of knowledge about fibromyalgia and the health care provider's negative attitude about their symptoms. Young-onset dementia presents similar challenges for affected persons in that its occurrence is unexpected in middle age and affected persons may spend a great deal of time and effort shuffling from one health care provider to another in search of an accurate diagnosis.

Regardless of etiology, psychosocial losses are a significant factor for younger adults coping with chronic illness (Sidell, 1997). For the person with young-onset dementia, a decline in function impairs one's ability to care for one's self and others and to contribute to society. This interruption in usual roles associated with middle age may result in feelings of unimportance. Like persons with other chronic illnesses, persons with young-onset dementia need to adapt or modify their prior roles to accommodate the illness as well as social expectations (Lewis & Lubkin, 2002a). The accommodation process is likely to produce role strain, including anxiety, depression, grief, hostility, and apathy (Hardy & Hardy, 1988).

Differences Between Dementia and Other Chronic Illnesses

Cognitive functions and psychological variables such as self-confidence and self-mastery peak during middle adulthood (Harden, 2005). An important distinction between dementia and other chronic illnesses is that middle-aged persons with chronic physical illness typically retain cognitive function. Dementia can erode confidence in mastery of expected roles. These speculations about the experience of dementia as different for middle-aged adults are consistent with studies of age differences in the psychosocial effects and meaning of other chronic illness (Bulsara et al., 2004; Burnie, 2000; Giddings et al., 2006; Harden, 2005; Wardini & de la Rosa, 2005).

Regardless of age, social isolation is a concern for people with dementia (Harris & Keady, 2004). For the person with young-onset dementia, this isolation may be compounded by the fact that dementia is seen as an “old person’s disease.” Like cognitive change, deterioration in everyday functional ability is a critical aspect of dementia. Dementia causes impairments in planning, organizing, and decision making. The resultant anxiety and depression may lead to mood and personality changes.

Rationale for the Study

I became poignantly aware that middle-aged persons with dementia have unique needs when I discovered an autobiographical account of young-onset dementia written by Dr. Richard Taylor (2007). Subsequently, I was privileged to communicate with Dr. Taylor and learned that there were other people living with young-onset dementia who longed to be heard. Dr. Taylor directed me to several online chat rooms in which individuals with young-onset dementia candidly and openly talk and support each other. I joined several of the chats and asked if chat participants would be willing to talk with me about their experiences of living with young-onset

dementia. The response was overwhelming. A 42-year-old gentleman named Joe wrote, “We need to talk to you. Somebody needs to hear what we have to say.” Joe gave me his personal e-mail address as well as his phone number. Tracy, a 48-year-old woman wrote, “Please talk to us. We are the forgotten victims of Alzheimer’s. I was diagnosed at 38. I was nurse for 20 years, and I miss it so much. Thank you for caring.”

Communications with Dr. Taylor, Joe, and Tracy led to further reflection on the phenomenon of young-onset dementia. How many younger adults are living with young-onset dementia? Do they all feel forgotten? Are they afraid of what the future will bring? Do they still plan for a future? Is the desire to talk about the experience universal? How did they feel when they learned of the diagnosis? These questions guided this proposal.

Summary

Nursing needs to understand the life experiences, needs, and concerns of middle-aged persons living with dementia to better meet their needs. Because so little research has been conducted to explore the unique needs of this study population, it is unlikely that health care and community service providers know how to care for middle-aged people with young-onset dementia. Information needed for training of caregivers is not available (Harris & Keady, 2004). Because the issues related to this population have not been documented, persons with young-onset dementia are often placed within a framework of care designed for the older adult. Treating a middle-aged person as an older adult can lead to a loss of self-esteem and social isolation. Knowledge gained from this study will help health care and community providers understand persons living with dementia by sensitizing them to the unique needs of middle-aged people with dementia. This knowledge, in turn, should improve quality and comprehensiveness of care for middle-aged persons with young-onset dementia.

Research Methods and Design

Hermeneutic phenomenology seeks to explore how persons make sense of the world and their place in it (Conroy, 2003). Van Manen's (1990) method of hermeneutic phenomenology was chosen to explore the meaning of the lived experience of young-onset dementia because it is compatible with the philosophy put forth by many leaders in the field about how to care for people with dementia—specifically that men and women who have dementia must be understood in their full humanity, as unique persons, as opposed to being labeled a dementia victim (Kitwood, 1997; Sterin, 2002; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997; Touhy, 2004). Consistent with van Manen's method, each participant will be interviewed twice, using semistructured interviews to generate and gather the data.

Phenomenological reflection and theme analysis will be used to grasp the essential meanings from the first interview. During the second interview, the themes will become the objects of reflection in a follow-up conversation. The two interviews will provide a mechanism for the researcher and each study participant to collaborate in the interpretation of the themes to discover the meaning of the experience of living with young-onset dementia.

Sample

Study participants will live anywhere in the United States. Inclusion criteria are persons who report being, formally diagnosed with mild dementia, are between the ages of 35 and 65, and have the ability to understand and speak English.

Participants will be recruited through online advertisement in dementia chat rooms and recruitment flyers placed in health care practices in Central Florida. A mental health care provider from south Florida and two primary care providers in central Florida have agreed to place recruitment flyers in their waiting rooms. The owner of the Dementia Rescue online chat

room has agreed to post a recruitment flyer. A dementia community educator in central Florida will distribute recruitment flyers to all of her dementia support group facilitators.

Sampling will be purposive to include participants who have a diagnosis of young-onset dementia and are able to reflect on their illness. The sample size is anticipated to be 8 to 12 persons. Additional study participants will be recruited, if needed, until the data are saturated or no further themes emerge from the data.

Potential study participants will contact the primary investigator (PI) by telephone or e-mail and will be prescreened for the ability to reflect on their illness. Persons in earlier stages of dementia are, most often, able to engage in self-reflection. The PI, who has experience caring for persons with dementia, will telephone interested persons and administer the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975), which was designed to assess for organic brain deficits in elderly patients and is easily administered by telephone (see Appendix A).

In addition to administering the SPMSQ (Pfeiffer, 1975), the PI will unobtrusively assess each participant's ability to describe the experience of being diagnosed and living with young-onset dementia. During the initial telephone conversation, the PI will pose the question, "Can you tell me a bit about why you are interested in participating in this study?" People who are able to answer questions with sufficient self-reflection and obtain a score of less than five errors on the SPMSQ will be scheduled for an in-person interview.

Informed Consent

The PI will initiate the first face-to-face or telephone meeting with the PI. During this meeting, the PI will explain again the purpose of the study, discuss how data will be gathered and utilized and how participant confidentiality will be maintained, offer to answer questions, and request verbal informed consent to participate. The participant's ability to withdraw from

the study at any time will be reiterated. Upon receipt of consent to participate, each participant will be assigned a number to ensure confidentiality and privacy are maintained. A password-protected database will be created to store participant information and the study number. The study number will be used on each form and the audiotape made to record each interview.

Prior to starting the formal interview process, participants will complete a demographic and health questionnaire (see Appendix C).

Data Collection Materials

The SPMSQ (Pfeiffer, 1975) (see Appendix A) is an easy-to-use, 10-item test that addresses orientation, personal history, remote memory, and calculation. When administered to community-dwelling older adults, the specificity was reported to be better than 90%, with sensitivity between 76% and 86% (Pfeiffer, 1975). Incorrect answers to the SPMSQ are summed. The total SPMSQ error score ranges from zero to 10. Nonresponses are scored as incorrect. A score of 0-2 errors indicates normal cognitive functioning; 3-4 errors indicates mild cognitive impairment; 5-7 errors indicates moderate cognitive impairment and 8 or more errors indicates severe cognitive impairment. Results from this questionnaire will be included as a description of the study sample as well as utilized to determine suitability for participation in the study.

A demographic and health questionnaire (see Appendix C) will be used to collect sociodemographic information including the age, gender, education, occupation, comorbidities, and medications taken by the participant.

The interview questions that will be asked during the first interview are as follows:

1. How did you feel when you were told that you have dementia?
2. How has your life changed since your diagnosis?

3. What does living with dementia mean to you?
4. What are your thoughts about the future?

Interview questions at the second interview will focus on the themes identified from the first interview with the objective of obtaining more in-depth descriptions of life experiences related to the themes.

Data Collection Procedure

For the participant's convenience, interviews will take place in person, in the participant's home or by telephone. At the first interview, the PI will repeat the description of the study and request informed consent. Upon receipt of informed consent, the participant will be requested to complete the demographic and health questionnaire (see Appendix C). Finally, the formal interview process, using the open-ended questions specified below, will be initiated.

Conversational interviews will use an open-ended question style to allow the participant to answer in his or her own words and not be constrained by a fixed set of possible answers. At the end of the first interview, the interviewer will schedule a follow-up interview.

Scheduling of the second interview will be coordinated to allow sufficient time for analyzing the first interview for themes. The selective or highlighted approach will be used to uncover themes from the initial interview. To accomplish this, the audio tapes will be transcribed and the PI will look for any phrases that stand out or sentences that seem to be thematic of the experience of living with young onset dementia. During the second interview, the themes will become the objects of reflection in a follow-up conversation.

Interviews will be audio taped. Journal notes, recording the interviewer's perceptions of the interview, will be kept. Journal notes and interviews will be transcribed, reviewed for

accuracy, and then loaded into a qualitative analysis program. Data will be unidentified and stored on a password-protected computer.

Pilot-Testing the Interview

Before the study is formally launched, the PI will pilot an interview of at least one person who has been diagnosed with early-stage dementia to ensure that the interview technique yields sufficient data. The pilot will include the initial interview and the follow-up interview. The interviews will be reviewed with the dissertation advisor, Dr. Karen Aroian, for feedback. Piloting and consultation will continue until the questions and techniques are determined to yield rich, informative data.

Plan for Data Analysis

Hermeneutic phenomenology, as described by Max van Manen (1990), will be used for data analysis. Analysis will be an ongoing process and will begin prior to the first interview. Prior to the first interview, the PI will engage in the process of “decentering” (Munhall, 2007), reflecting on her own beliefs, preconceptions, intuitions, and motives. A reflective journal will be kept to assist the PI in putting aside assumptions about the phenomenon of living with young-onset dementia as a middle-aged person.

The audio tape made during each interview will be listened to several times to discern statements or phrases that seem particularly revealing about the experience being described. Themes will be isolated through a selective approach. The final step in the analytical process involves describing and interpreting the expressions of meaning across four existential life worlds: spatiality, corporeality, temporality, and relationality.

Spatiality refers to the way each person experiences being in the day-to-day existence.

Corporeality refers to the bodily presence in the world. In the physical body, one both reveals

and conceals something about the self—neither consciously nor deliberately. *Temporality* is our way of being in the world (van Manen, 1990). Temporality is subjective time that may seem to speed up or slow down, depending on the experience being lived. *Relationality* refers to the relationship each person shares with others. While the four existential life worlds of spatiality, corporeality, temporality, and relationality can be differentiated, they cannot be separated (van Manen, 1990) because together, they form the lived world. The final product will be a description of the lived experience of young-onset dementia that communicates the unique needs of affected persons.

Limitations

The use of audiotapes to collect data poses a potential limitation. It is possible that portions of the conversations may not be audible and transcriptions will be incomplete or the audiotape may malfunction. To manage these potential limitations, two digital audiotapes will be made, simultaneously, during the interviews. Interviews will be transcribed within 1 week of their recording.

Another limitation is the inexperience of the researcher in application of the phenomenological method. Dr. Karen Aroian, an expert in qualitative research methods, will provide consultation to offset this limitation. Dr. Aroian will be available to advise on data collection and analysis, including interviewing techniques. Dr. Aroian will also review and critique manuscripts as they are prepared for publication.

Time Frame

This study is expected to take place over the course of 1 year. Appropriate IRB approval will be obtained prior to the start of this study. A preliminary schedule is presented in Figure 1.

M0	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12
Recruitment and Informed Consent												
	Interviews											
	Data Analysis											
									Dissemination of Results			

Figure 1. Preliminary schedule for proposed study (in months).

Protection of Human Subjects

Prior to beginning the research study, approval will be obtained from the University of Central Florida Institutional Review Board. All efforts will be made to maintain participant confidentiality and anonymity. Participant names will be replaced with numbers on all forms related to the study. All identifying information such as names and locations will be omitted for dissemination and publication. Informed consent will be obtained from all study participants.

There are minimal expected risks associated with participation in this study. The potential does exist for mild emotional stress during discussions related to a diagnosis of dementia but participants will have the right to stop the interview at any time in the event of prolonged emotional stress due to the interview questions. In the event that, during the initial telephone conversation, a person fails to qualify for the study, verbal consent will be obtained and a short telephone interview will be conducted. In this way, the individual's personhood and dignity will be acknowledged.

Reference List

- Alzheimer's Association. (2003). Early onset Alzheimer's brings special challenges. *Advances. The Alzheimer's Association Newsletter*, 22(4), 1-11. Retrieved from http://www.alz.org/national/documents/EarlyOnset_RL.doc
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.) (DSM-IV). Washington, DC: Author.
- Arai, A., Matsumoto, T, Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22, 1255-1261. doi: 10.1002/gps.1935
- Armstrong, M. (2003, August 1). The needs of people with young onset dementia and their carers. *Nursing Times.net*. Retrieved from <http://www.nursingtimes.net/nursing-practice-clinical-research/the-needs-of-people-with-young-onset-dementia-and-their-carers/199806.article>
- Baldwin, R. C. (1994) Service experiences of people with presenile dementia—Sperlinger and Furst [Letter to the editor]. *International Journal of Geriatric Psychiatry*, 9, 507. doi: 10.1002/gps.930090611
- Baltes, P. B. (1997). On the incomplete architecture of human ontogeny: selection, optimization, and compensation as foundation of developmental theory. *American Psychologist*, 52, 366-380. doi: 10.1037/0003-066X.52.4.366

- Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). "How can they tell?" A qualitative study of the views of younger people about their dementia and dementia care services. *Health & Social Care in the Community*, 12, 359-368. doi: 10.1111/j.1365-2524.2004.00505.x
- Bottino, C. M. C., Azevedo, D. Jr, Tatsch, M., Hototian, S. R., Moscoso, M. A., Folquitto, J., . . . Litvoc, J. (2008). Estimate of dementia prevalence in a community sample from São Paulo, Brazil. *Dementia and Geriatric Cognitive Disorders*, 26, 291-299. doi: 10.1159/000161053
- Bulsara, C., Ward, A., & Joske, D. (2004). Haematological cancer patients: Achieving a sense of empowerment by use of strategies to control illness. *Journal of Clinical Nursing*, 13, 251-258. doi: 10.1046/j.1365-2702.2003.00886.x
- Burnie, C. (2000). Breast cancer: A study of the psychosocial issues faced by women undergoing radiation therapy. *The Canadian Journal of Medical Radiation Technology*, 31(3), 119-128. Retrieved from <http://www.journals.elsevierhealth.com/periodicals/jmir/>
- Carpenter, B. D., Xiong, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., . . . Morris, J.C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatrics Society*, 56, 405-412. doi: 10.1111/j.1532-5415.2007.01600.x
- Conroy, S. A. (2003). A pathway for interpretive phenomenology. *International Journal of Qualitative Methods*, 2(3), 36-62. Retrieved from <http://ejournals.library.ualberta.ca/index.php/IJQM/index>
- Erikson, E. H. (1980). Generativity versus stagnation. In *Identity and the Life Cycle* (pp. 103-104). New York, NY: Norton.

- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading cognitive states of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.
- Giddings, L.S., Roy, D. E., & Predeger, E. (2006). Women's experience of ageing with a chronic condition. *Journal of Advanced Nursing, 58*, 557-565. doi: 10.1111/j.1365-2648.2007.04243.x
- Gustafson, L. (1993). Clinical picture of frontal lobe degeneration of non-Alzheimer type. *Dementia and Geriatric Cognitive Disorders, 4*, 143-148. doi: 10.1159/000107313
- Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: A review of the literature. *Cancer Nursing, 28*, 85-89. doi: 10.1097/00002820-200503000-00002
- Hardy, M. E., & Hardy, W. L. (1988). Role stress and role strain. In M. E. Hardy & M. E. Conway (Eds.), *Role theory: Perspectives for health professionals* (2nd ed., pp. 73-109). Norwalk, CT: Appleton & Lange.
- Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research, 16*, 484-502. 10.1177/1049732306286851
- Harris, P. B., & Keady, J. (2004). Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly, 5*, 111-122. Retrieved from <http://journals.lww.com/actjournalonline/pages/default.aspx>
- Harvey, R. J., Skelton-Robinson, M., & Rossor, M. N. (2003). The prevalence and causes of dementia in people under age of 65 years. *Journal of Neurology, Neurosurgery & Psychiatry, 74*, 1206-1209. doi: 10.1136/jnnp.74.9.1206

- Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer disease in the US population: Prevalence estimates using the 2000 census. *Archives of Neurology*, *60*, 1119-1112. doi: 10.1001/archneur.60.8.1119
- Hofman, A., Rocca, W. A., Brayne, C., Breteler, M. M., Clarke, M., Cooper, B., . . . Eurodem Prevalence Research Group. (1991). The prevalence of dementia in Europe: A collaborative study of 1980-1990 findings. *International Journal of Epidemiology*, *20*, 736-748. doi: 10.1093/ije/20.3.736
- Husband, H. J. (2000). Diagnostic disclosure in dementia: An opportunity for intervention?. *International Journal of Geriatric Psychiatry*, *15*, 544-547. doi: 10.1002/1099-1166(200006)15:6<544::AID-GPS241>3.0.CO;2-8
- Jha, A., Tabett, N. & Orell, M. (2001). To tell or not to tell—Comparison of older patient's reaction to their diagnosis of dementia and depression. *International Journal of Geriatric Psychology*, *16*, 879-885. doi: 10.1002/gps.412
- Kaiser, S., & Panegyres, P. K. (2007). The psychological impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Dementias*, *21*, 398-402. doi: 10.1177/1533317506293259
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Hightstown, NJ: McGraw-Hill Education.
- Knopman, D. S., Petersen, R. C., Cha, R. H., Edland, S. D., & Rocca, W. A. (2006). Incidence and causes of nondegenerative nonvascular dementia: A population-based study. *Archives of Neurology*, *63*, 218-221. doi: 10.1001/archneur.63.2.218

- Licht, E. A., McMurtray, A. M., Saul, R. E., & Mendez, M. F. (2007). Cognitive differences between early- and late-onset Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 218-222. doi: 10.1177/1533317506299156
- Lewis, P. R., & Lubkin, I. M. (2002a). Illness roles. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and interventions* (5th ed., pp. 25-51). Sudbury, MA: Jones & Bartlett.
- Lough, S., & Garfoot, V. (2007). Psychosocial interventions in frontotemporal dementia. In J. R. Hodges (Ed.), *Frontotemporal dementia syndromes* (pp. 277-325). Cambridge, England: Cambridge University Press.
- McGoldrick, M., & Carter, B. (2003). The family life cycle. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed., pp. 375-395). New York, NY: Guilford Press.
- McMurtray, A., Clark, D. G., Christine, D., & Mendez, M. F. (2006). Early-onset dementia: Frequency and causes compared to late-onset dementia. *Dementia and Geriatric Cognitive Disorders*, 21, 59-64. doi: 10.1159/000089546
- Mesulam, M. M. (2000). Aging, Alzheimer's diseases, and dementia: Clinical and neurobiological perspectives. In M. M. Mesulam (Ed.) *Principles of cognitive and behavioral neurology* (2nd ed., pp. 439-522). New York, NY: Oxford University Press.
- Munhall, P. L. (2007). *Nursing research: A qualitative perspective* (4th ed.). Sudbury, MA: Jones & Bartlett.
- Nandi, S. P., Biswas, A., Pal, S., Basu, S., Senapati, A. K., & Das, S. K. (2008). Clinical profile of young-onset dementia: A study from Eastern India. *Neurology Asia*, 13, 103-108.
Retrieved from http://neurologyasia.org/articles/20082_103.pdf

- Newens, A. J., Forster, D. P., & Kay, D.W. (1995). Dependency and community care in presenile Alzheimer's disease. *British Journal of Psychiatry*, 166, 777-782. doi: 10.1192/bjp.166.6.777
- Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & van de Bos, G. A. M. (2000). Patterns of caregiving experiences among partners of cancer patients. *The Gerontologist*, 40, 738-746. Retrieved from <http://gerontologist.oxfordjournals.org/>
- Pfeiffer, E. (1975). A short portable Mental Status Questionnaire for the assessment of organic brain deficit in elderly persons. *Journal of the American Geriatrics Society*, 23, 433-441. Retrieved from <http://www.americangeriatrics.org>
- Phinney, A., & Chesla, C. A., (2003). The lived body in dementia. *Journal of Aging Studies*, 17, 283-299. doi: 10.1016/S0890-4065(03)00029-X
- Russo, J., Vitaliano, P. P., Brewer, D. D., Katon, W., & Becker, J. (1995). Psychiatric disorders in spousal caregivers of care recipients with Alzheimer's dementia and matched controls: A diathesis stress model of psychopathology. *Journal of Abnormal Psychology*, 104, 197-204. doi: 10.1037/0021-843X.104.1.197
- Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal*, 80, 125-139. doi: 10.1136/pgmj.2003.011171
- Sidell, N. L. (1997). Adult adjustment to chronic illness: A review of the literature. *Health and Social Work*, 22, 5-11. Retrieved from <http://titania.naswpressonline.org>
- Söderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9, 575-587. doi: 10.1177/104973299129122090

- Sterin, G. J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia: International Journal of Social Research Practice, 1*, 7-10. doi: 10.1177/147130120200100103
- Steverink, N., Westerhof, G. J., Bode, C., & Dittman-Kohli, F. (2001). The personal experience of aging, individual resources, and subjective well-being. *Journals of Gerontology: Series B, Psychological Sciences & Social Sciences, 56*, 364-373. Retrieved from PsycNET database.
- Tappen, R. M., Williams-Burgess, C., Edelstein, J., Touhy, T. A., & Fishman, S. (1997). Communicating with individuals with Alzheimer's disease: Examination of recommended strategies. *Archives of Psychiatric Nursing, 11*, 249-256. doi: 10.1016/S0883-9417(97)80015-5
- Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.
- Touhy, T. A. (2004). Dementia, personhood, and nursing: Learning from a nursing situation. *Nursing Science Quarterly, 17*, 43-49. doi: 10.1177/0894318403260639
- Van Manen, M. (1990). Researching the lived experience: Human science for an action sensitive pedagogy. In P. Smith (Series Ed.), *The Philosophy of Education*. Albany: State University of New York Press.
- Vassilas, C., & Donaldson, J. (1998). Telling the truth: What do general practitioners say to patients with dementia or terminal cancer? *British Journal of General Practice, 48*, 1081-1082. Retrieved from <http://www.rcgp.org.uk/publications/bjgp.aspx>
- Wardini, Y., & de la Rosa, P. (2005). The effects of adapted logotherapy on the self-esteem of mid-life women with life threatening illnesses: Findings from a study in Indonesia. *Asian Journal of Nursing Studies, 8*(3), 39-49.

- Wickland, A. K., & Weintraub, S. (2005). Neuropsychological features of common dementia syndromes. *Turkish Journal of Neurology, 11*, 566-588. Retrieved from <http://www.tnj.org.tr>
- Williams, T., Cameron, I., & Dearden, T. (2001). From pillar to post—A study of younger people with dementia. *Psychiatric Bulletin, 25*, 384-387. doi: 10.1192/pb.25.10.384

APPENDIX B: IRB APPROVAL



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: UCF Institutional Review Board #1
FWA00000351, IRB00001138
To: Debra Ann Hunt
Date: February 11, 2010

Dear Researcher:

On 2/11/2010, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Initial Review
Project Title: The lived experience of young-onset dementia
Investigator: Debra Ann Hunt
IRB Number: SBE-10-06663
Funding Agency: None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Joseph Bielitzki, DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Janice Turchin on 02/11/2010 02:08:49 PM EST

IRB Coordinator

APPENDIX C: INFORMED CONSENT



EXPLANATION OF RESEARCH

Title of Project: The lived experience of young onset dementia

Principal Investigator: Debra A. Hunt

Faculty Supervisor: Karen Aroian, PhD

You are being invited to take part in a research study. Whether you take part is up to you.

- The purpose of this research is explore the experience of living with dementia for the middle-aged person.
- You must be between the ages of 35 and 65 years of age to take part in this research study.
- You will be asked to complete a Demographic and Health History Survey form and return it in the self-addressed envelope provided.
 - The form takes approximately 10 -15 minutes to complete. Participants may have assistance with the form from an individual who is familiar with the required information, if desired.
- You will be contacted and asked to participate in two conversational interviews, 1 – 2 weeks apart, with the investigator, Ms. Hunt. Interviews will be audio taped to allow the interviewer and participant to converse without the restrictions associated with note taking.
 - The interviews will be conducted face-to-face, in your home if your reside in Central Florida.
 - If you reside outside the Central Florida area you will be interviewed via telephone.
 - Each interview is expected to take approximately one hour to complete.
- All information will be kept confidential. Your responses will be de-identified and coded by the researcher so that the data cannot be matched to you. Audio tapes will be destroyed upon transcription.
- Anticipated risk for participation in this study is minimal. There is a possibility that discussing the experience of dementia could cause a participant to become upset. The participant has the right to withdraw from the study at any time.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints, please contact Debra Hunt, Doctoral Candidate, College of Nursing at dahunt@mail.ucf.edu or 352-250-0073. Or Dr. Karen Aroian, Faculty Supervisor, College of Nursing @ karoian@mail.ucf.edu or 407-823-2744.

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901.

**APPENDIX D: CERTIFICATE OF COMPLETION OF CONTINUING EDUCATION
FOR PROTECTION OF HUMAN PARTICIPANTS IN RESEARCH**

CITI Collaborative Institutional Training Initiative (CITI)

Social and Behavioral Responsible Conduct of Research Curriculum Completion Report Printed on 1/28/2011

Learner: Debra Hunt (username: arnp99)

Institution: University of Central Florida

Contact Information

4005 Beacon Ridge Way
Clermont, FL 34711 USA

Department: Nursing

Phone: 407-582-5689

Email: dahunt@mail.ucf.edu

Social and Behavioral Responsible Conduct of Research: This course is for investigators, staff and students with an interest or focus in **Social and Behavioral** research. This course contains text, embedded case studies AND quizzes.

Stage 1. Basic Course Passed on 12/30/09 (Ref # 3892630)

Elective Modules	Date Completed	Score
Introduction to the Responsible Conduct of Research	12/29/09	no quiz
Research Misconduct 2-1495	12/29/09	5/5 (100%)
Data Acquisition, Management, Sharing and Ownership 2-1523	12/30/09	5/5 (100%)
Publication Practices and Responsible Authorship 2-1518	12/30/09	4/5 (80%)
Peer Review 2-1521	12/30/09	4/5 (80%)
Mentor and Trainee Responsibilities 01234 1250	12/30/09	5/6 (83%)
Animal Welfare 13301	12/30/09	7/8 (88%)
Conflicts of Interest and Commitment 2-1462	12/30/09	5/6 (83%)
Collaborative Research 2-1484	12/30/09	6/6 (100%)
Human Subjects 13566	12/30/09	5/5 (100%)
The CITI RCR Course Completion Page.	12/30/09	no quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator

[Return](#)

APPENDIX E: INSTRUMENTS AND INTERVIEW GUIDELINES

Original Date:
Dates Revised:

DEMOGRAPHIC & HEALTH HISTORY QUESTIONNAIRE

All questions contained in this questionnaire are strictly confidential

Name <i>(Last, First, M.I.):</i>			DOB:	
Marital status:	<input type="checkbox"/> Single <input type="checkbox"/> Partnered <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed			
Ethnicity: <input type="checkbox"/> African American <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian <input type="checkbox"/> Hispanic		Gender: <input type="checkbox"/> M <input type="checkbox"/> F		
Occupation or Prior Occupation:		Employment Status: <input type="checkbox"/> Employed <input type="checkbox"/> Unemployed		
Education: <input type="checkbox"/> Grade School <input type="checkbox"/> Some High School <input type="checkbox"/> High School Graduate <input type="checkbox"/> Trade School <input type="checkbox"/> Some College <input type="checkbox"/> College Graduate				
PERSONAL HEALTH HISTORY				
Do you have any of the following conditions?				
	Hypertension <input type="checkbox"/>	Seizure Disorder <input type="checkbox"/>		
	Diabetes <input type="checkbox"/>	Anxiety <input type="checkbox"/>		
	Heart Disease <input type="checkbox"/>	Depression <input type="checkbox"/>		
	Other:			
Please list all medications that you currently take.				

Do you smoke? <input type="checkbox"/> yes <input type="checkbox"/> no	
Do you drink Alcohol? <input type="checkbox"/> yes <input type="checkbox"/> no How many drinks per day? Per week? Per month?	
List any medical problems that other doctors have diagnosed	

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (SPMSQ)

Question	Response	Incorrect Responses
1. What are the date, month, and year?		
2. What is the day of the week?		
3. What is the name of this place?		
4. What is your phone number?		
5. How old are you?		
6. When were you born?		
7. Who is the current president?		
8. Who was the president before him?		
9. What was your mother's maiden name?		
10. Can you count backward from 20 by 3's?		

SCORING:*

0-2 errors: normal mental functioning

3-4 errors: mild cognitive impairment

5-7 errors: moderate cognitive impairment

8 or more errors: severe cognitive impairment

*One more error is allowed in the scoring if a patient has had a grade school education or less.

*One less error is allowed if the patient has had education beyond the high school level.

Source: Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. Journal of American Geriatrics Society. 23. 433-41.

ERIC PFEIFFER, M.D.
3120 West Hawthorne
Tampa, FL 33611

May 31, 2010

Debra Hunt, MSN, ARNP
4005 Beacon Ridge Way
Clermont, FL 34711

Dear Dr. Pfeiffer:

This letter will confirm our recent telephone conversation. I am completing a doctoral degree at the University of Central Florida entitled "The Lived Experience of Young-Onset Dementia." I would like your permission to reprint in my dissertation your cognitive assessment tool entitled:

Short Portable Mental Status Questionnaire (SPMSQ)

The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you. Your signing of this letter will also confirm that you own or your company owns the copyright to the above-described material.

If these arrangements meet with your approval, please sign this letter where indicated below and return it to me in the enclosed return envelope. Thank you for your attention in this matter.

Sincerely,

Debra Hunt, MSN, ARNP



PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

By: 
Eric Pfeiffer, M.D.

Date: 06-05-10

Interview Guide

Phenomenology – The Lived Experience of Young Onset Dementia

- Introductions
- Answer questions about study
- Discuss interview procedures: recording, note-taking, questions, open answers, prompting etc.
- Review consent form and obtain signatures
- Review demographics form, obtain clarifications if needed

Start tape recorder

1. Ask about diagnosis
 - a. “Tell me when you first noticed changes”
 - b. “Did your family or friends notice changes in you?”
2. “How did you feel when you were told that you have dementia?”
3. “How has your life changed since your diagnosis?”
4. “What is it like to live with dementia?”
 - a. ask about family life
 - b. social interactions
 - c. work
 - d. health
 - e. ADLs
5. “What are your greatest stressors?”
6. “What does living with dementia mean to you?”
7. “What are your thoughts about the future?”
 - a. fears
 - b. goals
8. “Is there anything you would like to add?”
9. “Do you think there are any other questions I should be asking you?”
10. “What would you tell nurses and other health care providers who care for middle aged people who are living with dementia?”

Thank you

Schedule follow up interview 1-2 weeks later

Have you or someone you know been told, by a health care provider that you have young-onset dementia?

- *If you are between the ages of 35 and 65*
- *Have been told that you have young-onset dementia*
- *Would be willing to share your story about living with dementia*

You may be eligible to participate in a research study being conducted by a University of Central Florida Doctoral student to explore what it is like to be middle-age and living with dementia. Study participants will be required to participate in two conversational interviews either face-to-face in your home or by telephone. Interviews will each take one hour to complete.

For more information contact:

Debra Hunt, MSN

352-250-0073 / dahunt@mail.ucf.edu

UCF West Campus

1800 S. Kirkman Road, Building 11, Room 104

Orlando FL 32811

APPENDIX F: CURRICULUM VITAE

DEBRA COLLINS HUNT MSN, ARNP-BC

University of Central Florida College of Nursing
12201 Research Parkway Suite 300
Orlando, FL 32826
(407) 582-5689—Office
(407) 823-5675—Fax

EDUCATION

Year	Degree	Institution	Clinical Major	Role Preparation
2011	PhD(c)	University of Central Florida, Orlando, FL	Nursing	Research
1998	MSN	University of Central Florida, Orlando, FL	Advanced Practice Nursing	Nurse Practitioner
1996	BSN	Southern Adventist University, Orlando, FL	Nursing	Nurse Clinician
1991	ASN	Valencia Community College, Orlando, FL	Nursing	Nurse Clinician

LICENSURE/CERTIFICATION

ARNP	Florida, 2517052
FNP	ANCC 1999-current
GNP	ANCC 2009-current

EMPLOYMENT

ACADEMIC APPOINTMENTS:

08/07- present	Instructor , University of Central Florida College of Nursing, Regional Campus, Orlando, FL
08/04-07/07	Adjunct Instructor , University of Central Florida College of Nursing, Orlando, FL

CLINICAL APPOINTMENTS:

02/08-12/08	Nurse Practitioner , TakeCare Clinic, Lake Buena Vista, FL
03/04-present	Nurse Practitioner , South Lake Free Clinic, Clermont, FL
12/98-02/08	Nurse Practitioner , Cambo Medical Services, Davenport, FL
12/03-12/04	Nurse Practitioner , Total Family Health Care, Clermont, FL
02/96-12/98	HIV Outreach Educator , Hug-Me Program, Orlando Regional Healthcare, Orlando, FL
02/94-02/96	Critical Care Nurse Manager , Princeton Hospital, Orlando, FL
06/91-02/94	Staff Nurse , PCU, ICU, Neuro ICU, Florida Hospital, Orlando, FL

PUBLICATIONS

REFEREED JOURNALS: (* Data-based articles)

Hunt, D. (2011) (In press). Young-onset dementia: a review of the literature. *Journal of Psychosocial Nursing and Mental Health*. Slated for April 2011 issue.

NON-REFEREED JOURNALS OR PUBLICATIONS: (* Data-based articles)

Hunt, D. (2005). Hurricane Katrina: Stories from the field. *The Florida Nurse*. 53 (4).

ABSTRACTS: (* Data-based, # Refereed)

Hunt, D. (2010). Health care providers, researchers, and people with dementia: protecting or silencing? *Proceedings of the 7th International Conference on Frontotemporal Dementias*. Indianapolis, IN #

Hunt, D. (2009). An examination of observational tools for assessing pain in older adults with advanced dementia. *Proceedings of the 2009 Sigma Theta Tau, Theta Epsilon Chapter, Annual Research Conference*. Orlando, FL
*#

Hunt, D. (2008). An exploration of the concept of pain perception in elders with dementia. *Proceedings of the 8th Annual Interdisciplinary Research Conference, Trinity College of Nursing and Midwifery*, Dublin, Ireland. #

Hunt, D. (2008). Exploring pain perception in elders with dementia. *Proceedings of the 2008 Southern Nurses Research Society Conference*, Birmingham, AL: SNRS #

Hunt, D. (2007). Medication administration by unlicensed personnel in long-term care: who's really caring for mom and dad? *Proceedings of the 2007 Florida Nurses Association (FNA) Convention*. Daytona Beach, FL. FNA

Hunt, D. (1997). Choices and challenges: caring for the pediatric HIV patient. *Proceedings of the 6th Annual Florida HIV Conference*. Port St. Lucie, FL

RESEARCH GRANTS

Date	Role	Title	Agency	Type	Amount
2010-2011	PI	The Lived Experience of Young Onset Dementia PI: D. Hunt, ARNP	Lupus Foundation of Florida	Extramural	\$1,000
2010	PI	The Lived Experience of Young Onset Dementia PI: D. Hunt, ARNP	American Nurses Foundation	Extramural	Not funded
2009	PI	The lived Experience of Young Onset Dementia PI: D. Hunt, ARNP	Florida Nurses Foundation	Extramural	\$500.

PRESENTATIONS—NATIONAL/INTERNATIONAL

Date	Type	Title	Conference Title, City/State	Refereed/Invited
08/07/10	Poster	Health care providers, researcher, and people with dementia: protecting or silencing?	7 th International Conference on Frontotemporal Dementias, Indianapolis, IN	Refereed
02/21/08	Poster	Exploration of pain perception in elders with dementia.	Southern Nurses Research Society Research Conference, Birmingham, AL	Refereed
11/18/07	Podium	An exploration of the concept of pain perception in elders with dementia.	8 th Annual Interdisciplinary Research Conference, Trinity College of Nursing and Midwifery, Dublin, Ireland	Refereed

PRESENTATIONS—LOCAL/REGIONAL/STATE

Date	Type	Title	Conference Title, City/State	Refereed/ Invited
04/14/09	Podium	An examination of observational tools for assessing pain in older adults with dementia.	Sigma Theta Tau, Theta Epsilon, Annual Research Conference, Orlando, FL	Refereed
9/26/07	Poster	Medication administration by unlicensed personnel: who's really caring for mom and dad?	Florida Nurses Association, Biannual Conference, Daytona Beach, FL	Refereed
9/1996	Podium	Choices and challenges: caring for the pediatric HIV patient.	6 th Annual Florida HIV Conference, Port St. Lucie, FL	Invited

HONORS/AWARDS

Date	Award	Organization/Group
2010	Advocacy Award	Florida Nurses Association
2010	Advanced Education Traineeship Award	University of Central Florida, College of Nursing
2009	Advanced Education Traineeship Award	University of Central Florida, College of Nursing
2008	IDL, Web Course Development Workshop	University of Central Florida
2007	Advanced Education Traineeship Award	University of Central Florida, College of Nursing
2000	Alumni Achievement Award	University of Central Florida, COHPA
1998	Leadership Award	
	University of Central Florida, School of Nursing	
1999	Sigma Theta Tau International, Induction	Theta Epsilon Chapter
1997	Certificate of Appreciation	Orange County
	Public Schools	
1989, 1990	Deans List	
	Valencia Community College	
1990	Who's Who in Community College Students	Valencia Community College

PROFESSIONAL ACTIVITIES & COMMUNITY SERVICE

PROFESSIONAL ORGANIZATIONS:

Date	Organization	Role
2009-present	Gerontology Advanced Practice Association	Education Coordinator
2007-present	American College of Nurse Practitioners	Member
1999-present	University of Central Florida Doctoral Nurses Association	Member
1999-present	American Academy of Nurse Practitioners	Member
1999-present	Sigma Theta Tau, Theta Epsilon	Board of Directors 2010
1997-1998	UCF Graduate Nurses Association	Founding Member, President
1996-2000	Association of Nurses in Aids Care	Member

Date	Organization	Role
1992-1999	Association of Critical Care Nurses	Member
1991-present	American Nurses Association	Member
1991-present	Florida Nurses Association	2 nd Vice President 2007-present FNPAC Board of Trustees

COMMUNITY SERVICE:

Date	Organization	Role
2010	Alzheimer's Poetry Project	Data Collector
2010-present	South Lake Hospital Foundation	President
2010	Relay for Life, Orlando FL	Participant
2008,2009	Alzheimer's Memory Walk	Participant
2005	Hurricane Katrina Relief, Gulfport, Mississippi	Relief Worker
2004-present	South Lake Free Clinic, Clermont, FL	Volunteer Health Care Provider
2002-2009	South Lake Hospital, Board of Trustees	Gubernatorial Appointment
1996-1998	HIV/AIDS, STD Prevention Education, Orange County	Community Educator

UNIVERSITY ACTIVITIES

UNIVERSITY SERVICE: (Cumulative)

Date	Level	Committee	Role
2010-2011	University	WAC Director Search Committee	Member
2010-2011	College	Undergraduate APG	Member
2010	College	Undergraduate Search Committee	Member
2010	University	Knights Write Workshop	Faculty Presenter
2010	University	Game Day Ambassador	Faculty Participant
2010-2011	College	Student Nurses Association	Co-Advisor
2009-2010	College	Simulation Task Force	Member
2009-2010	College	Faculty Affairs	Member
2009-present	University	Faculty Travel Committee	Member
2008	College	Strategic Planning Task Force	Member
2007-2009	College	Undergraduate APG	Member
2007-2008	College	Undergraduate Search Committee	Member

COURSES TAUGHT:

Semester	Course	Course Name	Enrollment	Role
Spring 2011	NUR 3805 0051	Dimensions of Professional Practice	24	Instructor
	NUR 3806 0M50	Professional Socialization Seminar	24	Instructor
	NUR 3065 0W58	Health Assessment	36	Instructor
	NUR3065L 0W58,0W59	Health Assessment Lab	36	Instructor
Fall 2010	NUR 3065 0050	Health Assessment	28	Instructor
	NUR 3965L 0M50, 0M51	Health Assessment Lab	28	Instructor
	NUR 3065L 0W52	Health Assessment Lab	17	Instructor
	NUR 4286 0W59	Gerontology	23	Instructor
	NUR 4837 0W58	Health Care Issues Policy &	27	Instructor

Semester	Course	Course Name	Enrollment	Role
		Economics		
Summer 10	NGR 5638 0W61	Health Promotion	48	Instructor
	NUR 3065 CW58	Health Assessment	29	Instructor
	NUR 3065L CM56, CM57	Health Assessment Lab	29	Instructor
Spring 10	NGR 5638 0W61	Health Promotion	40	Instructor
	NUR 3065 0W59	Health Assessment	19	Instructor
	NUR 3065L 0M58, 0W59	Health Assessment Lab	19	Instructor
	NUR 4286 0W59	Gerontology	38	Instructor
Fall 09	NUR 3065 0W58, 0W59	Health Assessment	45	Instructor
	NUR 3065L 0M80, 0W57, 0W58, 0W59	Health Assessment Lab	45	Instructor
Summer 09	NGR 5638 DW61	Health Promotion	38	Instructor
	NUR 3065 CW58, CW59	Health Assessment	68	Instructor
	NUR 3065L CW56, CW57, CW58, CW59	Health Assessment Lab	68	Instructor
Spring 09	NUR 3065, 0W58	Health Assessment	63	Instructor
	NUR 3065L, 0M81, 0W58, 0W59	Health Assessment Lab	63	Instructor
	NUR 4286, 0W59	Gerontology	40	Instructor
	NGR 6242, 0M12	Adult II Clinical	4	Instructor (clinical)
	NGR 6941, 0034	Advanced Practice Practicum	3	Instructor (Clinical)
Fall 08	NGR 6240L, 0063	Adult I Clinical	7	Instructor (clinical)
	NGR 6941, 0004	Advanced Practice Practicum	7	Instructor (clinical)
	NUR 3065 0081 NUR 3065L, 0081, 0083, 0084, 0085	Health Assessment Health Assessment Lab	42 42	Instructor Instructor
Summer 08	NUR 3065, C080	Health Assessment	7	Instructor
	NUR 3065L, C080, C081	Health Assessment Lab	7	Instructor
	NUR 4286, C080	Gerontology	7	Instructor
Spring 08	NUR 3065, 0W58	Health Assessment	68	Instructor
	NUR 3065L, 0W58, 0W59	Health Assessment Lab	68	Instructor
	NUR 3805, 0083, 0089	Dimensions of Professional Practice	14	Instructor
Fall 07	NUR 3065, 0W59	Health Assessment	25	Instructor
	NUR 3065L, 0W57, 0W58	Health Assessment Lab	25	Instructor
	NUR 4636, 0W65	Community as Continuum	14	Instructor
Summer 07	NGR 6482L	Women's Health Clinical	8	Instructor (clinical)
	NUR 3065, CW91 NUR 3065L, CW92, CW93	Health Assessment Health Assessment Lab	26 26	Instructor Instructor

Semester	Course	Course Name	Enrollment	Role
Spring 07	NGR 6941, 0004, 0006	Advanced Practice Internship	14	Instructor (clinical)
Fall 06	NGR 5004L, 0011,0012,0013	Advanced Health Assessment Lab	26	Instructor