



University of Kentucky
UKnowledge

Theses and Dissertations--Gerontology

College of Public Health


2019

TOWARD AN UNDERSTANDING OF BEHAVIORAL AND SENSORY EXPERIENCES WHEN LIVING WITH DEMENTIA AND RELATED DISORDERS: AN ENVIRONMENTAL GERONTOLOGY PERSPECTIVE

Elizabeth K. Rhodus

University of Kentucky, elizabeth.rhodus@uky.edu

Author ORCID Identifier:

 <https://orcid.org/0000-0001-5108-0766>

Digital Object Identifier: <https://doi.org/10.13023/etd.2019.165>

[Right click to open a feedback form in a new tab to let us know how this document benefits you.](#)

Recommended Citation

Rhodus, Elizabeth K., "TOWARD AN UNDERSTANDING OF BEHAVIORAL AND SENSORY EXPERIENCES WHEN LIVING WITH DEMENTIA AND RELATED DISORDERS: AN ENVIRONMENTAL GERONTOLOGY PERSPECTIVE" (2019). *Theses and Dissertations--Gerontology*. 15.
https://uknowledge.uky.edu/geronto_etds/15

This Doctoral Dissertation is brought to you for free and open access by the College of Public Health at UKnowledge. It has been accepted for inclusion in Theses and Dissertations--Gerontology by an authorized administrator of UKnowledge. For more information, please contact UKnowledge@lsv.uky.edu.

STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Elizabeth K. Rhodus, Student

Dr. Graham D. Rowles, Major Professor

Dr. John F. Watkins, Director of Graduate Studies

TOWARD AN UNDERSTANDING OF BEHAVIORAL AND SENSORY
EXPERIENCES WHEN LIVING WITH DEMENTIA AND RELATED DISORDERS:
AN ENVIRONMENTAL GERONTOLOGY PERSPECTIVE

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Public Health
at the University of Kentucky

By
Elizabeth K. Rhodus
Lexington, Kentucky
Director: Dr. Graham D. Rowles, Professor of Gerontology
Lexington, Kentucky
2019

Copyright © Elizabeth K. Rhodus, 2019
<https://orcid.org/0000-0001-5108-0766>

ABSTRACT OF DISSERTATION

TOWARD AN UNDERSTANDING OF BEHAVIORAL AND SENSORY EXPERIENCES WHEN LIVING WITH DEMENTIA AND RELATED DISORDERS: AN ENVIRONMENTAL GERONTOLOGY PERSPECTIVE

Behavioral and psychological symptoms of dementia create challenges for those living with neurodegenerative cognitive impairment and their care partners. Pharmacological approaches for treatment of challenging behaviors seen in dementia have limited success and serious side effects. Because of this, nonpharmacological approaches are being investigated with increasing frequency. Of particular interest are nonpharmacological approaches involving environmental stimulation to change behaviors. Success of such approaches relies on sensory processing systems, personal preferences, and environmental congruence. There is limited evidence describing behaviors of persons with cognitive impairment in relation to these components. Currently, there is no guiding model for implementation of environmental and sensory-based strategies with this population. The overall goal of this project is to elaborate on an emerging model describing the relationship among environment, behavior, sensation, and cognitive impairment for community-dwelling adults with mild cognitive impairment or dementia.

Three studies allow for deeper understanding of this relationship. Study one compared behaviors seen in autism spectrum disorder (ASD) with exhibited behaviors of individuals with mild cognitive impairment or dementia. Of neurological conditions similar to dementia, ASD has been chosen as an exemplar for comparison of behavioral expression because evidence supports sensory-based theory and interventions to improve behaviors for those with ASD. Results indicate that ASD behaviors are reported in those assessed, with highest rates of behaviors in those with young age of onset and advanced cognitive impairment severity.

Study two described presentation of behavior, sensory processing, and environment for community-dwelling adults with cognitive impairment in the context of the caregiver situation. Findings reflect dyadic experiences for the person with cognitive impairment and the primary care partner. Emergent themes included consideration of the

passage of time, environmental contexts, behavioral adjustments while aging, and overall influences of living with cognitive impairment. Sensory processing assessment using the Adult Sensory Profile identified that all participants had some atypical sensory processing patterns, highlighting a need for attention to environmental congruence to promote adaptive behaviors.

Using data collected in study one and study two, a model was created describing interactions among the person with cognitive impairment, sensation, and the environment as these interactions evolve over time. Areas for future research are conceptualized for implementation of the model. Future research is needed for assessment of the model to test for validity and reliability. Creation of an instrument is needed to place individuals within the model given their behavior and cognitive impairment progression. And, future research is needed to create and test interventions in order to aid in environmental congruence. Long-term goals are to improve care for adults with cognitive impairment and dementia via environmental interventions.

KEYWORDS: Gerontology, Dementia, Environment, Sensory Processing

Elizabeth K. Rhodus

(Name of Student)

04/17/2019

Date

TOWARD AN UNDERSTANDING OF BEHAVIORAL AND SENSORY
EXPERIENCES WHEN LIVING WITH DEMENTIA AND RELATED DISORDERS:
AN ENVIRONMENTAL GERONTOLOGY PERSPECTIVE

By
Elizabeth K. Rhodus

Dr. Graham D. Rowles

Director of Dissertation

Dr. John F. Watkins

Director of Graduate Studies

04/17/2019

Date

DEDICATION

This dissertation is dedicated to my beautiful daughter, Aliana Marie. You have been such an amazing addition to my life during the doctoral process. My hope is that you follow your dreams for a life filled with happiness, courage, and exploration.

I love you, sweet girl.

ACKNOWLEDGMENTS

Several people must be acknowledged for their time, insights, and guidance in the development of this dissertation. My dissertation chair, Dr. Graham D. Rowles provided countless hours of mentorship, for both scholarly development and life circumstances. I will be forever grateful for the lessons and time you have shared with me. My dissertation committee has been supportive and encouraged creative exploration. Thank you so much, Drs. Beth Hunter, Nancy Schoenberg, and Gregory Jicha.

There are several other people I would like to acknowledge for their role and assistance with dissertation projects. Dr. Anne Harrison, you provide such wonderful insight and positive direction. It has been a pleasure to bounce around ideas from a rehab and gerontology stand point. Thank you for your time! Dr. Shani Bardach, your keen connection with my interests and the resources at UK allowed for me to follow my passion and build research in the exact area I was striving for. Thank you for being so supportive and always available. Justin Barber, I will always be thankful for your wizardly statistical coding and your time. I would like to thank all the staff and participants at Sanders Brown Center on Aging. The studies utilized University of Kentucky Alzheimer's Disease Cohort participants with funding provided by NIH/NIA P30 AG028383.

My family and friends kept me sane and moving along this doctoral process. I would not be to this point in my life without the amazing support of my parents, encouragement of my husband, friendships of my brothers, and the unconditional love from my aunt Jenny. I wish to sincerely thank all of my previous patients and their families for allowing me to grow and learn alongside you.

TABLE OF CONTENTS

ACKNOWLEDGMENTS	iii
LIST OF TABLES	vii
LIST OF FIGURES	viii
PROLOGUE	1
CHAPTER 1. INTRODUCTION	7
1.1 Statement of Problem.....	9
1.2 Purpose of Study.....	10
1.3 Specific Aims.....	11
CHAPTER 2. BACKGROUND	14
2.1 Behaviors Associated with Dementia and ASD	14
2.1.1 Pharmacological intervention.	17
2.1.2 Nonpharmacological intervention.....	19
2.2 Involvement of Care Partners within the Environmental Context.....	24
2.3 Sensory Processing Abilities across the Lifespan.....	27
2.3.1 Sensory processing theory	29
2.3.2 Application in pediatric conditions	31
2.3.3 Application in old age.....	35
2.4 Toward an Environmental Gerontology Theoretical Perspective.....	40
2.5 Conclusion	49
CHAPTER 3. BEHAVIORS CHARACTERISTIC OF AUTISM SPECTRUM DISORDER IN A GERIATRIC COHORT WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA 51	
3.1 Introduction.....	51
3.2 Methods.....	52
3.2.1 Participants.....	52
3.2.2 Diagnostic criteria.....	52
3.2.3 Measures	53
3.2.4 Statistical analysis.....	55
3.3 Results.....	55
3.4 Discussion.....	60
3.5 Conclusion	63

CHAPTER 4. EXPLORATION OF ENVIRONMENT AND BEHAVIORAL EXPRESSION IN COMMUNITY-DWELLING OLDER ADULTS WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA	65
4.1 Introduction.....	65
4.2 Methods.....	66
4.2.1 Participants.....	66
4.2.2 Procedures.....	67
4.2.3 Analysis.....	72
4.3 Findings.....	73
4.3.1 Behavioral analysis.	74
4.3.2 Emergent themes.....	82
4.4 Discussion.....	98
4.5 Conclusion	100
 CHAPTER 5. TOWARD A DYNAMIC MODEL OF THE RELATIONSHIP AMONG ENVIRONMENT, BEHAVIOR, SENSATION, AND COGNITIVE AGING.....	 101
5.1 Introduction.....	101
5.2 Application of Theory to Cognitive Impairment	102
5.3 A Systems Approach to the Relationship among Environment, Cognition, and Behavior.....	103
5.3.1 Environment (E).....	104
5.3.2 Sensation transduction	104
5.3.3 Person’s central nervous system (P = CNS).	106
5.3.4 Response(s).....	110
5.3.5 Behavior (B).....	110
5.4 Dynamic Model of Environment Interaction for Those with Neurodegenerative Cognitive Impairment	111
5.4.1 Environment.....	112
5.4.2 Time	114
5.4.3 Primary care partner.....	114
5.4.4 Person with dementia.....	115
5.4.5 Trajectory of interaction	117
5.5 Discussion and Implications	119
5.6 Conclusion	121
 CHAPTER 6. SYNTHESIS	 122
6.1 Limitations	125
6.2 Future Research	127
6.3 Conclusion	132

EPILOGUE 133

APPENDICES	135
APPENDIX A. CAREGIVER SEMI-STRUCTURED INTERVIEW GUIDE	135
APPENDIX B. ADULT SENSORY PROFILE	136
APPENDIX C. GILLUM AUTISM RATING SCALE, 2 nd EDITION.....	141
APPENDIX D. RECRUITMENT FLYER.....	145
REFERENCES	146
VITA.....	176

LIST OF TABLES

Table 2.1	Nonpharmacological therapies	20
Table 2.2	Common changes in aging sensory systems.....	28
Table 2.3	Sensory processing thresholds	30
Table 3.1	Participant characteristics	56
Table 3.2	Between group comparison of GARS-2 AIS and subscores	58
Table 4.1	Data collection schedule	70
Table 4.2	Observation chart.....	71
Table 4.3	Participant demographics.....	74
Table 4.4	Adult sensory profile results	75
Table 5.1	Sensory receptors with corresponding stimuli to which they respond	105

LIST OF FIGURES

Figure 2.1 Ecological model of aging.....	41
Figure 2.2 Person-Environment-Occupation model	43
Figure 2.3 Ecological systems theory	45
Figure 3.1 AIS throughout diagnoses	57
Figure 3.2 Frequently observed behaviors.....	59
Figure 3.3 AIS across CDR scores	60
Figure 4.1 Study design	69
Figure 5.1 Systems model of environment-person relations on behavior	103
Figure 5.2 Sensory pathways	106
Figure 5.3 The ecological model of care: Aging with dementia behaviors	115

PROLOGUE

Throughout my life, I have been intrigued by the power of environmental influences on human behavior. Having spent my early years in a Montessori school, my environment was prepared to foster individuality, creativity, and exploration. Growing up with a younger brother who has Down syndrome allowed me to witness the empowerment gained from environmental supports and social supporters. As a teenager, I became completely dependent on my physical and social environments following a severe car accident in which I suffered a traumatic brain injury and multiple bodily fractures. My environment was transformed with the help of therapists, family and friends to support relearning how to walk, talk, and regain cognitive abilities. These life experiences inspired me to help others as an occupational therapist.

Occupational therapy is a unique rehabilitation discipline which combines external tasks (occupations) and environments to promote human function. Occupational therapy is often employed in promoting independence for those with disabilities. During my training, neurological processing associated with environmental engagement and behavior captivated my attention. Environments are perceived through sensory stimulation. Without proper functioning of sensory acquisition and neurological processing or perception, a person is unable to appropriately adapt and accommodate to the surrounding environment. This creates incongruences in personal abilities and environmental affordances, thereby limiting function and well-being. Components of environmental and sensory processing theories offered a framework, or lens so to speak, for my growth as a therapist.

Numerous opportunities during years as a student and young therapist utilized sensory-based theories across the lifespan and with multiple neurological conditions. An internship at an inpatient psychiatric hospital offered an opportunity to lead groups of patients with severe psychiatric illnesses such as schizophrenia, bipolar disorder, and depression. Working with staff occupational therapists, I led groups in sensory exploration and stimulation. Activities included listening to and playing music, aromatherapy, massage, colorful scarf throwing, and other sensory-eliciting activities. Patients had positive experiences with the sensory-based groups and were eager to return.

Another, more in-depth, internship at a community-based program for adults with traumatic brain injuries added to my understanding of neurological impairment. In this setting, I was tasked with designing and leading a new group for participants. A sensory-based group was an obvious choice for me. Themed sensory groups were a hit with participants and staff. The first group was dedicated to the sensations of a day at the beach, with smells of sunscreen, buckets of sand, and sunglasses among other things associated with the beach. After several weeks of leading the sensory-based group, staff were excited to see participation from group members and continued to offer this group after my internship completion.

As an excited new occupational therapist, my first job was at an out-patient sensory clinic. I treated pediatric patients with autism, sensory processing disorder, developmental delay, Down syndrome, and a myriad of other conditions. My mentor was highly trained in sensory integration theories and provided solid guidance as I utilized sensory-based interventions for my young patients. Behavioral analysis of environmental stimuli for patients with autism spectrum disorder became my specialty. Challenges of

the disorder included patients who had difficulty with expressive and receptive communication, aggression, apathy, depression, repetitive behaviors, and resistance or fear of environmental stimulation. I enjoyed working with the patients and their families to help overcome such challenges to promote adaptive responses and engagement with the environment.

Continuing to diversify my experience as a practitioner, I left the outpatient clinic and started working at a skilled nursing facility. This was my introduction to gerontology. Long-term care patients with dementia quickly filled my caseload. For the first time, I was faced with helping those with advanced dementia. Observation was a valuable tool to understand the challenges which the patients and staff were facing. Commonalities were seen between the behaviors observed in those with dementia and behaviors I worked with for patients with autism spectrum disorder. Both sets of patients exhibited difficulty with communication, aggression, apathy, repetitive behaviors (i.e., rocking, moaning, tapping) and difficulty with successful engagement of the environment. The lens of sensory processing theories encouraged me to use similar interventions for patients with dementia as I did with those who had autism spectrum disorder. To my delight and the surprise of other therapists, the techniques, such as lap weights, music, and massage were successful in decreasing rocking, moaning, and avoidance. In fact, the interventions promoted eye contact, object exploration, and periods of calmness. *It was at this moment, I realized I wanted to pursue a doctoral degree to explore the relationship between autism and dementia, as well as investigate helping those with dementia using environmental and sensory-based theories and techniques.*

Personal and family obligations delayed immediate enrollment in doctoral education. This delay allowed continued clinical exploration of environmental and sensory-based theories utilized for behavioral management of those with dementia. Several patient success stories were gained throughout the following five years of such practice.

Sarah (pseudonym) was a 76-year-old frail woman living with advanced dementia in a personal care facility. She was referred to occupational therapy for difficulty with feeding. Upon meeting Sarah, she was standing in the corner of the main living space, speaking in gibberish and appeared to be hallucinating. I helped her to the lunch table to assess her self-feeding skills. Her environment was set up well for her success, but she did not reach toward her food and fumbled when it was placed in her hands. As part of her evaluation, I spoke with her daughter who told me Sarah is legally blind. Yet, Sarah was not wearing her glasses during her meal. With some staff training, Sarah began feeding herself again when she was wearing her glasses. At one of our therapy sessions, I noticed scratches and bruises on Sarah's arms. Nursing staff reported that Sarah required five staff members for all toileting, bathing, and dressing tasks.

Sarah's difficulty with vision, poor communication, and aggression led to severe fighting during self-care tasks. As her therapist, I felt obligated to investigate and offer some strategies to help, if possible. Sarah and I walked into her bathroom to assess the environmental setup. Sarah's verbal expression was unintelligible gibberish, but as we crossed the threshold into the bathroom, she began to mutter the words, "please don't hurt me" repeatedly. We immediately walked out of the bathroom and sat quietly on her bed.

She had associated the bathroom with pain and fear. Using environmental and sensory theories, I formed an intervention plan.

The intervention plan required staff support and implementation. Thankfully, Sarah's staff members were encouraged by the new approaches and dutifully heeded my suggestions. Because Sarah was afraid of her bathroom environment, we shut the door and stopped using that room. We placed a bed side commode in the corner of her bedroom under a new 'restroom' sign, and covered it with red duct tape to help her visually recognize the commode. Her daughter placed lavender throughout her bedroom to elicit calming aromas in her safe space. Sarah sang acapella in earlier years, so a small CD player was turned on playing her favorite hymns. I brought a 5-pound weighted vest to be worn 15-20 minutes prior to toileting tasks to encourage proprioceptive stimulation, which is calming to the nervous system. While she wore her weighted vest, she sat in a rocking chair and rocked at her own pace.

After one week of the environmental and sensory-based interventions, Sarah was able to be changed and dressed with only two staff members. After two weeks, Sarah was able to sit on the bedside commode and successfully void for the first time in two years. After I felt the staff was comfortable with the new routines, occupational therapy ended. But, Sarah's gains continued. She began talking in simple sentences with staff and other residents, she started sweeping the floor, and she engaged with her family upon visits. The transformation Sarah exhibited with the above interventions fueled my desire to investigate such interventions.

Initial review of evidence as a clinician did not provide much information or guidance in the field. Gaps in literature and theoretical understanding of such

similarities, as well as environmental influences on such behaviors encouraged doctoral exploration. Passion for enhanced aging experiences, especially when faced with cognitive impairment, guided me to gerontology. Specific aims of this dissertation were created to help fill gaps in gerontological understanding and move toward guiding theory development and intervention strategies to improve the lives of those living with cognitive impairment and dementia considered from an environmental gerontology perspective. My personal goal is to prolong residence in natural home environments for those with dementia and related disorders by promoting environmental fit and decreasing challenging behaviors.

"When a flower doesn't bloom, you fix the environment in which it grows, not the flower."

-Alexander den Heijer

CHAPTER 1. INTRODUCTION

Interactions with one's surroundings evolve throughout life. There are high levels of dependency in infancy and early childhood. Infants depend on caregivers and children rely on supervising adults to maintain a safe environment by removing hazards, restricting access to dangerous areas, and encouraging interaction with appropriate environmental features. Typically, children grow into healthy adults who are able to use their environment. Examples include exercising on hiking trails, dimming lights for relaxation, or surrounding themselves with friends. Abilities continue into old age, and for some, remain strong, allowing for independence and adequate function until death. But, aging also brings about biological and physical changes to the body. Decreased coordination, rigidity, and cognitive decline are often seen in old age. An increase of dependency may reoccur in late life as abilities decline, creating heightened reliance on environmental supports. A supportive environment promotes function, independence, quality of life, and well-being. Conversely, an unsupportive environment may create significant barriers and limitations to quality of life and independence (Kahana, 1982; Iwarsson et al., 2005).

Cognitive impairment and dementia accentuate challenges seen in old age. Advanced cognitive impairment, often dementia, causes challenging behaviors which hasten need for expensive medical and nonmedical interventions and caregiving, as well as cause discomfort for the individual. In the United States, the monetary value of care for those with dementia exceeds \$215 billion annually (Alzheimer's Association, 2016). Beyond the individual and economic burdens of dementia, primary care partners involved often have significant burden with decreased quality of life, higher rates of depression,

and personal injury (Lee, 2008). This burden has been directly linked to placement of the person with dementia into long-term care facilities despite well documented desire of older adults to remain in their home until death (Chung & Cummings, 2000; Eska et al., 2013).

Inappropriate behaviors associated with cognitive impairment have historically been treated with medications (Risco et al., 2015). Recent evidence demonstrates use of antipsychotic drugs for such behaviors has negative effects and insufficient efficacy in controlling behaviors (US Food and Drug Administration, 2013). Trends now focus on ways to decrease medication use in this population.

The Centers for Medicare and Medicaid Services suggest that environmental approaches, such as social interactions with staff, negotiability, and use of routines, should be attempted prior to use of medication for behavioral management of dementia (Gurvich & Cunningham, 2000). Environmental approaches for behavioral management are an increasing focus of scientific investigation. Influence of the environment on behavior is a function of a closed loop system between the sensory abilities of the person and the environment (Buckley & Toyozumi, 2018). Environmental stimuli activate sensory modalities (i.e., sound, vision, smell, touch) of the person. Once activated, sensory processing at the cognitive level allows for perception and awareness of the external and internal environments. Humans are able to use sensory stimuli to intentionally or reflexively produce movement and behavior. When any part of this system is not functioning properly, maladaptive behaviors may occur.

Neurological disorders that impair cognition can alter how environmental stimulation is perceived and utilized (Bakker, 2003; Behrman, Chouliaras, & Ebmeier,

2014). Of neurological conditions similar to dementia, autism spectrum disorder (ASD) is known to have sensory processing deficits. Evidence supports sensory-based theory and interventions for those with ASD to improve behavioral expression (Fazlıođlu & Baran, 2008; Pfeiffer et al., 2011). The relationship between environmental sensory processing and behavioral expression has not yet been defined in a geriatric population, especially those with cognitive impairment attributed to dementia.

Statement of Problem

Behavioral phenotypes of dementia have been compared to other neurological disorders including schizophrenia, Parkinson's disease, and ASD (Laviola et al., 2008). Relationships and causalities of similar behaviors among these conditions are not fully understood in science. Yet, medical practitioners and researchers have used pharmacological treatment options across conditions. For example, antipsychotic drugs approved for conditions such as schizophrenia have been used for behavioral treatment in those with dementia for decades. More recently, FDA approved Alzheimer's disease (AD) medications have been used in successful treatment for children with autism (Rossignol & Frye, 2014). Commonalities between behaviors of ASD and dementia have not been fully described in the literature. If commonalities of behaviors are established, overlap of environmental theory and intervention may be warranted.

As nonpharmacological options for behavioral management continue to evolve, the significance of environmental influences on behavioral expression among these conditions needs to be addressed. Sensory experiences from the natural and built environments of persons with cognitive impairment have not been fully explored.

Currently, there is no theoretical model guiding implementation of environmental strategies for behavioral management for those with cognitive impairment.

Purpose of Study

The overall goal of this project is to elaborate on an evolving model describing the relationship among environment, behavior, sensation, and behavior for community-dwelling adults with dementia. Development of the model builds from exploration of behaviors which may be correlated with environmental stimuli. Of neurological conditions comparable to dementia, ASD has the largest body of evidence supporting successful implementation of sensory-based theory and intervention. Behaviors characteristic of ASD have been selected as an exemplar for behavioral comparison in order to expand understanding of similar behaviors across comparable conditions from an environmental perspective. Evidence supporting the model has been collected through multiple methods including a cross-sectional questionnaire, qualitative observation, interview and sensory preference exploration of community-dwelling adults with cognitive impairment and their care partners. Collected data and supporting evidence elucidate components of a model designed to facilitate an understanding of behavioral and sensory experiences when living with dementia and related disorders from an environmental gerontology perspective.

Specifically, illustrations of environmental stimulation related to sensation, perception, and behavior are explored. Temporal progression of interaction between the primary caregiver and person with dementia is explained within the context of environmental surrounds. The model provides a foundational framework for opportunities to facilitate adaptive behavioral responses in this population.

This dissertation will allow for future development of assessments, intervention protocols, and implementation strategies. Long-term objectives of the overall research program are to improve quality of life for persons with dementia by decreasing maladaptive behaviors due to environmental incongruence, prolong successful residence in the home, promote care partner well-being, and enhance awareness and accommodation to environmental demands for those with cognitive impairment.

Specific Aims

Three interwoven projects provide building blocks culminating in the elaboration of an emergent model. These projects have been designed to achieve the following specific aims.

Specific Aim 1: To examine the relationship of behaviors observed in autism spectrum disorder and dementia. Neurological conditions, such as schizophrenia, Parkinson's disease, ASD, are being increasingly compared to dementia (Chung & Cummings, 2000; Hornberger, Piguet, Kipps, & Hodges, 2008; Laviola, Hannan, Macri, Solinas, & Jaber, 2008; Rossignol & Frye, 2014). Behaviors characteristic of ASD have been selected for comparison with behaviors observed in those with dementia. This will allow for enhanced environmental and sensory comparison. Autism and dementia present with similar challenging behavioral phenotypes, but characteristic behaviors have not been compared thoroughly in the literature. Causes of behavioral expression in the disorders are not clear, nor do they have easy pathways for treatment. A cross-sectional design was used with participants with cognitive impairment enrolled in a larger longitudinal cohort.

Specific Aim 2: To investigate environmentally-related behavioral manifestations of dementia in community-dwelling adults in a caregiving context. Limited literature describes behaviors of dementia in community-based settings through a lens of environmental and sensory influences. Investigation of behavioral manifestations is related to: 1) caregiver perceptions; 2) environmental conditions; and 3) individual sensory processing patterns. Analysis provides a holistic picture of contextual factors which influence adaptive behavior. Expansion in understanding environmental influences on behavior is needed for those with dementia in order to improve clinical intervention, improve quality of life, and reduce caregiver burden. Data collection and analysis employ descriptive qualitative approaches.

Specific Aim 3: To elaborate on a model depicting the relationship among environmental factors, sensation, and cognition as related to behavioral expression for community-dwelling adults with dementia and their primary care partners. Existing environmental gerontology theory and models lack explanation of social and biological factors when explaining person-environment interactions. Specifically, sensation and perception of environmental input for those with dementia is inadequately incorporated in existing theory. This specific aim synthesizes environmental gerontology theory, biology, and neuroscience frameworks to refine a dynamic model of person-environment interaction in terms of behavioral expression for adults with dementia. In addition, the role of primary caregivers in influencing the person-environment relationship for the person with cognitive impairment is explored. Components of environment and sensory processing will be used to enhance understanding of behavioral

expression. This model is designed to guide the development of assessments and interventions for environmental adaptation and utilization.

CHAPTER 2. BACKGROUND

Understanding maladaptive behavioral expression seen in persons with neurodegenerative conditions provides a path toward further explanation of the problem. This section will describe the area of interest, behaviors associated with dementia and ASD, and lead into exploration of the relationship of potential causal factors from an environmental perspective. Care partner involvement must be considered due to the nature of increasing dependency with the progression of dementia. With this understanding of the problem, application of environmental gerontology theories will afford grounding of concepts within the overall understanding of the relationship among behavior, sensory processing, and environment for older persons with cognitive impairment due to dementia. The following sections will explore: behaviors associated with dementia and ASD; involvement of care partners within the environmental context; sensory processing abilities across the lifespan; and move toward an environmental gerontology theoretical perspective.

Behaviors Associated with Dementia and ASD

Neuropsychiatric and behavioral symptoms are increasingly identified as a significant component of AD and related dementias. Behavioral and psychological symptoms of dementia (BPSD) are defined as, “Signs and symptoms of disturbed perception, thought content, mood, or behavior that frequently occur in patients with dementia” (Finkel et al., 1996, p. 1060). Presence of these behaviors often begins while individuals are living at home, causes significant stress to the person with dementia,

increases caregiver burden and hastens the need for institutionalized care (Chung & Cummings, 2000; Eska et al., 2013).

BPSD have been reported to affect over 80% of those with dementia, yet these behaviors have received minimal attention for individualized care and intervention (Finkel et al., 1996; Lyketsos et al., 2002). Research prior to the late 1990's was focused on cognitive processes and function associated with dementia. Little attention was given in research in terms of healthcare and intervention related to the behavioral and psychological symptoms. Continued investigation is needed to more clearly describe BPSD in terms of the experience, causes, and interventions (Zhoa et al., 2016).

Most common behaviors are apathy, depression, aggression and agitation, anxiety, and sleep disorder (Boyle et al., 2003; Zhao et al., 2016). Apathy is the most common psychiatric symptom in those with dementia (Landes et al., 2001). Apathy is defined as “reduced initiative, interest, motivation, spontaneity, affection, energy, enthusiasm, emotion, and persistence as well as blunted affect” (Brodaty & Burns, 2012, p. 549). Depression is similar to apathy, but defined separately as described by the American Psychological Association (APA) in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V) (APA, 2013). Agitation in this population has been defined by Cohen-Mansfield (1986) as inappropriate verbal, vocal, or motor activity that is not explained by needs or confusion. BPSD present significant issues in dementia care (Ecerejeira, Lagarto, & Mukaetova-Ladinska, 2012).

Many BPSD share similarities with those described in ASD (Kim & Lord, 2013), including anxiety, depression, executive functioning deficits, and communication deficits (Wallace et al., 2016). Diagnostic criteria for ASD are defined in the DSM-V to include,

but are not limited to: deficits in social communication and social interaction; restricted, repetitive patterns of behavior, interests, or activities including repetitive movements, use of objects, or speech; inflexibility in terms of routines, ritualized patterns of verbal or nonverbal behavior; fixated interests; and hyper- or hypo-reactivity to sensory input (American Psychiatric Association, 2013). In order for diagnosis, ASD symptoms must begin in childhood or early adolescence and not be due to developmental or intellectual disability. The underlying etiology of ASD is not fully understood. Both ASD and dementia lead to behavioral disruptions associated with increased caregiver burden, use of antipsychotic medications, and increased direct care needs (Baez & Ibanez, 2014; Hornberger, Piguet, Kipps, & Hodges, 2008).

Recognition of possible relationships among clinical features of ASD and dementia has sparked recent scientific investigation (Caselli, Langlais, Dueck, Locke, & Woodruff, 2018; Rossignol & Frye, 2014; Zeidan-Chulia et al., 2014). Scientific literature significantly lacks representation of the aging experience for those with diagnosed ASD and high functioning individuals with undiagnosed ASD (Geurts & Vissers, 2012; Happe & Charlton, 2012; James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006). Existing evidence does lead to speculation that selective neuroanatomical involvement or shared mechanisms of the two disorders might contribute to such overlapping behavioral sequela. Anatomical and behavioral similarities overlap in Frontotemporal Dementia (FTD) and ASD, including frontal and temporal lobe cortical thickness and volume deficit, alterations in communication and impaired social abilities (Baez & Ibanez, 2014; Hilde, Geurts & Marlies, Vissers, 2012; Mendez, Shapira, & Miller, 2005; Midorikawa & Kawamura, 2012; Raznahan et al., 2010). Additionally,

beta-amyloid precursor protein (β APP) levels, a key protein associated with Alzheimer's disease (AD), have been shown to be higher in blood plasma levels of children with severe autism and aggression than neurotypically-developing controls (Sokol et al., 2006). Other studies have shown behavioral improvements in children with autism while using FDA-approved AD medications that modulate both acetylcholinergic and glutamatergic function, suggesting possible overlap in pharmacological responses in these distinct syndromes (Rossignol & Frye, 2014; Zeidan-Chulia et al., 2014).

Biological, psychological, and environmental factors including age, disease duration, setting, education level, and severity of cognitive impairment influence presence and frequency of these behaviors (Van Vracem, Spruytte, Declercq, & Van Audenhove, 2016; Zhoa et al., 2016). Specific causal mechanisms are not fully understood. Due to the multidimensional relationship of influencing factors on behavior, intervention for improvement has been a challenge. Lack of behavioral management in community-dwelling adults with dementia is significantly correlated with caregiver burden, lowered quality of life for both the care partner and person with dementia, and heightened rates of institutional care (Finkel et al., 1996; Risco et al., 2015). Current pharmacological treatment for behaviors presents challenges and has resulted in recent changes in best practice (Jicha, 2011).

Pharmacological intervention. Pharmacological intervention options for behavioral management in care of those with dementia have not been ideal in both community-dwelling and institutional care settings. There is not one type of drug that drastically improves behavior with minimal side effects. Historically, misuse and abuse of antipsychotic medications was prominent prior to 1987, at which time the Omnibus

Budget Reconciliation Act set guidelines and policies delineating and limiting use of such medication (Briesacher et al., 2005). Despite limitations on antipsychotic use, an increase in administration of these medications was seen in the early 2000's. Because of the lack of medication specific for behaviors in persons with dementia, there is a group of drugs that are commonly used, but most were not created for those with dementia. Types of medications used in the management of BPSD include: cholinesterase inhibitors; NMDA antagonists; antidepressants; mood stabilizers; sedatives; stimulants; anti-hypertensives; anti-Parkinsonian agents; agents for pseudobulbar affect; and agents for motor neuron disease (Jicha, 2011).

The *Journal of the American Medical Association* published an investigation of prescription usage from a national data set from the Medicare Current Beneficiary Survey (Briesacher et al., 2005). Additional data including Medicare part A and B claims, MDS assessments, and monthly medication usage reports were collected. The sample included 1096 nursing homes representing 2.5 million nursing home residents. Results indicate 45% (approaching one half) of nursing home residents received antipsychotic medications, with more than one third receiving more than the recommended dosage. Atypical antipsychotics were the most commonly used, with Risperidone as the highest prescribed. Over 200,000 residents received the medication without proper indication and were more likely to present with behavioral problems and depression, echoing other similar studies (Lau, 2004). Memory problems, nonaggressive behavior, and depression were among the top causes of prescription outside of guideline recommendations. Nearly 40% of patients continued to have inappropriate behaviors after drug administration including screaming, disrobing in public, and throwing food or feces. Pharmacological

researchers continue to create new drugs in hopes to ward off such behavioral distress. But, the continued lack of an effective medication to address behavioral concerns has encouraged a surge in attention of nonpharmacological interventions from researchers and clinicians.

Similar misuse and overuse of medications occurs in community-dwelling adults with dementia. Living at home creates additional struggles with determining appropriate medication, because the medical practitioner is reliant on caregiver report and symptom expression at time of examination (Jicha, 2011). Illnesses often go undiagnosed in community-dwelling adults with dementia, which further promotes neuropsychiatric behaviors (Hodgson, Gitlin, Winter, & Czekanski, 2011). Challenges throughout the care continuum exist in pharmacological intervention for behaviors of dementia.

Nonpharmacological intervention. Overutilization of psychotropic medication has resulted in a recent trend to decrease use of medications leaving providers and caretakers without many options to manage BPSD (Cohen-Mansfield, Thein, Marx, & Dakheel-Ali, 2012; Verkaik, van Weert, & Francke, 2005; Zuidema, de Jonghe, Verhey, & Koopmans, 2011). There is an increasing presence of nonpharmacological intervention application in the literature and clinical practice (Olazaran et al., 2010). Table 2.1 illustrates common nonpharmacological interventions used in dementia care.

Table 2.1. Non-pharmacological therapies. (Douglas, S., James, I., & Ballard, C., 2004, p. 172)

Non-Pharmacological Therapies
<u>Standard therapies</u>
Behavioral therapy
Reality orientation
Validation therapy
Reminiscence therapy
<u>Alternative therapies</u>
Art therapy
Music therapy
Activity therapy
Complementary therapy
Aromatherapy
Bright-light therapy
Multisensory approaches
<u>Brief psychotherapies</u>
Cognitive behavioral therapy
Interpersonal therapy

Despite implementation of such strategies, there are not sufficient assessments or protocols to identify useful environmental, neurological, and behavioral interventions for individuals with AD and other dementias (Cohen-Mansfield et al., 2015; Kong et al., 2009; Schaaf, Miller, Seawell, & O'Keefe, 2003; Vozzella, 2007; Zeisel et al., 2003; Zuidema et al., 2010).

Ayalon and colleagues (2006) evaluated the state of nonpharmacological research with a systematic review examining the impact of such interventions on BPSD. Their study used randomized control trials, randomized crossover designs with washout periods, and single cross-over designs that used the participant as their own measure over time. Analysis found three randomized studies and six single cross-over designs which met the required criteria. Findings were described in three nonpharmacological

intervention categories: unmet needs; learning and behavioral models (behavioral intervention and caregiver intervention); and environmental vulnerability and stress-threshold response. A need for increased rigor of evidence with blinded assessment and use of intervention protocol was apparent. The authors concluded that a focus on caregiver training and perceptions may decrease burden and other distress as a result of these behaviors.

Specific types of interventions have also been explored. Wilkes and colleagues (2005) used an environmental approach to better understand agitation in dementia. They noted agitation in dementia affects up to half of all individuals with the condition. Some types of agitation including verbal agitation, aggression, and physically non-aggressive agitation have significant influence on caregiver burden and distress. Wilkes and colleagues used a quasi-experimental design to evaluate the changes in agitated behaviors in residents with dementia after moving from an older nursing home to a special care unit (SCU) for persons with dementia. Environmental components of the SCU which differed from standard nursing home settings included unrestricted access to garden areas, wandering paths, domestic areas with activities (sweeping, wiping tables), private rooms with large bay windows and sitting chairs, an open floor plan in common areas, skylights, railings built on all walls, addition of personal pictures and artwork, access to clocks and calendars, private bathrooms, and a multisensory Snoezelan room. The Cohen-Mansfield Agitation Inventory was used as an outcome measure. Twenty-three residents were included and assessed weekly for one month prior to the move, weekly for one month after moving, and once at three months and six months after the move. Physically non-aggressive acts, such as pacing and wandering, decreased significantly at three months.

Verbal aggression also significantly decreased over time and was sustained for those who moved to a specialized dementia unit. These results demonstrate that environment does impact behaviors observed in this population.

Van Vracem and colleagues (2016) sought to identify environmental factors associated with agitation in persons with dementia. They conducted expert panel discussions with family members, home health professionals, and long-term care facility professionals. Seven environmental factors were identified including light, smell, noise, temperature, time outdoors, color, and spatial configuration of the residence. Families reported common agitation from the person with dementia and this agitation created caregiver burden. Of environmental stimuli, home-like or domestic smells were helpful in decreasing agitation while increased noise raised agitation, except with music and white noise. People with dementia were reported to be calmest in warm situations. Nature and animals were reported to improve mood. High contrast and open spaces were also associated with decreased unwanted behaviors. The authors reported that professionals were more likely to be aware of environmental techniques; in contrast, family caregivers were less familiar with such approaches. Intervention tailored to the individual's needs and interests was most appropriate, as well as a need for research regarding education techniques for caregivers. Physical environment factors including natural light, bright lights, sensory stimulation, outdoor walks, animals, and lighting during meals influence agitation. Additionally, environments that allow and encourage everyday activities including cleaning, folding garments, and gardening, lead to improved quality of life.

Verkaik and colleagues (2005) acknowledged nine categories of intervention including validation of emotional care, reality training, multisensory intervention (decreasing apathy in early stages), reminiscence, psychomotor therapy (reducing agitation in nursing home residents), skills training, behavior therapy (decreasing depression for community-dwelling adults), art therapy, and gentle care. Wilks et al. (2017) also noted improvement in behaviors and quality of life with prepared environments using Montessori-based activities. Despite the availability of numerous intervention options, there are minimal guidelines and lack of training for implementation by care partners in addressing behaviors associated with dementia (Verkaik et al., 2005).

Guerriero Austrom et al. (2004) completed a study investigating protocol development with care partner training in order to target problem behaviors. Their study used a randomized trial method to evaluate primary-care management for those with AD and their caregivers. Crucial elements of the study included collaboration between care providers and patients, personalized treatment plans, outcomes monitoring, consultative services, and following a protocol. Study procedures took steps for using a screening and diagnosis protocol, implementation of care coordination by a geriatric nurse practitioner, and longitudinal tracking. Aims of the study were geared toward family caregivers with outcomes measured in behaviors, caregiver burden, and health care utilization. The nonpharmacological intervention was caregiver training on specific behaviors using protocols established for this study. These behavioral protocols addressed depression/anxiety; aggression/agitation, delusions/hallucinations/paranoia, personal care, mobility, and sleep disturbances. The intervention arm used the above noted protocols which were distributed based on the ‘Memory and Behavior Problems

Checklist' completed by caregivers. The caregivers also completed the Patient Health Questionnaire-9 to determine caregiver stress and depression. Following training in the use of the protocols, the nurse practitioner of the clinical team conducted weekly calls to answer questions, monthly face to face visits for the first three months and then quarterly meetings for up to 12 months. In addition, caregivers attended monthly groups for education on topics pertaining to behavior management. Findings demonstrated decreased caregiver burden, increased safety and independence, and prolonged residency of the participant in their home. Given improvements in behavior and care associated with nonpharmacological interventions, protocol development and care partner training is relevant and needed.

Involvement of Care Partners within the Environmental Context

Care partners and the person they are caring for create a unique dyad. Care partners often understand and know the person with dementia the best. They are often able to distinguish observable behaviors as specific needs, similar to a parent and infant. There are varying roles aside from the care partner responsibility. For example, the majority of care partners are spouses (Hodgson & Craemer, 2013), with other types of care partners including children, friends, relatives, and paid service people. Heterogeneity in the makeup of care partner dyads can create challenges for prescribed or protocol-based intervention. Interactions vary between partners, and so implementation of assessment and intervention can become dependent on the success of the relationship. Individualized care partner training is needed to fully maximize the potential for behavioral improvement.

Evidence supports individualized interventions for care partner training including: professional support, psycho-educational, behavior management/skills training, counseling/psychotherapy, self-care/relaxation techniques, and environmental redesign (Gitlin, Marx, Stanley, & Hodgson, 2015; Hebert et al., 2003). Interventions with care partners have been noted to improve relationships and decrease negative appraisal of observed behaviors in the person with dementia (Mittelman, Roth, Haley, & Zarit, 2004). Additionally, training with families, as well as outside care providers has been shown to be effective in decreasing caregiver burden (Hepburn, Tornatore, Center, & Ostwald, 2001; Teri, McCurry, Logsdon, & Gibbons, 2005).

Jicha (2011) recognized the importance of involvement of care partner perceptions into the medical management of frontotemporal lobe dementia (FTD). He described how FTD presents with significant changes in function and behavior; but there are minimal treatments for the disorder. FTD is often seen in younger populations, accounting for 15% of dementias in individuals 65-years-old and younger. This form of dementia presents with unique characteristics cognitively, behaviorally, psychologically, and with movement when compared to AD, and can mimic phenotypes of ASD. Additionally, there is great heterogeneity of behaviors in those with FTD, further complicating assessment and treatment. Treatment options are often varied and complex requiring additional training or experience. Environmental factors and stressors often play a role in symptom expression and fluctuation in function. These factors must be considered when addressing medication changes. Jicha noted the need for collaboration and partnership with caregivers to adequately address symptoms associated with FTD. The care partners are the primary liaison for reporting challenging behaviors,

environmental triggers, changes in symptoms associated with medication initiation or withdrawal. Care partners report behaviors which are influential in the assessment process. They also engage in intervention implementation and communication regarding on-going impact of interventions. Clinicians and researchers rely on care partners to advance understanding and utilization of all types of intervention approaches. Quality communication among all care providers has the potential to decrease unwanted negative behaviors and increase quality of life for both the person with dementia and their care partner.

The role of caregiving for someone with dementia can create significant burden for the care partner. Increased depression, stress, pain, decreased quality of life, and decreased patient functioning are a few of the consequences of caring for persons with cognitive impairment on the care partner (Caserta, Lund, & Wright, 1996; Hodgson & Craemer, 2013). This often is termed as caregiver burden. Caserta, Lund, and Wright (1996) sought to better understand multidimensional aspects of caregiver burden. A sample of 160 caregivers was used (52 from an adult day center and 108 from support groups). Eighty-two percent of the sample was female, 52% were spouses of the person, and 37% were daughters of the person being cared for. The Caregiver Burden Inventory, the Memory and Behavior Problem Checklist, the Center for Epidemiological Studies Depression Scale, a checklist of caregiver tasks, and the caregiver satisfaction subscale were used. Time burden was associated with the amount of time with the patient and patient functioning. Emotional burden was associated with caregiver satisfaction. Caregivers who felt deprived were more likely to be depressed. Physical burden was associated with depression. Caregiver burden creates a barrier to implementation of

behavioral interventions. Caregivers must be the ones to initiate and provide interventions, but if the burden is too great, they will not be able to add an additional component of care into daily routines.

In addition to the barriers noted above, system regulations of long-term care facilities create barriers to implementation of behavioral assessment and intervention for older adults and those with dementia (Rabig et al., 2006). Standard nursing homes have minimal access to behavioral assessments and intervention tools. There is also minimal time allotted for nonpharmacological intervention from the care staff (McGreevy, 2016). Historical models of medically-based long-term care have diminished opportunities for individualized or person-centered care (Kitwood & Bredin, 1992; Koren, 2010). Recent changes in long-term care environmental design are encouraging (Rabig et al., 2006). The culture change movement within long-term care has promoted increased access to multidimensional environmental exploration (Kane, 2001). But, the large majority of long-term care continues to be stricken with systematic barriers for implementation of behavioral assessment and intervention (Rahman & Schnelle, 2008).

Sensory Processing Abilities across the Lifespan

Sensation and perception involve a complex matrix of biological systems as well as psychological interpretation (Gutman, 2008). Early philosophers, John Locke, George Berkeley, and Thomas Hobbes were a few of the founding theorists in utilization of sensation and perception. They believed that all knowledge is gained through the senses and existence revolves around sensory experiences. Psychosocial theories have helped develop an understanding of sensation and perception in terms of cognitive awareness and response. Behaviorists, such as Pavlov used sensory stimulation in relation to

behavior change, as evident by experiments with his dog involving auditory stimulation with a bell creating behaviors in preparation for food. In humans, sensory stimuli are applied to cognitive constructs from lifetime experiences and memories to form perception and guide behavior.

Abilities in sensory processing change throughout the lifespan. Infants are born with sensory systems set up structurally, but these systems only attain full functionality with maturation. For example, vision is not fully developed until the age of seven years.

Auditory processing is present at birth, but recognition for meaningful use is not developed. Tactile input is reflexive at birth, but quickly develops within the first year.

With continued aging, sensory abilities change in terms of development and

degeneration. Sensory acquisition systems mature through childhood, are most efficient

in adulthood, and decline in function beginning around the age of 50 years (Humes, 2015;

Reynolds & Cronin, 2005). Table 2.2 illustrates examples of specific sensory system

changes common with advanced age.

Table 2.2. Common changes in aging sensory systems. (Reynolds & Cronin, 2005).

Sensory System	Changes common with advanced age
Visual (vision)	Presbyopia, cataracts, glaucoma, macular degeneration
Auditory (hearing)	Presbycusis
Vestibular (sense of movement)	Presbyastasis, disequilibrium
Olfactory (smell)	Hyposmia
Gustatory (taste)	Hypogeusia
Tactile (touch)	Loss of acuity
Proprioception (sense of body position)	Arthritis

For older adults, effects from these sensory-based changes are often addressed through compensatory mechanisms. For example, presbyopia is improved by addition of glasses, presbycusis is accommodated by the use of hearing aids, and presbyastasis is

often aided by the use of a walking cane or walker for increased stability. Cognitively intact older adults may also increase their awareness to such deficits and adapt behaviors to adjust, such as the older person with increasing disequilibrium that reports increased diligence and attention to steps and slowed speed when traversing stairs to remain safe.

Dementia often creates additional sensory and perception changes. Specifically, slower processing speed, impaired sensory recognition and distorted perceptions hinder ability to cognitively react to sensations (Gutman, 2008; Reynolds & Cronin, 2005). Impaired communication abilities in dementia further complicate understanding of sensation and perception. Limited communication creates barriers to maintaining engagement in environments wherein a person considers themselves to be most comfortable.

Sensory processing theory. Occupational therapy is a discipline that has developed theoretical understanding and intervention frameworks to address abilities of sensory integration and modulation. Work in this area originated in pediatrics (Ayres, 1989). Jean Ayres pioneered sensory integration interventions in the 1970's for children with sensory processing disorder, often seen in children with autism. Her interventions supported theoretical development of intervention styles and assessment. Patricia Wilbarger (1997) built additional interventions to prompt neurological reorganization in nervous systems that may be overreactive to stimulation. Occupational therapist, Winnie Dunn, developed an assessment tool, the Sensory Profile, to better understand individual sensory preferences and thresholds so that one can better understand linkage to behaviors and neurological needs (Dunn & Westman, 1997). She touted occupational therapy as a

discipline that is prepared to identify and work with behavioral manifestations of impaired sensory processing and utilization.

Sensory-based theorists have given recent attention to assessment and evidence supporting sensory processing approaches in dementia care. Sensory processing theories, as defined by Dunn indicate sensory patterns and needs specific to each individual (Dunn & Bennett, 2002). These sensory needs depict thresholds for optimal function of the nervous system, specific to each individual’s preferences (Table 2.3).

Table 2.3. Sensory Processing Thresholds. (Dunn & Bennett, 2002).

Neurological threshold continuum	Behavioural response continuum	
	Accordance	Counteract
High	<p>LOW REGISTRATION Behavioural responses in accordance to high neurological thresholds, i.e., less aware of sensory information or requiring stimuli of high intensity for recognition. <u>ASP item examples:</u> I trip or bump into things. I don't seem to notice when my face or hands are dirty.</p>	<p>SENSATION SEEKING Behavioural responses counteract high neurological thresholds, i.e., tendency to seek sensory information to counteract a high threshold. <u>ASP item examples:</u> I add spice/herbs to my food. I like wearing colourful clothing.</p>
Low	<p>SENSORY SENSITIVITY Behavioural responses in accordance to low neurological thresholds, i.e., more likely to be sensitive or respond easily to sensory information. <u>ASP item examples:</u> I feel dizzy easily. I am distracted when there is a lot of noise around.</p>	<p>SENSATION AVOIDING Behavioural responses counteract low neurological thresholds, i.e., tendency to control or avoid overwhelming sensory information. <u>ASP item examples:</u> I only eat familiar foods. I stay away from crowd.</p>

Winnie Dunn and others created an assessment tool, the Adult Sensory Profile, to best understand personal sensory processing preferences (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001). The tool has been validated in adults with dementia (Chung, 2006). When paired with environmental stimuli, the result is behavioral expression. The use of the Sensory Profile is functional in many settings and validated in age groups

across the lifespan. Dunn's Sensory Profile has been validated in an adult population (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001). Additionally, the Adult Sensory Profile has also been validated for those with dementia (Chung, 2006). Sensory Profile assessment allows for individualized recognition of neurological needs and tailored treatment development (Behrman et al., 2014). Utilization of the assessment is also effective in various settings.

Nursing is another discipline which has identified the role of sensory processing on behavior. The term *sensoristasis* has been defined as regulation of the nervous system via external sensory system activation, similar to homeostasis for internal biological regulation of processes such as temperature and blood pressure (Kovach, 2000). Sensoristasis is a notion of balance between stimulation and deprivation of sensory environments to create a balance of input and processing to the neurological system. Mechanisms involved in sensoristasis may help guide a tailored approach to address the complexities involved in sensory-based interventions.

Experimental involvement of sensory-aimed techniques among multiple disciplines exists, but there is a lack of consistent definition and theoretical framework for implementation in dementia care. Sensation and perception have been shown to have significant changes with age, but there is a void of theoretical and conceptual representation for old age. Heavy emphasis, theoretically, clinically, and in the literature, is seen in pediatrics and early development.

Application in pediatric conditions. Children with neurological conditions, such as autism, attention deficit hyperactivity disorder, and sensory processing disorder have a high likelihood of underdeveloped or poor integration and modulation of sensory

processing abilities (Dunn & Bennett, 2002; Lane, Young, Baker, & Angley, 2010). Therapists have used theories in sensory processing to develop targeted approaches for enhanced integration and utilization of sensory information in the pediatric setting. Wilbarger (1984) recognized the need for individualized exposure of sensory stimulation in pediatrics. She coined the term ‘sensory diet’ to express the nervous system’s need for sensory stimulation to properly function, just as the body needs food to effectively operate. Sensory diets are created by occupational therapists to reflect unique stimulation needs of the individual. Recent evidence supports significant improvements of sensory-based problems in children with severe autism through implementation of sensory diets (Fazlioglu & Baran, 2008; Green & Ben-Sasson, 2010).

Sensory diets offer an enriched sensorimotor experience, which has been shown to improve dendritic branching, synaptic density, and neurogenesis (Woo & Leon, 2013). Further enriched sensory experiences have been shown to improve behaviors associated with: brain lesion, toxin exposure, exposure to addictive drugs, brain trauma, stroke, seizures, aging, hypoxia, Down syndrome, Alzheimer’s disease, Huntington’s disease, Parkinson’s disease, schizophrenia, and autism. Some mouse models have been shown to reverse or ameliorate symptoms of autism following exposure to enriched environments. Specifically, enriched environment has been shown to reduce motor deficits, improve learning and memory, reduce aggressive behavior, decrease anxiety, decrease repetitive/stereotypic activity, and increase exploratory and social activity. Environmental and sensory deprivation, such as in institutionalized orphans, can create autism-type symptoms, called post-institutional autistic syndrome. Symptoms include stereotypic behaviors, inability to identify human emotion, and impaired communication,

language, cognition, and attachment (Woo & Leon, 2013). These behaviors can be decreased with sensory and environmental stimulation. Once placed into enriched environments (foster homes), children's scores on intelligence tests, language, social engagement, and mental health scales all improve.

Woo and Leon (2013) completed a randomized control trial with 28 male children diagnosed with autism from the age of 3-12. Children continued with their normal care therapies, except no sensory-based therapies were permitted during the trial. Parents of children in the enrichment group received kits to provide sensorimotor experiences for the children throughout the day. Kits included seven vials of essential oils and cotton balls, squares of various textures, various objects for manipulation, objects for oral play and crafts, a portable CD player and classical music CD, a balance beam, spa treatment supplies, household objects, and various items for exercise and walking paths. Parents were also given written instructions for 34 sensorimotor enrichment exercises and a training session. The set of exercises changed every two weeks and lasted 6 months to enhance novelty. The exercises took 15-30 minutes, twice a day. Results indicate that 42% of the enriched group had clinical improvement in the Childhood Autism Rating Scale and 69% of parents from the enriched group reported improvement in autism symptoms. Conclusions from the study confirm reduction in autism symptoms overall severity and improvements in cognitive performance. The authors note olfactory ability is often impacted in autism, and can in fact underlie autism development. Additionally, olfactory stimulation and tactile stimulation, when combined, create a 300% increase in norepinephrine which maintains elevation for at least two hours. Significance of this increase of norepinephrine is important because of its influence on cognitive functioning

thereby stimulating production of brain-derived neurotrophic factor, glutamate, and dopamine. Norepinephrine also promotes neurogenesis, prevents neural cell death, and diminishes effects of inflammatory reactions.

Institutionalization creates a level of sensory deprivation that can be harmful for individuals across the lifespan. Wilbarger and colleagues (2010) reviewed effects of institutionalization on orphaned or abandoned children and noted association with sensory deprivation and decreased social nurturing. Infants and children in these situations had decreased ability to develop self-regulatory behavior and modulate sensory input from the environment. Modulation is the ability to appropriately respond and adapt to environmental stimuli on neurological, physiological, and behavioral levels. Specifically, children demonstrated “sensory avoidance and aversion, stereotypic rocking, unusual sensory interests or seeking, self-injury, eating problems, and autistic-like behaviors” (Wilbarger et al., 2010, p. 1105). Most children presented with development delays in multiple areas. Significant improvement was seen after adoption, but some deficits continued in areas of behavioral, social, and emotional regulation. In sum, institutionalization is shown to be associated with increased deficits sensory processing abilities including sensory modulation and self-regulation, which may in turn present as behaviors characteristic of autism.

Using the short sensory profile, one of the only validated tools to assess sensory processing modulation, Wilbarger et al. (2010) assessed 297 children from the ages of 8 to 12.5 years after 12 months post-institutionalization. Children were grouped into three categories of institutionalized, foster care/early adoption, or non-adopted. Researchers found that prolonged institutionalized care promoted sensory processing deficits, whereas

foster care and non-adopted children had no difference. Post-institutional children had increased sensory aversions and increased sensory-seeking behaviors. Tactile responses were altered with at least one year of institutional care. The measures were only associated in negative responses to stimuli. Findings demonstrated several behavior consequences of poor sensory modulation as a result of institutionalized care.

Application in old age. Aging and dementia cause changes in sensory system abilities. Further, person-environment fit changes as a result of cognitive and motor changes, creating risk of sensory deprivation or overstimulation. Trends in sensory-based interventions demonstrate decreased unwanted behaviors in those with cognitive impairment. Champagne and Stromberg (2004) described significant improvement in distress ratings of individuals at inpatient psychiatric hospitals, as well as a significant reduction in seclusion and restraint use at the hospital with use of sensory-based intervention, such as multisensory rooms. They acknowledged the need for person-centered care, individualized sensory diets, and inclusion of occupational therapy when working with sensory-based interventions.

Neurological investigation has recognized sensory stimulation causes activation of cholinergic systems in the brain (Neidl et al., 2016). These systems are involved with increased excitation of neural cells, increased processing abilities, and cellular growth (Picciotto, Higley, & Mineur, 2012). Cholinergic activation involves release of acetylcholine (ACh), a neurotransmitter which is a target for various pharmacological therapies for dementia. Inglis and Fibiger (1995) completed a study with rats, in which novel environments were shown to increase ACh in the hippocampus and frontal cortex. ACh in these regions was also released following auditory, visual, olfactory, and tactile

stimulation. Using 12 adult rats, brain microdialysis was performed. Following baseline assessment, rats were exposed to one of four conditions of auditory, visual, olfactory, or tactile stimulation. Observations of behavior were collected during the 20 minute sensory exposure. In the auditory group, rats responded with a fear response that was habituated within the 20 minutes. Visual stimulation increased exploration, consumatory and grooming behaviors. Olfactory stimulation increased sniffing and burrowing, grooming, consumatory and some sleeping behaviors. Tactile input resulted in freezing behavior and increased alertness. ACh increases in the hippocampus reached significance for visual, auditory, and tactile input. Cortical increases in ACh were significant in auditory and tactile input. Tactile input appeared to create the highest response in both regions. Authors noted similar release of ACh seen in sensory stimulation as compared to pharmacological intervention. All sensory stimuli increased exploratory and locomotive behaviors.

Kong, Evans, and Guevara (2009) explored nonpharmacological interventions targeted specifically at decreasing agitation. A systematic review of nonpharmacological interventions to address agitation was completed. Fourteen articles were included for review. Seven were randomized controlled parallel trials and seven were randomized crossover designs. Sample sizes ranged from eight to 118. Duration was from 10 minutes to one year. Nonpharmacological interventions included: aromatherapy, thermal bath, calming music and hand massage, simulated presence, pet therapy, rocking chair, therapeutic recreation, bright light, behavior management, abilities focused morning care, stimulation-retreat program, ADL intervention, and way finding training. The studies related to sensory interventions found significant difference in agitation indicating

moderately beneficial effects. Social contact, activity interventions, environmental modification with caregiver training, combination therapy, and behavioral therapy had no significant influence on agitation. Of the seven groups of interventions, sensory intervention was the only nonpharmacological intervention which was statistically significant in decreasing agitation.

Utilization of sensory-based interventions for people with dementia as a nonpharmacological approach has anecdotal and preliminary evidence to elicit improved behavioral regulation, increased environmental engagement, and enhanced care partner interactions (Moore & Henry, 2002; Woo & Leon, 2013). Yet, implementation and use of sensory-based interventions in dementia care is not well-understood (Boecker et al., 1999; Geurts & Vissers, 2012; Heller, 2002; May-Benson, 2009; Rhodus & Hunter, 2017). Collective evidence on sensory-based interventions lacks sensory-based assessment, individualization of intervention, use of protocols, and is plagued with methodological errors creating mixed results (Letts et al., 2011; Miller, Coll, & Schoen, 2007; Parham et al., 2007; Strom, Ytrehus, & Grov, 2016; Witucki & Twibell, 1997).

To date, the majority of sensory-based intervention studies in dementia care have focused on multisensory environments and single sensory interventions (Collier, McPherson, Ellis-Hill, Staal, & Bucks, 2010; Crowe, 2014). Multisensory environments often elicit simultaneous activation of multiple sensory systems via lights, aroma, music, and/or touch, defined as an intermodal sensory approach. Single sensory, or unimodal, stimulation research investigates effects of interventions targeting one sensory system, including smell (aromatherapy), touch (massage), or sound (music). Evidence supports

use of such interventions but lacks a clear path to theoretical understanding and implementation.

Current evidence does not highlight individual assessment and tailoring of sensory programs to meet the individuals' specific neurological needs (Gonzalez & Kirkevold, 2015). Decreased higher-level cognitive functioning in dementia creates increased dependency on environmental cues obtained through sensory input and processing ability (Behrman, Chouliaras, & Ebmeier, 2014). For this reason, it is crucial to understand the individual's ability to use and react to sensory input. Wilbarger (1997) identified potential risks of hyper- and hypo- arousal of the nervous system if individual assessment is not implemented. Risks associated with sensory hyper- and hypo- arousal have been documented in autism, a condition often associated with sensory processing disorder, to include agitation, apathy, and aggression, but these risks have not yet been investigated in those with dementia (Green & Ben-Sasson, 2010). Utilizing Dunn's Model of Sensory Processing (Dunn & Westman, 1997), Chung (2006) validated the use of the Adult Sensory Profile in determining sensory preferences for adults, geriatrics, and those with dementia. With a valid and reliable assessment, practitioners have an opportunity to utilize effective sensory-based interventions to treat adult and geriatric populations in ways that are tailored to individual preferences and ability (Chung, 2006; Mori, 2015; Witucki & Twibell, 1997).

Existing research on sensory-based intervention lacks consistent use of protocols grounded in neuroscience theories and behavioral frameworks to guide intervention. Selection, duration, and sequence of sensory intervention in dementia care vary throughout the evidence causing difficulty for replicability and widespread use (Lorusso

& Bosch, 2017). Review of evidence surrounding sensory-based interventions across the lifespan also reveals inconsistent protocols and results (Lang et al., 2012; Parham et al., 2007; Pfeiffer, Koenig, Kinnealey, Sheppard, & Henderson, 2011). With increased focus on nonpharmacological interventions in dementia care, effective behavioral protocol development needs to become a priority (Guerriero Austrom et al., 2004). It is imperative that sensory interventions are supported with evidence-based protocols that can be replicated and implemented by care partners.

Reliability of sensory-based intervention in dementia care is limited due to diverse outcome measures used in existing literature (Parham et al., 2007). Outcomes measuring agitation, participation in self-care, cognitive functioning, and depression were included. Without a specific outcome with repeated evidence, conclusive report of validity is difficult. Along with lack of specific outcomes related to sensory-based intervention, there is a lack of homogeneity in participants with a diagnosis of dementia. Severity of dementia was spread across the continuum from mild to severe.

Implementation of current sensory-based literature and approaches in dementia care is primarily in institutional settings. This presents theoretical concerns due to inherent sensory deprivation by nature of institutionalization (Wilbarger, Gunnar, Schneider, & Pollak, 2010). In understanding institutionalized environments, one can recognize opportunities for sensory deprivation, boredom, and limited activity engagement. Cohen-Mansfield et al. (2015) described the top three unmet needs of individuals with dementia, including sensory deprivation, loneliness, and lack of meaningful activity as directly related to agitated behavior. An influx of multisensory environments in dementia care has produced mixed results in its effectiveness (Lorusso &

Bosch, 2017; Padilla, 2011). Most multisensory studies do not involve individualization of sensory input.

Observation of behaviors associated with dementia highlight a lack of easy and efficient intervention options for improved mood and well-being. Care partners offer an opportunity to provide keen insight on lifestyle aspects which may influence behavior. Involvement of care partners also allows for implementation of various interventions with the intent of decreasing unwanted behaviors. Sensory-based interventions are an increasingly popular and effective approach to improved behaviors. Yet, protocols for implementation have not been defined. Sensory-based interventions utilize and manipulate aspects within the surrounding environment in order to alter behavior. For example, music can be played during meal time to promote food consumption, thereby stimulating auditory sensory networks. Another example is seen with aromatherapy, where olfactory sensation elicits behavioral change as in lavender diffusion. Considerations of the environment, along with processes of aging, and environmental gerontology theories offer guiding perspectives to understand the phenomena involved in behavioral and sensory experiences in those with dementia.

Toward an Environmental Gerontology Theoretical Perspective

Over the last six decades, environmental gerontology has evolved theoretically and empirically from numerous disciplines including psychology, geography, sociology, demography, and anthropology (Moore, 2018). Multi-disciplinary perspectives allowed for holistic representation and investigation of the interplay among environmental influences involved in aging. Historical and contemporary evolution of theoretical perspectives provides insight and guidance in creating and maximizing environmental

influences for older adults. Bodily changes often seen in older age, especially cognitive and sensory impairment, can alter environmental interactions.

Kurt Lewin was the first theorist to explore relationships between the person and their environment as it relates to behavior. *Lewin's Equation* defines **Behavior** as a function of the **Person** and **Environment** (Lewin, 1936, p. 12):

$$\mathbf{B} = \mathbf{f}(\mathbf{P}, \mathbf{E})$$

Continuing to explore and refine environmental influence in behavior, psychologist Robert Kleemeier published literature exploring relationships of the aging body and external environment as it relates to human behavior (Kleemeier, 1959). Kleemeier noted that old age is associated with decline of bodily, sensory, and cognitive functioning resulting in changing interactions and use of the external environment. Following Kleemeier's contribution, Lawton and Nahemow (1973) presented The Ecological Model of Aging as seen in Figure 2.1.

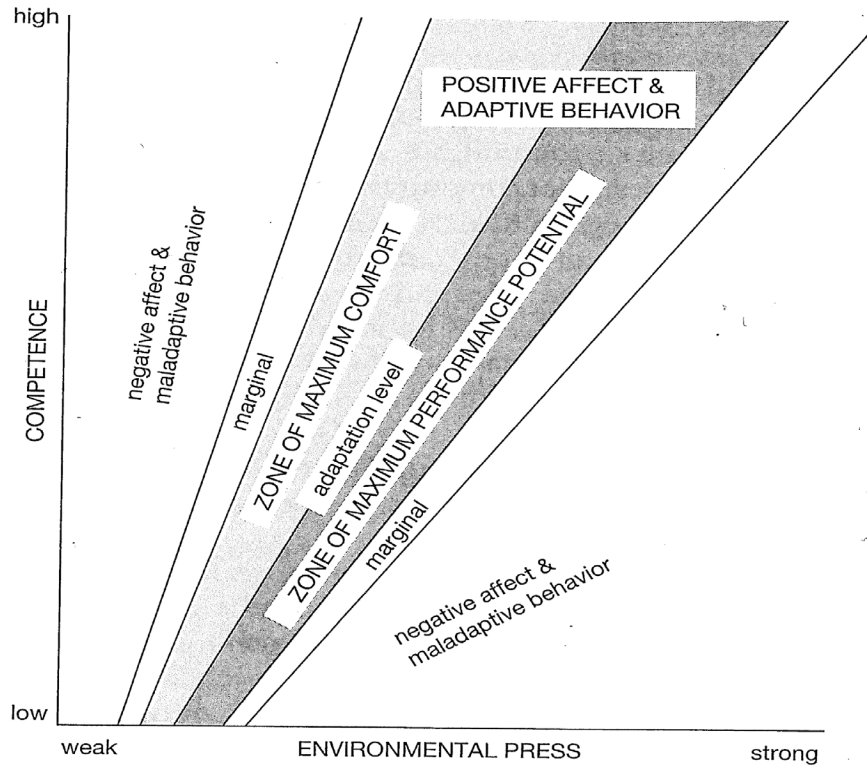


Figure 2.1. Ecological Model of Aging. (Lawton & Nahemow, 1973).

The model depicts behavior as a result of human competence and environmental press. Further, Lawton and Simon (1968) identified what they defined as the environmental docility hypothesis which expressed the relationship between declining competence in aging and the increased impact of environmental factors (Lawton & Simon, 1968, p. 108): the hypothesis is that

...the more competent the organism--in terms of health, intelligence, ego strength, social role performance, or cultural evolution--the less will be the proportion of variance in behavior attributable to physical objects or conditions around him [sic]... With high degrees of competence he will, in common parlance, rise above his environment. However, reduction of competence, or deprived status, heightens his behavioral dependence on external conditions.

Continuing the idea of human competencies and environmental affordance, Kahana (1982) recognized the need for congruence and a ‘goodness of fit’ between the person and the environment. Person-environment fit is a vital concept for well-being, quality of life, and usability of one’s environment as this fit promotes activity and engagement (Iwarsson, Stahl, & Lovquist, 2013).

Lawton and Nahemow (1973) acknowledged the aging body experiences declines in physical and cognitive functioning and late life is often increasingly susceptible to environmental influence. For most aging individuals, environments also change for varying reasons, including need for additional care services, inability to navigate physical features of the home, and advancement in resources available, such as the addition of technology (Brorsson, Ohman, Lundberg, & Nygard, 2011). An example can be seen in the changes to most public bathrooms. There is no longer a switch, lever or button to turn on the light, flush the toilet, dispense soap, turn on and off the water, or to obtain a hand towel because of newly added automatic features. The automatic features of the bathroom offer convenience and ease for those able to quickly adapt to environmental demands, as their bathroom at home likely does not have these same aspects. However, a person who cannot adapt to these environmental changes, such as someone with cognitive impairment, may become frightened if the automatic light does not turn on or frustrated when they cannot locate the lever to turn on the water faucet.

Physical features of an environment can worsen functional impairments if there is incongruence of usability. For example, a person who is independent with wheelchair mobility will face impairment when faced with a set of stairs. But, when stairs are accompanied by a ramp, the person can continue to be independent in mobility.

Modifying environmental conditions to acknowledge and compensate for this may promote independence and success in the environment. With attention to interactions among the person, environment, and desired activity, also known as occupation, then maximized environmental usability can be achieved. Law and colleagues (1996) established the person-environment-occupation (PEO) model to help depict such interactions, Figure 2.2.

Figure 2.2. Person-Environment-Occupation Model. (Law et al., 1996).

The theory employs a transactional model of occupational performance. Occupational performance occurs when the person, environment, and occupations combine to create opportunity for engagement. The transactional view indicates that the person, their behaviors, and the environment are interdependent and cannot be separated from contextual, temporal, physical, or psychological factors. The three components can exist independently, yet, there is interplay among the three for optimal functioning. Christiansen, Baum, and Bass-Haugen (2015) later added performance as a fourth component to enhance the importance of individual factors within the understanding of the person-environment-occupation model.

Law (1991) defined environment as “contexts and situations which occur outside individuals and elicit responses” including personal, social, and physical settings. The

person is seen as a holistic entity encompassing all their attributes including self-concept, personality, background, and personal history. The environment is also broadly defined to include cultural, socio-economic, institutional, physical, and social aspects. Nested together, activity, task, and occupation involve units of activity which occupy one's time. Person, environment, and occupation is portrayed through three overlapping circles with the center being occupational performance, the outcome of the transaction.

During the same decade as the release of Lawton's (1973) ecological model, Bronfenbrenner (1979) published the ecological systems theory, Figure 2.3. His theory depicts nested levels of environmental influence based on proximity to the person. Levels of influence include micro (personal and intimate in proximity) and macro (social, political, or other larger influences) sources. These levels influence individuals throughout their life course (Alwin, 2012). Life course theory echoes tenants of the ecological systems theory. From the time of conception, the era that one is raised, and the cohort in which they move throughout time, micro and macro environmental factors shape development, access, and opportunity (Barker, Eriksson, Forsen, & Osmond, 2002).

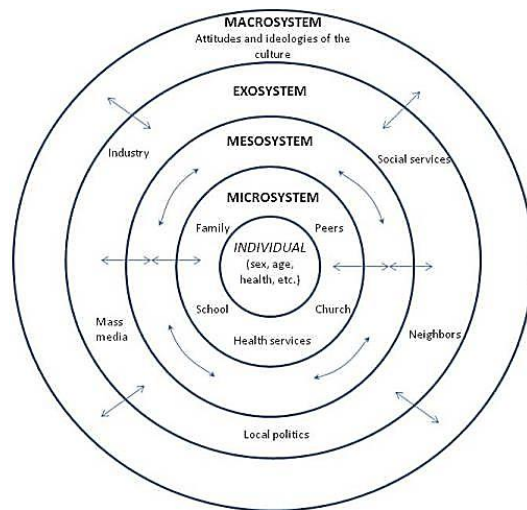


Figure 2.3. Ecological Systems Theory. (Bronfenbrenner, 1979)

Rowles (1978) contributed to environmental gerontology through his awareness and insight into the experiences of older adults within place. His hypothesis of changing emphasis added dimensional exploration of being in place and the changing emphasis of meaning and emotion observed throughout aging (Rowles, 1978, 1991). He identified a temporal component within the multi-dimensional exploration of meaning and place, which evolves and selectively intensifies with time. Recognition of the meaning of place for older adults is paramount in consideration of relocation throughout late life for emotional well-being and quality of life (Rowles & Bernard, 2013; Rowles, 2018). Environments evolve from space to place throughout a person's life course via the development of attachment and meaning (Rowles & Watkins, 2003).

Geographer, Cutchin employed pragmatism in describing person-place relationships (Cutchin, 2001). He describes relationships not as cause and effect, but as evolving as one entity. Continual transactions between the person and their environment create inseparable linkage whereby forming experiences. Cutchin's contributions create an image of the person nested within their surrounds with assimilated belonging swaying to instabilities of change and adjusting negotiability (Cutchin, 2018).

The importance of home environment to the well-being of older adults was documented by Iwarsson et al (2005). Connections with home environments are paramount to well-being in late life. Wahl, Iwarsson, and Oswald (2012) present an integrative model of components involved in aging well, including person-environment resources, cognitive development, life-course factors, and historical context. Numerous supports promote the value of environments and its significance for the well-being of

older adults. But, there continues to be limited consideration of aging well with cognitive impairment, and the relationship with the environment.

Inferences from evolving theories of environmental gerontology related to competencies, congruence, transactions, and meaning reflect challenges in cognitive and sensory decline associated with aging. As cognition deteriorates, reliance on environmental support increases of necessity. Cohen and Weisman (1991) established eight environmental attributes needed to support those with impaired cognition and dementia termed therapeutic goals. These focus on safety, awareness and orientation, privacy, sense of control, functional participation, socialization, regulation of environmental stimulation, and personhood. Exploration of environmental frameworks and interventions provide understanding of potential supports which may prove useful in caring for those aging with cognitive impairment. Involvement of the physical and social environments, as well as encouraged activity participation allows for maximized well-being and adaptive responses.

Rowles and Teaster (2016) described environmental supports and care for aging individuals with decreasing function as a long-term care continuum. The long-term care continuum includes informal and formal care for health, personal care, and social support. At one end of the continuum is community-based care, informal care in the home, and formal care services provided in the home. Moving toward the other end of the continuum are levels of increasing formal care and relocation. Institutional levels of care can include independent living facilities, personal care facilities, group homes, assisted living facilities, and skilled nursing facilities. Medical care in hospitals can occur throughout the continuum. Each level of institutional care has specific

requirements of function and independence with skilled nursing facilities as the least independent. Hospice care is often the end of the continuum providing palliative and end-of-life care.

Maladaptive behaviors associated with dementia can sometimes be attributed to environmental incongruence with the individuals' sensory needs, as defined in environmental press theory (Calkins, 2004; Lawton & Nahemow, 1973). Our environment is perceived through the ability to acquire and process sensory information. For example, physiological changes in normal aging often cause sensory receptor changes seen in decreased hearing and vision (Humes, 2015). Onset of cognitive impairment also has changes in how the individual seeks out and processes sensory stimulation. Apathy, a symptom commonly seen in dementia, decreases engagement in activity and environmental interaction potentially leading to sensory deprivation (Behrman, Chouliaras, & Ebmeier, 2014). Additionally, under-stimulating environments, such as historical long-term care settings, can lead to external sensory deprivation (Schanberg & Field, 1987; Wilbarger, Gunnar, Schneider, & Pollak, 2010). Sensory deprivation and overstimulation can be attributed to maladaptive behaviors as a person seeks stimulation or withdraws from sensory input. Cognitive impairment also often decreases the ability to verbalize sensory discomfort or needs. As a result, an increase in agitation, restlessness, aggression, or its antithesis, apathy, may be seen as a consequence of personal incongruence with the sensory environment. If demands of the environment are not compatible with sensory processing abilities and preferences, then the individual may not behave optimally. An environmental (physical and social) and behavioral, nonpharmacological approach may be most effective in promoting ideal

sensory experiences whereby decreasing BPSD (Cummings et al., 2014; Fitzsimmons, Barba, & Stump, 2014; Kovach, 2000).

Conclusion

Living in a supportive environment can have a dramatic influence on a person's sensory, cognitive and behavioral performance as well as their quality of life.

Conversely, an unsupportive environment has been shown to impede function, hasten cognitive decline, and promote maladaptive behaviors. Attention to contextual influences is crucial in promoting quality of life for those impacted by dementia.

Dementia presents with numerous challenges infiltrating all aspects of life for the person with the disorder and their caregivers. Exploration and creation of avenues for understanding offer hope toward enhanced quality of life and elimination of such heavy burden on all levels of care. Experiences throughout life are possible due to the intricate matrix of sensation and perception. Aging normatively diminishes abilities to collect sensory information, therefore altering perceptions of the surrounding environment. Neurological disease and impairment further reinforce deficits in sensorial acquisition and utilization. Borrowing from environmental and behavioral theories, a relationship can be seen in abilities to perceive the environment and in associated behavior. The lack of sensory-based theories and conceptual frameworks in geriatrics hinders advancing knowledge and research. Further work is needed to illuminate avenues for utilization clinically and in research.

Sensory-based interventions in home or community settings for individuals with dementia are rarely described in the literature. With an aging population who wish to remain home until death, evidence from studies conducted in non-institutional settings

can support interventions which enhance behavior and decrease caregiver burden (Wheatley & Baker, 2007). This study focuses on non-institutional settings. Evidence investigating caregiver involvement in sensory interventions is limited despite dependency on caregivers to provide routine sensory interventions. Environmental assessment and caregiver involvement is crucial for the success of sensory interventions and behavioral nonpharmacological management of individuals with dementia remaining at home (Marshall, Myers, & Pierce, 2017; Shelton, Orsulic-Jeras, Whitlatch, & Szabo, 2017)

For a holistic scientific understanding of the lived experience of behavioral expression as it relates to environmental influences, multiple methods are needed. The following research projects have been created to reflect the need for multiple avenues of data collection, as well as incorporate various levels of detail regarding behaviors and the lived experiences of adults with cognitive impairment living in community settings. The first, which examines the relationship of behaviors observed in autism spectrum disorder and dementia will allow possible insight into overlap of behaviors which may be related to sensory processing impairment as seen in both conditions. The second will explore behavioral manifestations of community-dwelling adults with cognitive impairment or dementia in the context with the relationship of their primary care partner. Finally, data obtained are incorporated and reflected in an emerging model of the relationship among environment, behavior, and sensory processing in community-dwelling adults with dementia.

CHAPTER 3. BEHAVIORS CHARACTERISTIC OF AUTISM SPECTRUM DISORDER IN A GERIATRIC COHORT WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA

Introduction

In this chapter, the first of the three specific aims of the dissertation is addressed to examine the relationship of behaviors observed in autism spectrum disorder and dementia. Literature is increasingly linking similarities of behavioral phenotypes in those with dementia and autism. But, the behavioral relationship of ASD and dementias has not yet been identified.

Specific areas of neuroanatomical involvement may manifest similar behavioral phenotypes as seen in ASD and FTD (Baez & Ibanez, 2014; Geurts & Vissers, 2012; Mendez, Shapira, & Miller, 2005; Midorikawa & Kawamura, 2012; Raznahan et al., 2010). Both conditions have pathological involvement of the frontal and temporal lobes of the cerebral cortex. These areas are active in sensory processing and perception formation, and impairment may occur as a result of neuropathology. FTD has been said to mirror symptomology of ASD explicitly.

Cholinergic systems, which are routinely targeted by medications for dementia, have recently been used to successfully manage behaviors of children with ASD (Sokol et al., 2006; Rossignol & Frye, 2014; Zeidan-Chulia et al., 2014). Sensory stimulation has also been shown to significantly elevate ACh levels in rats, which again, may be a possible binding factor in similar behaviors of two conditions with impaired cholinergic systems (Inglis & Fibiger, 1995; Picciotto, Higley, & Mineur, 2012).

These factors do not illuminate causation of behavioral similarities but do raise the possibility of potential overlap among mechanisms of impairment in autism and a

variety of late-life degenerative dementias. To date, FTD is the only dementia-type known to present with behaviors characteristic of ASD. There is little known regarding frequency of behavior, types of behavior, and specific comparison to ASD diagnostic criteria. The current study sought to explore presence of ASD-type behaviors in participants with mild cognitive impairment (MCI) or dementia in a community-based cohort.

Methods

Participants. Participants in this study were drawn from the University of Kentucky's Alzheimer's Disease Center (UK ADC) longitudinal cohort (Schmitt et al., 2012). Participants consent to extensive annual cognitive and clinical examinations and enroll at any point in the cognitive continuum, but are preferentially enrolled while still cognitively normal. Full details of annual assessments and inclusion/exclusion criteria have been described elsewhere (Schmitt et al., 2012). Each participant in the cohort has a study partner, who is usually a caregiver. ADC participants in the current study met inclusion criteria of diagnosis of MCI or dementia, a caregiver willing to participate, and a full clinical assessment within 24 months of current study participation (n=330). This study was approved by the University of Kentucky Institutional Review Board.

Diagnostic criteria. The diagnosis of MCI was determined according to the consensus guidelines developed by the Second International Working Group on MCI (Winblad et al., 2004) and further adopted by the National Institute on Aging-Alzheimer's Association Workgroup on Diagnostic Guidelines for Alzheimer's Disease as follows: (1) a cognitive complaint by the subject or informant, or evidence for longitudinal decline on cognitive test performance (at least 1.5 standard deviation

decline); (2) generally intact global cognition; (3) no or minimal functional impairment; (4) not demented according to DSM-IV criteria. The diagnosis of dementia was based on the criteria set forth by the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) (American Psychiatric Association, 1994). Cause-specific dementia criteria include the Joint Working Group of the National Institute of the Neurologic and Communication Disorders and Stroke-AD and Related Disorders (NINCDS-ADRDA) criteria for AD (McKhann et al., 1984), NINDS-AIREN criteria for vascular dementia (Roman et al., 1993), AHA/ASA criteria for MCI due to cerebrovascular disease (VCI) consensus criteria for frontotemporal dementia (Neary et al., 1998), and the 2005 Dementia with Lewy bodies (DLB) Consortium revised criteria (McKeith et al., 2005).

Measures. Study partners and caregivers of UK ADC participants, including spouses/partners and adult children of participants, were asked to complete the Gilliam Autism Rating Scale-Second Edition (GARS-2) (Gilliam, 2006). GARS-2 identifies frequency of ASD-type behaviors and is well established for screening and diagnosis of autism in pediatric and adolescent populations (Gilliam, 2006; Montgomery, Newton, & Smith, 2008). The assessment is a reliable and valid measure with normative data for individuals aged 3-22 years (Gilliam, 2006; Montgomery, Newton, & Smith, 2008). GARS-2 was chosen despite lack of validation for older adults because there is not a validated observation-based tool assessing autism-type behaviors for those in late life. The GARS-2 presents with face validity promoting use in this study. The tool is used here as means for exploration and identification of behaviors characteristic of autism in a sample of older adults with cognitive impairment, not for diagnostic purposes. Other assessments used for screening autism were evaluated but deemed inappropriate for this

study. The Autism Spectrum Quotient (AQ) was not selected because it is most often administered directly to the person via interviewing without caregiver involvement (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). Our sample is known to have cognitive impairment and possible communication deficits as a result and is not well-suited for the AQ assessment. Additionally, the Social Responsiveness Scale, another assessment often used to diagnose ASD, was not selected due to its limited scope of behavioral assessment. This study sought to explore a breadth of behaviors characteristic of autism as observed in our older adult cohort.

The GARS-2 questionnaire (APPENDIX C) was mailed to study partners of UK ADC participants. To complete the GARS-2, study partners ranked 42 objective statements of characteristic ASD behaviors based on observable frequency. Examples of behaviors included: staring at hands, objects, or items; withdrawing from social groups; engaging in ritualistic behavior; and failure to ask for things he or she wants. Each item was ranked on an ordinal scale from 0-3 (0 indicates the behavior is never observed, 1 is seldom observed, 2 is sometimes observed, and 3 is frequently observed). The assessment is grouped into three subscales: behaviors, communication, and social interaction. Standard scores of the subscales were combined and used to determine the Autism Index Score (AIS) (Gilliam, 2006). AIS were categorized according to GARS-2 guidelines as follows: ‘Autism Possible/Very Likely’ ($AIS \geq 70$) and ‘Autism Unlikely’ ($AIS < 70$). We note that to date there is no evidence establishing normative data for characteristics of ASD in the geriatric population. Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975), Clinical Dementia Rating (CDR) Sum of Boxes

(CDRSUM) (Hughes, Berg, Danziger, Coben, & Martin, 1982; Morris, 1993), and Geriatric Depression Scale (GDS) (Yesavage et al., 1983) were used to characterize severity of global cognitive impairment and assess comorbid depression (Pernecky et al., 2006).

Statistical analysis. Demographic and clinical features of ADC participants classified as Autism Possible/Very Likely and Autism Unlikely based on caregiver responses to the GARS-2 were compared using t-test or chi-square tests. Participant characteristics associated with AIS were further evaluated using logistic regression, where the outcome of interest was group membership (Autism Possible/Very Likely vs. Unlikely), and linear regression, where the outcome of interest was the AIS. Backward selection was used to identify the most parsimonious model, using stepAIC() function of the MASS package in R (Lüdecke, 2018). To further assess the relationship between ASD-type behaviors and cognitive impairment, AIS was compared between CDR global score (i.e., 0, 0.5, 1, 2, or 3) and diagnosis (i.e., MCI vs. dementia) using two-way ANCOVA and Tukey's HSD pairwise comparisons to compare CDR global scores (Lüdecke, 2018). Age, sex, and education were included as covariates. Statistical significance was set at 0.05, and all statistical analyses were performed using the R 3.5.1 console (Lüdecke, 2018).

Results

One-hundred and forty-eight questionnaires were returned out of 330 that were sent. Data from six respondents were excluded because the participants' most recent clinical assessment was more than two calendar years from the time of GARS completion, leaving 142 surveys for analysis. There were no significant differences

between the UK ADC participants whose caregivers did or did not respond to the survey in basic demographics or clinical status (age, gender, education, CDR sum of boxes, or dementia diagnosis). Aside from trend differences in age, the six excluded ADC participants did not differ from included participants on basic demographics or clinical status. Demographic and clinical characteristics of the study sample are presented in Table 3.1. None of the participants were known to have a diagnosis of autism or ASD prior to survey completion.

Table 3.1. Participant Characteristics

Continuous Variables ^a	All Participants		ASD Unlikely		ASD Possible/Likely		<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age at GARS	79.84	8.39	80.41	8.00	76.96	9.87	0.126
Age of Cognitive Impairment Onset	75.67	8.98	76.65	8.25	71.14	10.90	0.034
Years of Education	16.35	3.43	16.28	3.33	16.70	3.97	0.641
MMSE	22.00	7.39	22.95	6.33	16.50	10.41	0.014
GDS	2.26	2.24	2.13	2.14	2.54	1.27	0.330
CDR sum of boxes	5.08	5.05	4.23	4.28	9.50	6.38	0.001
Years Since Diagnosis	4.44	3.62	4.17	3.24	5.73	4.90	0.166
Years Between Visit & GARS	0.42	0.63	0.40	0.60	0.52	0.79	0.501
Discrete Variables ^b	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>p</i>
Female	67	0.47	56	0.47	11	0.48	0.946
Caucasian	133	0.94	112	0.94	21	0.91	0.612
≥1 Copy of ApoE4 ^c	35	0.27	28	0.26	7	0.37	0.314
MCI Diagnosis	48	0.34	46	0.39	2	0.09	0.005
Dementia	94	0.66	73	0.61	21	0.91	0.005

Diagnosis

Note: *GARS* = Gilliam Autism Rating Scale (2nd Edition); *ASD* = Autism Spectrum Disorder; *MMSE* = Mini-Mental Status Exam; *GDS* = Geriatric Depression Scale; *CDR* = Clinical Dementia Rating; *MCI* = Mild Cognitive Impairment.

^aT-tests between ASD Unlikely and ASD Possible/Likely groups.

^b χ^2 -tests between Unlikely and Possible/Likely groups.

^cApoE data available for only 128 participants; 109 in ASD Unlikely and 19 in ASD Possible/Likely.

As shown in Figure 3.1, 60.9% (14 of 23) of the respondents in the Autism Possible/Very Likely group were diagnosed as having dementia due to AD, including three with mixed AD and vascular dementia (VD). The remaining participants in the Autism Possible/Very Likely with non-AD dementias include FTD (n = 3), DLB (n = 2), and VD (n = 2). One participant diagnosed as having MCI and one diagnosed as having VCI also scored in the ‘Possible/Very Likely’ range, suggesting the presence of behaviors characteristic of ASD with milder forms of cognitive impairment, which has not been previously described.

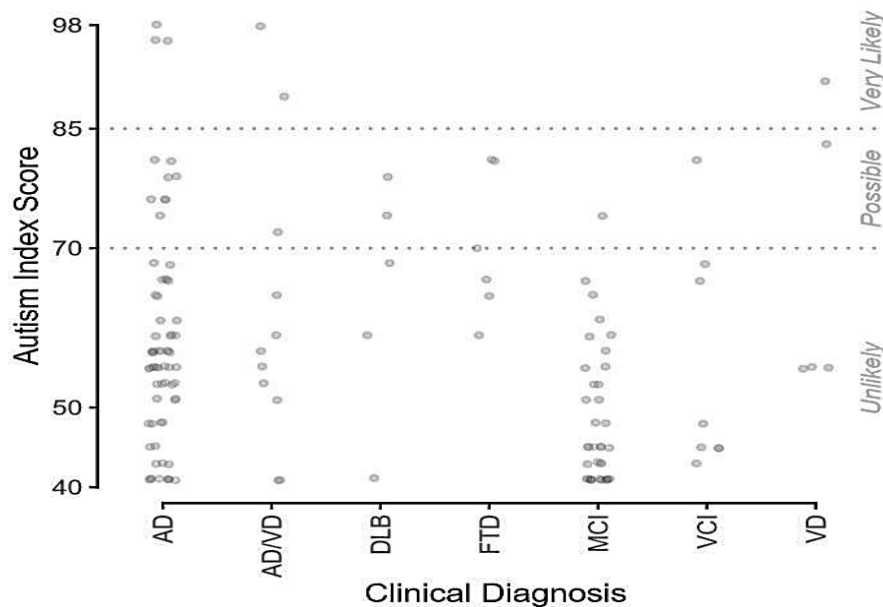


Figure 3.1. AIS throughout diagnoses.

Between-group comparisons of the Autism Unlikely and Autism Possible/Likely groups demonstrated associations of high AIS scores with younger age of onset of cognitive impairment and increased severity of impairment (Table 3.1). This result tended to persist when the respondents were restricted to just those whose study partner was a person with dementia (Possible/Very Likely, $n=21$ and Unlikely, $n=74$): 71.8 ± 8.8 vs. 76.1 ± 10.7 ($p = 0.10$). ADC participants rated in the Possible/Very Likely range were also younger at the time of the GARS-2 survey and more likely to have a dementia diagnosis relative to the Unlikely group (Table 3.1). As expected, participants in the Autism Possible/Very Likely group had significantly higher subscale scores in all three domains: social interaction, communication, and stereotyped behaviors (Table 3.2). Scores on the behavior subscales (behavior, communication, social interaction) were lowest overall in both groups (Table 3.2). Collected from the GARS-2, the most frequently observed ASD-type behaviors are shown in Figure 3.2.

Table 3.2. Between Group Comparisons of GARS-2 AIS and Subscales

	All Participants		ASD Unlikely		ASD Possible/Likely	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
AIS	56	14	51	8.	81	8.
Behavior	.58	.05	.68	51	.96	56
Communication	2.	1.	2.	1.	5.	1.
Social Interaction	76	77	24	31	48	31
	3.	2.	2.	1.	8.	2.
	62	73	71	72	30	10
	3.	2.	2.	1.	7.	2.
	54	51	72	55	78	26

Note: AIS = Autism Index Score; ASD = Autism Spectrum Disorder. For group comparisons, all $ps < 0.001$

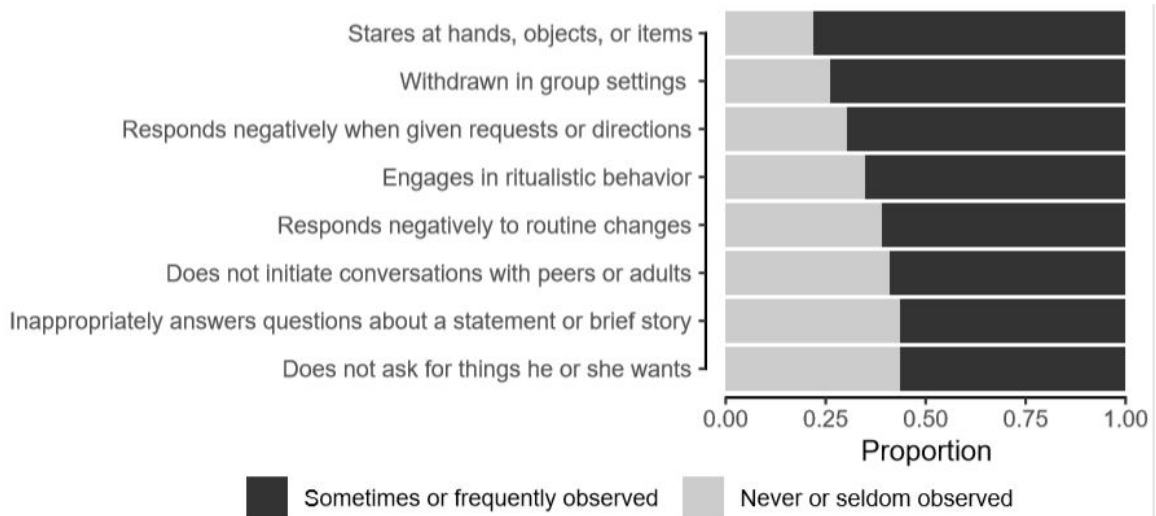


Figure 3.2 Frequently observed behaviors.

In the full multiple logistic regression model, where autism being Possible/Very Likely vs Unlikely was the dependent variable, only CDRSUM (OR for 1-point increase in CDRSUM = 1.17, 95% CI [1.00, 1.38], $p = 0.055$) approached significance at the 0.05 level. In the reduced model, CDRSUM (OR = 1.17, 95% CI [1.07, 1.28], $p < 0.001$) and age at onset of cognitive impairment were retained (OR = 0.95, 95% CI [0.90, 1.01], $p = 0.09$), though age at onset only trended toward significant. In the full linear regression model with AIS as the dependent variable, CDR sum of boxes was the only significant predictor (for a 1-point reduction in CDR, $\beta=1.51$, $SE(\beta)=0.35$, 95% CI [0.81, 2.20], $p<0.0001$). In the reduced model, CDR sum of boxes ($\beta=1.51$, $SE(\beta)=0.30$, 95% CI [0.92, 2.10], $p<0.0001$) and age ($\beta=-0.27$, $SE(\beta)=0.14$, 95% CI [-0.54, -0.01], $p = 0.05$) were retained.

As is evident in Figure 3.3, there were significant main effects of CDR global, $F(4, 132) = 9.085$, $p < 0.001$, $\eta^2 = 0.21$, 95% CI [0.11, 0.35], and age, $F(1, 132) = 3.915$, $p = 0.05$, $\eta^2 = 0.02$, 95% CI [-0.02, 0.08]. There was a trend effect of diagnosis, $F(1, 132) = 3.584$, $p = 0.06$, $\eta^2 = 0.02$, 95% CI [-0.01, 0.06] and no effect of sex or education, $ps >$

0.68. Pairwise comparisons showed that AIS was significantly higher on CDR global scores of 1, 2, and 3 compared to CDR 0.5, $ps < 0.02$. CDR 3 was also significantly higher than CDR 0, $p = 0.02$. All other comparisons were nonsignificant, $ps > 0.11$. *Post hoc* results were similar when excluding the four participants with CDR 0.

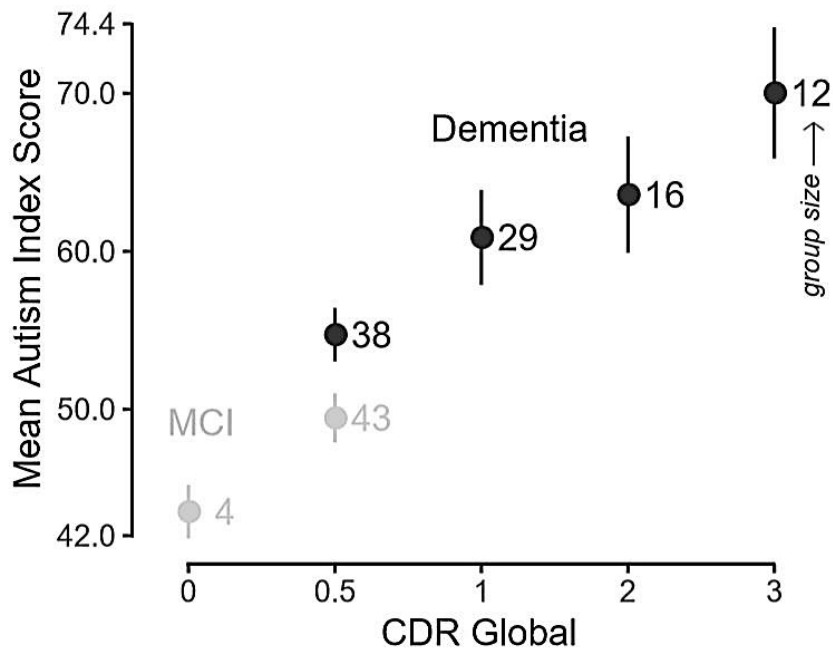


Figure 3.3. AIS across CDR scores.

Discussion

In this study, we found that ASD-type behaviors are commonly reported by caregivers of community-dwelling persons with cognitive impairment and dementia. Based on AIS scores, 16.2% of participants would be classified as Autism Possible/Very Likely. Dementia due to AD was the primary or contributing diagnosis for 61% of participants with behaviors characteristic of ASD (i.e., Autism Possible/Very Likely). Participants with other types of dementia (FTD, DLB, VD) were also identified as having ASD-like behavior. While previous research identified increased behavioral

characteristics of ASD in individuals with FTD (Baez & Ibanez, 2014; Geurts & Vissers, 2012; Mendez et al., 2005; Midorikawa & Kawamura, 2012), prior reports have not explored a possible relationship with other dementias, such as AD. Additionally, characteristics of ASD were reported for some participants who carried diagnoses of MCI. These findings suggests that behaviors characteristic of ASD may emerge as a result of neurodegenerative processes because the frequency of ASD-like behaviors increased with advancing severity of cognitive impairment.

Age of onset of cognitive symptoms was significantly earlier in the Autism Likely group than those in the Autism Unlikely group. It is possible that lifelong subclinical ASD may manifest only when neurological function is compromised by the development of even the mildest of cognitive pathologic insults in older adulthood (Caselli et al., 2018; Hilde, Geurts, & Vissers, 2012; Midorikawa & Kawamura, 2012). Pathological overlap in neuroanatomical structures and systems in ASD and dementia may create earlier behavioral burden in the presence of degenerative disease, as evidenced by age of onset of cognitive impairment and presence of behavioral symptoms (Hornberger et al., 2008; Moreau, Rauzy, Viallet, & Champagne-Lavau, 2016; Rossor, Iversen, Reynolds, Mountjoy, & Roth, 1984). Given the limited sample size, these results should be interpreted cautiously.

Consistent with the extant literature, younger age was also associated with increased cognitive impairment severity (Rossor, Fox, Mummery, Schott, & Warren, 2010). Savva and colleagues (2009) found similar patterns of heightened impairment at younger ages when looking at neuropathological onset of Alzheimer's disease, cerebral atrophy, and cerebrovascular disease. Neurochemical abnormalities have also been

identified to be most widespread and severe in patients with dementia in their 7th and 8th decade of life compared to later ages (Rossor et al., 1984). The current study revealed that increased severity of impairment is related to increased likelihood of ASD-like behaviors. Widespread and global cortical involvement in both ASD and neurodegenerative disease may produce similar behavioral features that are responsible for the identification of characteristics of ASD in our cohort (Courchesne, Redcay, Morgan, & Kennedy, 2005; Kim & Lord, 2013; Powell et al., 2017; Rossor et al., 1984).

The GARS-2 uses three subscales (behavior, communication, and social interaction) to determine the AIS. Interestingly, this study demonstrated high involvement of all three subscales in those with dementia who engage in behaviors associated with ASD. High involvement of all subscales may be indicative of widespread, overlapping neuroanatomical involvement in both conditions (Courchesne et al., 2005).

Several limitations inherent in the current study deserve comment. First, the use of a retrospective cross-sectional design can show association, but causality cannot be inferred. Limitations also include response and retrospective reporting biases given the nature of the GARS-2. The survey instrument, while validated in childhood autism has not been validated in older adults. In addition, the response rate of 58% may indicate self-selection bias among the respondents. Finally, the study participants were predominately European American, with high educational attainment living in one geographical region, limiting generalizability of the study findings.

Despite these weaknesses, there are several strengths of this study. It is, to our knowledge, the first investigation of similarities among behaviors characteristic of ASD

(behavior, communication, and social interaction) and late-life neurodegenerative disease including AD in a cohort without diagnosed ASD. Utilization of caregiver reporting and symptom assessment has been established as an effective and reliable tool for symptom reporting in dementia care (Jicha, 2011). Despite the lack of a validated measure to assess behaviors characteristic of ASD in late-life dementia, our use of a widely-used and valid tool (GARS-2) specific to autism, strengthens the present findings.

These data demonstrate that late-life degenerative dementias and ASD share common behavioral symptoms across dementia etiologies and across the cognitive continuum in some individuals. Again, while causality cannot be inferred from these findings, it is intriguing to hypothesize that shared neuroanatomical substrates and pathological underpinnings are responsible for the associations seen in this study. Given the significant morbidity and caregiver burden associated with behavioral and psychological symptoms in ASD and dementia, an enhanced understanding of such behavioral expression may aid in the identification of effective interventions for late-life degenerative dementias. The emergence of behaviors typically associated with ASD in degenerative cognitive impairment deserves further study as science moves forward in seeking an integrated understanding of the behavioral sequelae of neurologic dysfunction across the lifespan.

Conclusion

In this chapter we have demonstrated a significant overlap in behaviors characteristic of autism in an older adult cohort with cognitive impairment. These results confirm hypotheses observed in the field while treating geriatric patients with dementia. It is also now evident that ASD behaviors are more prevalent in later stages of dementia,

at which point quality of life is greatly hindered and caregiver burden is at its peak. Having dealt with this, we turn to specific aim 2 which will attempt to validate this study's findings using a qualitative, observation-based approach. Sensory processing preferences will also add depth to these findings.

CHAPTER 4. BEHAVIORAL EXPRESSION IN COMMUNITY-DWELLING OLDER ADULTS WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA

Introduction

Exploration of behaviors associated with dementia offers the potential for enhanced understanding of causes and potential techniques for reducing challenging behaviors. Patterns of behaviors observed in dementia have been identified as resembling behaviors characteristic of autism, a neurodevelopmental condition (Baez & Ibanez, 2014; Geurts & Vissers, 2012; Mendez, Shapira, & Miller, 2005; Midorikawa & Kawamura, 2012). Autism, similar to dementia, has a behavioral phenotype associated with communication deficits, aggression, altered social interactions, and repetitive behaviors.

In addition to observable behaviors, both autism and dementia have deficits in sensory processing abilities (Champange & Stromberg, 2004; Crowe, 2014; Miller, Coll, & Schoen, 2007). When sensory processing abilities are irregular, individuals have difficulty processing environmental stimuli, which can lead to non-typical behaviors, such as avoidance, aggression, apathy, and decreased communication (Chung, 2006; Kovach, 2000). Minimal evidence exists depicting sensory processing patterns and associated behavioral expression in individuals with dementia. Similarly, relationships between observed behaviors in autism and dementia have not been fully examined through scientific inquiry. In-depth investigation of these relationships may allow researchers to identify behavioral approaches to promote increased quality of life for the individual with dementia, decrease caregiver burden, and decrease the need for institutional care.

As established in chapter 3, behaviors characteristic of autism are present in those with mild cognitive impairment or dementia. Given the limited nature of data collection offered by cross-sectional design, this study is framed to qualitatively assess behaviors reported on the GARS-2 form in some participants identified in chapter 3. Sensory processing patterns and preferences are also assessed in relation to behavioral expression because of the possible linkage between ASD and dementia. The purpose of this study is to investigate environmentally-related behavioral manifestations of dementia in community-dwelling adults.

Methods

A home-based observational study was undertaken. This study involved interviewing a sample of persons with cognitive impairment or dementia and their care partners in a home setting. Assessment of sensory processing patterns for the person with cognitive impairment was completed to better understand personal sensory preferences. Observations were also completed in the home to collect data on environmental features of the home and behavioral manifestation of the person with cognitive impairment.

Participants. This study was designed to observe and confirm behaviors characteristic of autism in adults with MCI or dementia who participated in the study as described in chapter 3. All participants were active in the University of Kentucky Alzheimer's Center longitudinal study and included in their participant database. Demographic information, cognitive test results, contact information, as well as information on the informant/care partner relationship were collected from the database.

From the participants in the first study, those who scored in the autism likely/probable group according to the GARS-2 (n=17) were contacted for recruitment in

this study. Because of this small n, recruitment also included participants who completed the GARS in 2017 (n=92). This included individuals with a range of reported ASD behaviors from no ASD behaviors to ASD likely/probable. All 92 Sanders Brown Center on Aging (SBCoA) participant charts were reviewed for inclusion criteria, and 37 people were contacted for participation in this study.

Participants across the cognitive impairment continuum with clinical diagnosis of mild cognitive impairment or dementia were invited for participation. Other inclusion criteria were that the individuals were aged 55 or older, deemed appropriate for participation by an MD and/or social worker at SBCoA, were living at home with a care partner who was willing to participate in this study, and that both participants of the dyad unit were able to speak and understand English. Residence in institutional or facility-based care was an exclusion criterion in order to focus on experiences of those living with cognitive impairment in the community. There were no exclusion criteria based on sex, race, or ethnic groups. Dyads, the participant with cognitive impairment and their informant/care partner, were the unit of analysis for purposes of data collection.

Procedures. Approval was obtained by the University of Kentucky Institutional Review Board (IRB) to ensure safety and appropriateness of the current study. Diagnosis of mild cognitive impairment or dementia creates significant cognitive impairment which may interfere with ability to provide informed consent (Dewing, 2002). Because of this, informed consent was described to each participant and their care partner simultaneously for maximum communication of the criteria for consent and participant understanding of what their participation would entail.

Data collection used a variety of qualitative approaches to best triangulate sources of data (Creswell, 2013; Kvale, 1994). Research in gerontology and with participants with dementia often uses a qualitative approach offering enhanced opportunity to personalize data collection for a population that is marginalized due to communication deficits (Onwuteaka-Philipsen, W. Pasman, van Gennip, Oosterveld-Vlug, & Willems, 2014; Phoenix, 2018). Data included interviews with primary informants/care partners, multiple field observations within each participant's home environment, and completion of the Adult Sensory Profile by the person with cognitive impairment. Assistance in completing the form was offered if the participant had questions or requested help. The study design is illustrated in the concept diagram below (Figure 4.1) which is followed with written description of its various components.

Study Design: Investigation of behaviors characteristic of ASD in individuals with mild cognitive impairment or dementia

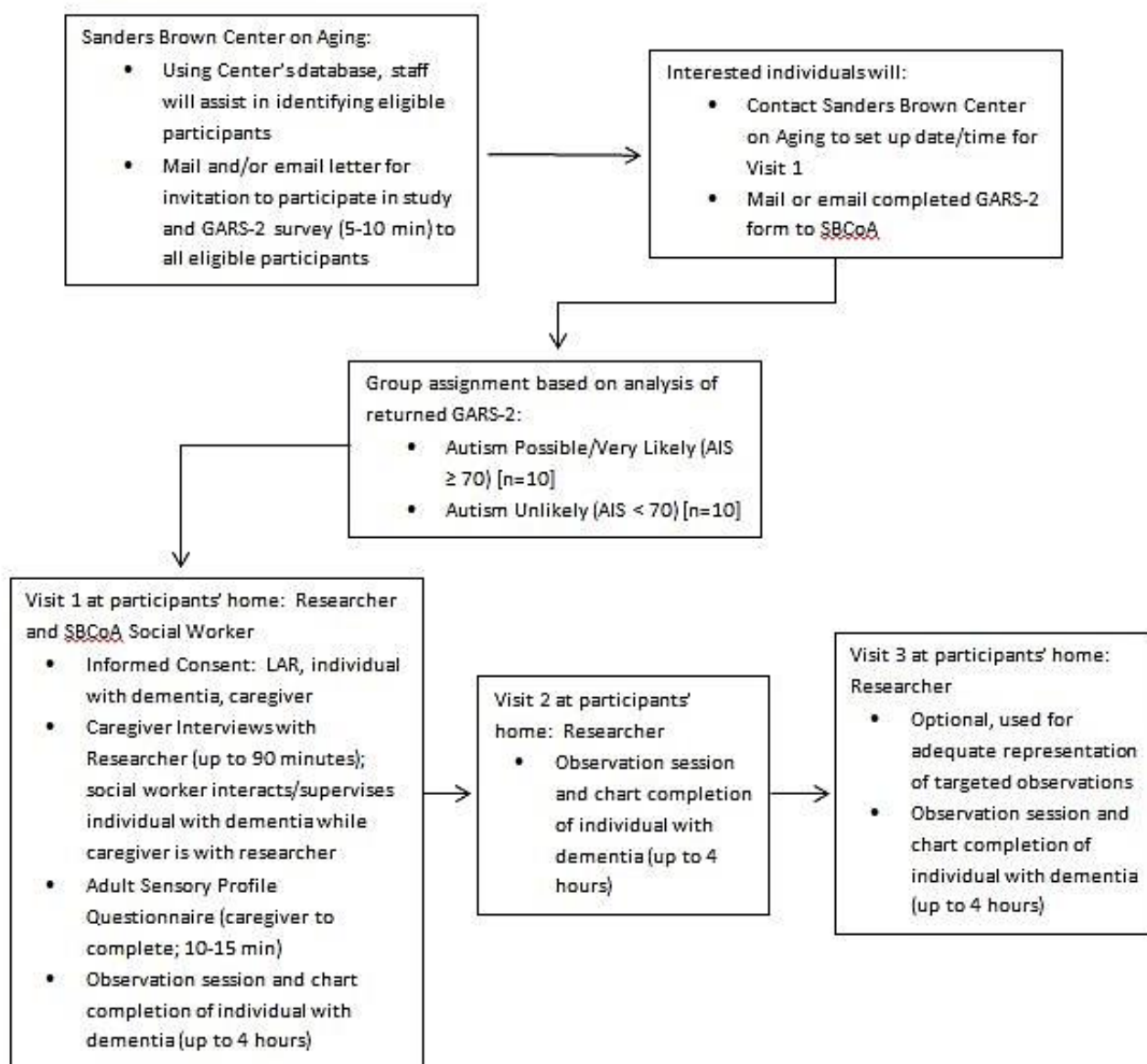


Figure 4.1 Study design.

Recruitment was based on review of SBCoA participants who completed the GARS-2 survey. Potential participants were contacted via a telephone call and flyer (APPENDIX D) with an invitation to participate in the current study. Data were collected at the participants' place of residence as noted in Table 4.1.

Table 4.1. Data collection schedule.

<i>Tasks</i>	<i>Visit 1</i>	<i>Visit 2</i>	<i>Visit 3 (optional)</i>
Informed Consent and Confidentiality Review for: Caregiver; cognitively impaired participant	X		
Caregiver Interview (audio-recorded, up to 90 minutes)	X		
Sensory Profile Questionnaire (10-15 minutes)	X		
Observation Session and Chart Completion (up to 4 hours)	X	X	X
Complementary Home Safety Assessment (up to 30 minutes)		X	

The first visit was at a mutually agreed upon time at the individuals' home with the researcher, social worker from SBCoA (if requested by social worker or participant), care partner/legally authorized representative, and the individual with cognitive impairment. Explanation of consent and confidentiality was provided and informed consent was obtained from the legally authorized representative, the individual with cognitive impairment, and their informant/care partner (if not the legally authorized representative). Semi-structured interviews were then conducted using an established interview guide (APPENDIX A). Following completion of the interview, the Adult Sensory Profile Questionnaire (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001) (APPENDIX B) was completed by the participant with cognitive impairment with assistance for completion as needed from the researcher. The assessment categorizes observed behaviors into sensory processing patterns: low registration, sensation seeking, sensory sensitivity, and sensation avoiding (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001; Chung, 2006). Figure 2.3 (chapter 2) offers description of these four

categories. Sensory processing patterns offer insight into how the individual’s brain processes sensory stimuli. The patterns indicate personal preference in sensory stimulation.

After completion of the interview and questionnaire, observations were completed using the observation chart (Table 4.2).

Table 4.2. Observation chart.

Autistic Type Behavior (Gilliam, 2002)	Neuropsychiatric Symptoms of Dementia (Cummings et al, 1994)	Environmental Context (Stark, Somerville, & Morris; 2010)	Social Context
Repetitive Behaviors:	Delusions/Hallucinations:	Lighting/Sounds:	Caregiver present:
Task Transitions:	Irritability:	Smells/Temperature:	Interactions (empathy, ToM, facial recognition):
Tolerance to Sensations:	Anxiety/Agitation:	Visual aids/distractions:	Lives with:
Object manipulation:	Depressions/Dysphoria/Apathy:	Position (seated/standing/walking):	Alertness:
Visual gaze:	Disinhibition:	Inside/outside:	Communication (figurative language, nonverbal):
Body Movement:	Aberrant Motor Behavior:	Time of day:	Response to social contact:
Vocalizations:	Appetite/Eating Changes:	Access to home:	Participant’s Mood:
Emotional awareness to others:	Night-time Behaviors:	Engagement with environment (decision making):	Routine interactions:
Field Notes:	Field Notes:	Field Notes:	Field Notes:

Observations were focused on behaviors and environmental features surrounding the participant with cognitive impairment in their home. The observation chart was adapted to include components of three validated assessment tools: Gilliam Autism Rating Scale-2 (Gilliam, 2006); Neuropsychiatric Inventory (Cummings et al., 1994); and the In-Home

Occupational Performance Evaluation (Stark, Somerville, & Morris, 2010). These assessments were used to guide observation of behaviors characteristic of ASD, behaviors associated with BPSD, and engagement with the home environment. As the observer, I acted as a participant-observer so that verbal interaction between the participant and myself occurred, if appropriate, but was not solicited.

At the conclusion of the first visit, if the dyad demonstrated behaviors which warranted additional observation, such as those with ASD-like behaviors, a second visit was arranged for additional observation time. Second visits only included observation of the participants and was conducted at a time of day opposite of the first visit (morning vs. afternoon) to promote adequate representation of behaviors throughout the day. A third visit was optional in the design. This visit was added if necessary in order to seek adequate representation of targeted observations as listed on the observation chart which I determined during data analysis.

Analysis. A descriptive qualitative approach was used to describe observed environment, behavior presentation, patterns of sensory processing patterns, and care partner perceptions associated with experiences surrounding behaviors characteristic of autism. Prior to data collection, I used principles of bracketing and reflexivity to acknowledge my background as an occupational therapist may impact analysis (Creswell, 2014). I recognize biases that my background may bring, such as emphasis on occupations and sensory-based behaviors. Avenues to ensure validity and reliability of results were used including peer debriefing with SBCoA researchers, constant comparison of emergent findings, and triangulation (Creswell, 2013).

Data analysis began following the first interview, and used a constant comparison approach in which continual comparative assessment was undertaken as each new set of data was collected. Peer debriefing with SBCoA researchers and expert consulting with the SBCoA clinical director was used throughout data collection. Meetings were arranged to create an effective study design, to provide consultation for recruitment, and discussion of preliminary findings. I audio recorded and transcribed all interviews verbatim. Transcribing the data allowed me to stay closer to the data creating a deeper understanding of expressions and nuances of participants. Transcriptions were coded using HyperResearch 4.0.2 (Researchware, Inc., 2018). Observation charts were compiled and field notes were analyzed for commonalities, description, and contextual reference. Sensory profile questionnaires were scored and used as supportive data in describing participants' sensory processing patterns and behaviors.

Findings

A total of 16 participants were enrolled. One dyad was made up of a married couple, both living with cognitive impairment, yet still capable of providing consent to participate. Nine individuals with cognitive impairment participated. For description specific to cognitive impairment involvement, demographics of the participant with cognitive impairment are depicted in Table 4.3. Pseudonyms are used for all participants. Eight interviews (average length of 54 minutes) were conducted, along with 14 observations (totaling 34.75 hours). Two participants were observed one time, and all others had two observation visits.

Table 4.3. Participant demographics.

Name:	Age	Sex	Race	Diagnosis	CDR-SUM	AIS/ Autism Category	Care Partner	Length of relationship with Care Partner-yrs
Betty	73	F	White	MCI	0	41/ Unlikely	Samuel	50
Chris	93	M	White	MCI	0	0/Unlikely	Karen	50
Adam	85	M	White	MCI	0.5	43/ Unlikely	Ellen	20
Charlotte	88	F	White	MCI	0.5	68/ Unlikely	Ronald	58
Ronald	83	M	White	MCI	0.5	70/ Probable	Charlotte	58
Pamela	67	F	Black	MCI	0.5	74/ Probable	Alex	50
Walter	82	M	Black	MCI	1	76/ Probable	Laura	48
Ricky	81	M	White	MCI	1.5	41/ Unlikely	Janelle	10
Vicky	81	F	White	Dementia	5	53/ Unlikely	John	61

Observation of behavior and sensory processing analysis. All dyads consisted of one person with cognitive impairment and their care partner. Care partners in this study were all spouses with extensive longevity in their relationship. Three participants were reported to have behaviors characteristic of autism according to the GARS-2 completed in the first study. Assessment of the Adult Sensory Profile results indicated minimal variation of participants from typical adults of similar age. For grounding of the dyad's experiences, brief narratives are provided below. Description of behaviors observed and sensory profile results are also discussed in each narrative.

Adult Sensory Profile. Results of the Adult Sensory Profile questionnaires are listed in Table 4.4. All nine participants with MCI or dementia had sensory processing patterns

different from normative data of same-aged older adults (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001).

Table 4.4. Adult sensory profile results.

Participant	Low Registration	Sensation Seeking	Sensory Sensitivity	Sensation Avoiding
Betty	More than most	Similar	Similar	More than most
Adam	More than most	Similar	Less than most	Much more than most
Chris	Similar	Less than most	Similar	Less than most
Charlotte	More than most	Similar	More than most	More than most
Ronald	More than most	Similar	Similar	More than most
Pamela	More than most	Similar	Similar	Similar
Walter	More than most	Similar	Similar	Similar
Ricky	More than most	More than most	Similar	Similar
Vicky	Similar	More than most	Less than most	Similar

Sensory processing patterns reflect functioning of nervous system utilization of sensory stimulation. Personal preferences to stimulation are intertwined with patterns of sensory processing, but preferences may be a directly related to individual nervous system functioning. For example, someone who prefers to not be touched may have poor tactile processing. These data are used for descriptive purposes in this study.

Abnormalities seen in all cognitively impaired participants indicates that sensory processing may play a role in environment-person fit.

Betty lives with her husband of 50 years, *Samuel*, in a two-story home where they have been for 48 years. Betty described a lifetime of volunteering, working with children as a mathematics teacher, and being very active in philanthropy. Both of her parents had dementia. She said she expected to be diagnosed. Betty scored a zero on the Clinical Dementia Rating Scale Sum of Boxes (CDR-SUM), indicating minimal cognitive impairment involvement. Of the participants, she had the most upbeat attitude. She discussed her drive to fully participate in all areas of her life but recognized the need to

decrease leadership roles and train upcoming replacements. She and her husband were excitedly preparing for a cross-country trip by railroad with multiple stops and visiting friends.

During observation and as reported on the GARS-2, Betty had no signs of behaviors characteristic of autism. She described situations where she avoided sounds. For example, she and her husband slept in separate rooms but this was because she couldn't stand the sound of his snoring. Samuel reported slight changes in her behavior related to sensation, such as a notable increase in whistling and tapping with her hands during times that she is waiting, such as at stop lights. Her sensory profile results indicated low registration and sensory avoidance more than others her age, indicative of her behaviors to avoid arduous sounds.

Chris is a 93-year-old living with his wife of 50 years, *Karen*, in a two story home, where they have been for 48 years. Along with mild cognitive impairment, he has Parkinson's disease. He is very active, exercising multiple times throughout the week. He talked about needing some assistance with self-care for his feet, but he continues to be independent in all other self-care routines. The home has been adapted to allow for access to all areas except the basement. For example, there are rails added to the toilet, a bench in the shower, and a recliner placed in the living room to help him sleep at night. His wife does the cooking, shopping, finances, driving, and hires a person to clean the home when needed. She is much younger than he, and presented with energy and enthusiasm.

Observations of Chris's behaviors were consistent with what was reported on the GARS-2. He had no signs or indications of behaviors consistent with ASD. He was an

ex-catholic priest and had a very calm and level demeanor. The sensory profile showed that he was sensation seeking and sensation avoiding less than most people his age. This is consistent with his calm personality and behaviors to accept environmental stimulation rather than seek out or avoid stimulation.

Adam is a retired university professor who is having increasing difficulty with his memory, self-care, and transitions from task to task. He lives with his wife, *Ellen*, in a home where he has resided for over 50 years. Adam enjoys daily walks around the neighborhood with his wife, working in his garden, playing on his computer, and socializing at church and happy hour. He and Ellen talked about an increase in agitation at times with difficulty calming down, but this has not caused them any notable problems.

From observation and discussion of behaviors, Adam did not present with behaviors characteristic of autism at the time of data collection, nor were such behaviors reported on the GARS-2. Adam referenced specific sensory preferences that he has had throughout his life. For example, he does not like noises, and said he often asks people to turn down background noise. He also said he likes lights, especially at night when he is going to sleep. A bright street light shines into his bedroom which helps him calm down and sleep. His sensory profile indicates he has low registration and sensory avoidance more than most people his age. This matches his descriptions for the need to decrease background noise, especially during conversations.

Charlotte lives with her husband of 58 years, *Ronald*. Ronald also has cognitive impairment. They talked about significant assistance in their day-to-day function from their daughters. Charlotte says her daughters often take her shopping, as she loves to shop, but Ronald does not. They hire a person to clean their home weekly, but Charlotte

does light cooking and laundry. Charlotte was on oxygen during the observations. She said that the need for oxygen and the cords restrict her from being more active in and out of her home, and that she is much more sedentary now than when she was younger. She and Ronald had a conversation regarding the need to move into a home with more formal assistance and easier upkeep. But, Ronald strongly expressed he did not want to move. She talked about feeling isolated in her home and depressed. Her daily routine was to sleep until around 11am, although sometimes, she sleeps all day. Her routines were expressed thoroughly, including television shows and daily alcoholic drinks in the afternoon.

Charlotte's GARS-2 AIS was 68. The cutoff for autism probable/unlikely is 70. During observations, she did not present with behaviors characteristic of autism, but did have some irritability and strongly expressed a need for consistent routines. Her sensory profile preferences indicated low registration, sensory sensitivity, and sensory avoidance more than most people her age. This is consistent with her need for routine and prediction of times for sensory stimulation.

Ronald is *Charlotte's* husband. In the same living situation as described above with Charlotte, Ronald is happy in his home and hopes to remain living there for as long as possible. He is an active driver and participates in several community activities, including a weekly breakfast with the guys at McDonalds, YMCA exercise classes, church, and offering transportation to disabled friends. He enjoys driving, which he did throughout his career as a regional sales representative. Ronald has a medical history of having a stroke, high blood pressure, and mild cognitive impairment.

According to the GARS-2, Ronald is reported to have enough behaviors consistent with autism to be classified as ‘autism likely/probable.’ On observation, he presented with behaviors such as dominating conversation, interrupting, and insistence on being correct. He had some non-purposeful motor movement on the right side, but this is most likely attributed to his stroke. His sensory profile also indicated three of the four sections that were different than most others his age. He had low registration more than most, sensory sensitivity less than most, and sensation avoiding much more than most. Low registration and lowered sensory sensitivity are consistent with a tendency to interrupt in conversation. Sensation avoiding was evident in reluctance to grocery shop, resistance to moving or new situations, and a work history of traveling alone.

Pamela is an active 67-year-old who is living with mild cognitive impairment. She enjoys creating and selling wreathes at community events throughout the year. She lives with her husband of 50 years, *Alex*, in a home where they have lived for the majority of their marriage. They both participate in regular exercise three to four days per week. She and Alex engage in weekly volunteering with meal delivery for their church. They both also attend the local senior citizen’s center for social engagement.

Pamela’s GARS-2 indicated that she was likely or probable to have autism. Observation and conversation with her and husband regarding behaviors and her history were consistent with a pattern of behaviors associated with high functioning ASD. She described a history and present care from a psychiatrist and psychologist for behaviors and thought patterns similar to that of ASD. Pamela and Alex said that she has a tendency to get very upset, and “fly off the handle.” She had preference for repetitive tasks, routine, and object manipulation. She also tended to dominate conversation and

interrupt others. Unlike those with ASD, she had minimal variation on the sensory profile while having low registration more than most and all other areas typical to those her age. Given her distinct psychiatric past, preference for routine, but marginal involvement of sensory processing impairment patterns, behaviors characteristic of ASD cannot be confirmed or ruled out.

Walter lives with his wife of 48 years, *Laura*, in a large three-story home.

Walter's wife talked about their adventurous past, traveling throughout North America by car. Walter is a retired preacher and state worker, as well as an army veteran. He described his past as courageous because he was the first African American to work in the state government office from which he retired. He was also the only African American in his unit of the army when he was younger. Walter has always had and continues to have a passion for cars and driving, despite recent accidents and growing concerns from Laura for his safety. She talked about struggles in their partnership in terms of communication and working together as he is very determined in his ways and beliefs with minimal room for negotiation with her. They have minimal outside support or help from their family. The home was cluttered and needed attention. They both agreed that the house has become difficult to care for and maintain. She said they often argue and have been physically aggressive with one another.

During observations, Walter was friendly with me but became very agitated and yelled at his wife throughout the observation. There was difficulty in redirection or transition during tasks, and he demonstrated perseveration on topics that were aggravating him. He dominated conversation with me and interrupted. These behaviors are consistent with behaviors seen on the spectrum of ASD. His GARS-2 indicated he

has behaviors consistent with ASD. From the sensory profile, low registration was the only section that appeared to be more than most others his age. All other areas of sensory processing and patterns appeared typical. Low registration is evident by his tolerance of clutter throughout the home and yard, also with frequent small car accidents as he may not register all needed environmental precautions while driving.

Ricky and his wife, *Janelle*, live in a small condo in a gated community for older adults. He has mild cognitive impairment, but is articulate, appropriate and polite. The two talked about their active participation in church and in maintaining an exercise routine. *Janelle* has Parkinson's disease and chronic back pain requiring continual prescription medication. Because of this, he is an active care partner for her as she is for him. They talked lovingly about their marriage and partnership over the last 18 years, and seemed to be happy with their environment. He did report appreciation for routine to help cope with his memory loss. He also talked about being raised by a father who was an alcoholic and the implications on his previous relationships and temper. They both participate in homemaking tasks and have a regular cleaning assistant for the home. *Ricky* talked about increasing concern for memory, but he is able to compensate with routine and the use of his cell phone at this time. He is the driver in their relationship and his wife navigates.

During observation, *Ricky* did not appear to have behaviors associated with ASD, consistent with his score on the GARS-2 form. His environment was well maintained, clean and easy to navigate. The sensory profile indicated that he had low registration and was sensation seeking compared to most people his age. This is consistent with his desire to drive, but need for navigational assistance.

Vicky is a pleasant, quiet 81-year-old living with her husband of 61 years, *John*, in a home where they have resided for nearly their entire marriage. Vicky is the only participant in the study who had a diagnosis of dementia with a CDRSUM of 5. Her husband described her as a wonderful wife who had a life time of helping with home chores, raising their children, and working. He reported no current or previous concerns regarding her behaviors or attitude. She has had a history of falls, joint replacements, and other conditions which needed significant caregiving, but that she is independent in self-care tasks at this time. He manages her medication, appointments, shopping, meal preparation, and driving. Vicky's husband described the pair as steadfast in their daily routines of bible reading, prayer, television shows, and a daily trip to various restaurants for lunch.

During observation, Vicky had limited initiation during conversation, but was enthusiastic while describing her home and pictures. She presented with no signs or behaviors associated with autism, consistent with what was reported on the GARS-2. Her sensory profile revealed sensation seeking more than most her age and sensory sensitivity less than most her age. This indicates that she enjoys sensory experiences, such as community outings, visits from family, and engagement in desired activities. Her environment seems to be appropriate for her patterns of sensory processing.

Emergent themes from interview data. Four themes emerged from qualitative data obtained during interviews with care partners. *Time: past, present, and future* offered grounding of the participant's narratives as they talked about their lives through time. Description of *environmental context* in terms of social and physical environments was like building blocks to support their behavior. *Behavioral adjustment* associated

with aging was described in terms of changed behaviors and daily life. *Living with cognitive impairment* was a central theme in terms of behaviors in the present and future. Themes appeared as layers creating the narrative of participants' experiences with cognitive impairment, the environment, and their behavior.

Time: Past, present, and future. All participants discussed their lives by describing their past, talking about present situations, and exploring future possibilities. This temporal theme was grounding for the narrative of their life story. There was specific reflection on old routines, the history of their partnership, experiences with work life, raising children, and geographical orientation with their home and cities of residence from the past. Present daily activities and routines were also described. These routines offered structure to life for the participants, all of whom were retired. Routines allowed for consistency and expectation of environmental stimulation and predictable behaviors.

John (Vicky's husband): *Well, I think we are creatures of habit. Pretty much everything we do is repetitive over and over. We get up in the morning and get dressed. We have our reading and prayer, go out to eat, come back and watch certain shows. It's all repetitive.*

Adam and his wife talked about the weekly structure of their routines with daily walks, participation at happy hour once a week, and Saturday breakfasts at the local bakery. Sunday is filled with church and a meal with his son. Ronald and Charlotte have daily drinks, and Betty and her husband watch a daily television show, MASH. Walter's wife described challenges of not having set routines:

Laura (Walter's wife): *He hasn't set a pattern, though. That's the problem, and now that he doesn't work, he does what he wants to do. And you can't tell him, "We got to do it this way."*

Changes in routines associated with retirement allowed for increased time to engage in desired activities and hobbies. Pamela created wreathes and was scheduling craft shows for the upcoming year. Vicky loved to look at and cut out pictures of her family. Walter, Betty and Samuel enjoy traveling to various places near and far from home. Reading was a common hobby for several of the participants. These hobbies offered enjoyment in their day and autonomy despite declining cognition.

As the participants adjust to living with cognitive impairment and aging, they discussed changes in their routines based on energy levels and function. Betty was actively decreasing the role she had in leadership positions while volunteering because of upcoming cognitive decline. Pamela discussed feeling forced to slow down. Charlotte described being more sedentary now compared to when she was younger because of medical conditions. Ronald said his obligations helped him continue to engage in activities.

Ronald: *I like to stay in bed, but like, tomorrow is breakfast with the guys, and I'm picking up an older man who doesn't drive anymore. And when I go to the Y, I pick up another guy who doesn't drive anymore.*

For care partners with an active caregiver role, there was some expression of fatigue with present daily routines and expectations.

Karen (Chris's wife): *You know once you get older, I have a degree in home economics, flat out I'm tired of cooking. I am tired of cooking. So I try to have a good meal maybe twice a week and we eat out.*

Chris: *Or have a TV dinner.*

Participants also discussed future plans. Housing options and possible needs to move to a different setting as cognitive impairment advanced was discussed by most dyads. Several of the female care partners expressed worry regarding their ability to continue to provide appropriate care as their husband's cognitive impairment advanced.

Laura (Walter's wife): *My worry sometimes is that he is going to have a deadly accident. He's already had one. The police said it's a wonder he's still alive and he just had a bump on his head. But I'm fearful. How do we stop him from doing things he used to do and still thinks he can do? And we can't do anything about it.*

Environmental Context. This study was based in the community. All participants lived in city suburbs and were in close proximity (within 5 miles) to shopping, restaurants, and health care. Physical environments of the home and community and social environments with care partners, family and friends seemed to influence past, present, and future routines and plans. As seen with Ronald, his environment and abilities prompted him to behaviorally engage in activities and social interaction. Social environments were described by all the participants in terms of who provides care or the primary care partner, contact with family, and other social supports. Physical environments included and surrounded the home. Neighborhoods and access to transportation in the physical environment were described.

Social environment. All nine dyads were married couples. This spousal relationship created thematic dialog regarding their partnership in terms of their marriage, residence, home life, and community supports as evolving of time and with cognitive impairment. Length of marriages ranged from 10 years to 61 years. Participants described commitment, passion, and perseverance with one another. Karen talked about her commitment to take care of Chris as part of her role as his wife, regardless of new needs associated with cognitive impairment.

Karen (Chris's wife): *We tease each other, we tease back and forth a lot. I think two things that are very necessary for a marriage, you have to have faith and you have to have a sense of humor because if you don't have a sense of humor, everything is going to be a mountain and it's hard to come down from a mountain. And, it's hard to come down when you go up so quickly and you have to come down it very carefully and gracefully. But he has been a wonderful husband and he thanks me for all that I do for him. But to me it's just what a wife would do, but he is the love of my life and he is the only person I've ever been in love with.*

Most participants discussed companionship with their spouse. Betty and her husband talked about doing daily puzzles together. Other participant's discussed mechanics of their relationship and degradation due to onset of cognitive decline.

Laura (Walter's wife): *I'm his wife I guess. Not quite. At this age, we still companion with each other. I cook and clean, and uh, he provides some money for his care I guess, and upkeep of the house, he works outdoors.*

Family and involvement of children was also discussed by most dyads. Adam had weekly contact with his son. Vicky also had daily contact with her children. Betty's children live three blocks away from her and have daily contact. She also provides childcare for her grandchildren. Ronald and Charlotte depend on close contact with their daughters for doctor's appointments and meals. They both have mild cognitive impairment and have become increasingly dependent on their children for necessities, such as food and medical care.

Charlotte: *They have to know everything that is in our refrigerator, and what we eat...One calls at 5 o'clock every day and wants to know what we are cooking, and the next one calls in the morning to know what we ate.*

Elizabeth: *Is it too much?*

Charlotte: *No, if I didn't have it I'd be dying.*

Ronald: *It's nice to know they care.*

Charlotte: *We are very fortunate with our children.*

Walter and Pamela did not have consistent contact with their family, but spoke highly of their children. Ricky and his wife do not have children or close family. They talked about their neighbors and close friends as their family and as fulfilling needs for social support and assistance.

Ricky: *This neighborhood is a community with 120 condos in here. They are all filled. And uh, we have, the men have a breakfast once a month, and the women have a lunch once a month. And we have social hour once a month, and it just is a good place to live.*

Social environments for the participants offered emotional support, connectedness, and assistance in care, as needed. Participants described a variety of individuals, such as spouses, children, friends, and neighbors, within the social environments. Proximity was a factor in frequency of interaction with various people in their lives. For example, Pamela and Alex's children lived too far away for regular contact, but Pamela and Alex were very close as a married couple. Ricky and Janelle also spoke highly of their close neighbors who they routinely engaged with. Because Janelle no longer drives, and Ricky does not navigate well, having strong relationships and support with close neighbors enabled them to maintain social environments without the need to drive. These neighbors also offered assistance occasionally for care, such as transportation. As declining independence is associated with progression of cognitive impairment, reliance and assistance from the social environment is paramount to the success of home-based residence.

Physical environment. Within the theme of contexts, the home was a significant focus of conversation for all participants. The majority resided in their home for a very long time, some over 50 years. Janelle said, "*I look around every time we come in and say 'Thank you Lord, we're home.'*" The participants had adapted their homes to maximize safety and function, as well as to meet their needs for cognitive impairment in the home environment.

Adam: *For example, you can look up there too on the top left corner. This is the keeping track of my water consumption.*

Ellen (Adam's wife): *Seems to work.*

Adam: *We try to hang stuff up where we need it. Everything is supposed to be where it's supposed to be, and everything is in its place supposedly.*

Upkeep of the house was discussed by all dyads as changing needs related to energy level, function, and cognition. Several participants used outside help to clean their homes. Others put cleaning off and did not clean regularly. Other home tasks, like cleaning dishes and laundry were typically shared between both partners. Dyads talked about downsizing or exploring senior living options in their city. Some had committed to waiting lists, while others were unsure of the best next location. Female care partners were more concerned with relocation, yet male care partners did not express the need for relocation as an upcoming need.

Walter: *Well, it was beautiful. It needs a lot of cleaning and painting and a few things. But when you get 82 years old, you know, you're surprised you've lived that long. And you doubt you'll live a whole lot longer, so we think about moving.*

Neighborhoods surrounding the home were also discussed in terms of access and familiarity. Participants described aspects of their neighborhoods in terms of physical and social support for daily activities. Pamela and her husband know all their neighbors and check on them often. Adam and his wife use their neighborhood for active exercise routes and know their neighbors well. Charlotte expressed displeasure in her neighborhood because she did not know the neighbors. She was also more confined to her home due to the need for oxygen. Transportation was impacted as a result of cognitive impairment for all dyads. Six dyads had only one driver. Home-based residence requires acquisition of food and other goods. Without limited ability for transportation or ability to navigate throughout the community, participants may not be

able to obtain needed supplies to live in the community. Further, limited navigation of the surrounding community or physical environment increases chances of depression and isolation.

Contexts of the social and physical environments were pivotal in discussion of participants' experiences. Once the temporal aspect of past, present, and future was established for their narratives, description of context was the next building block to describing their behavior.

Behavioral Adjustment: "I'm slower, I get slower every day." Participants described various factors leading to behavioral adjustment as they aged with cognitive impairment. For example, changes in energy, onset of new medical conditions, self-care tasks, memory, and caregiving for their spouses. Behaviors were not discussed in terms of sensory processing or advanced cognitive function beyond memory. These issues are not commonly known and participants may not be aware of changes in behavior specific to sensory processing changes. Participants described onset of various medical conditions that forced changes in their behavior which they associated with aging. Conditions included COPD, arthritis, joint replacements, circulatory problems, diabetes, hypertension, stroke, malaise, and poor balance leading to falls.

Pamela: I have a hard time with that, because I don't want to slow down, but I have to because my body won't let me go. Yesterday it was hurting, and I just got so tired, but I didn't want to say anything because I want to keep going. So then I go over there and (Alex) is like "Well, you're tired aren't you? Why don't you sit down?" But I just want to keep going. I want to clean up my house, do my

laundry, be outside and all that, but I just can't. So it tells me that I can't keep going anymore, so I just have to sit down and listen to it.

With onset of such medical conditions, independence in self-care can often be impacted. For those living with cognitive impairment, issues surrounding self-care often lead to increased tension between the care partner and person with cognitive impairment. All participants discussed aspects of self-care. Independent self-care was reported by eight of the nine participants with cognitive impairment. There was acknowledgement that self-care tasks do take longer than before. Chris said, *“It takes me twice as long to do everything as it used to whether it's getting dressed or whatever, and that's frustrating.”* Laura also said Walter is slower at getting dressed, *“I'm glad that he's not bedfast and can still dress himself. Not real fast. We are late to church, but he still dresses himself and waits on himself.”*

Access to areas for self-care, such as toilets, bathtubs, and the kitchens may become limited and can create barriers to living in the community. For example, when a person with dementia no longer remembers where the bathroom is, they may use a trashcan in a public place as a toilet. Daily toileting and hygiene was not a concern for any of the participants at the time of interview. But, Karen and Ellen had increasing concern regarding nighttime toileting routines for their husbands. Bathing tasks were also completed independently. Eight of the nine participants with cognitive impairment used equipment, such as grab bars, stools, and benches. This type of equipment offers helpful modification and adaptation to the physical environment to increase safety and access.

Of the self-care tasks, eating was most prominently discussed by the dyads. Mealtime is a strong bonding time for couples and aspects of meal preparation, meal time set up, and eating together were described. Roles of caregiving were evident in dialog with the participants as a result of cognitive impairment. But, couples worked together to determine what to eat. Ricky and his care partner described how they typically work together to figure out meals.

Ricky: For dinner, whatever she suggests is fine. And since she had surgery Monday, I got out today. I went to the store, and got six frozen dinners, three pair so that will last us through the next three days.

Janelle (Ricky's wife): We will figure out something by then and Panera delivers.

John said they eat out every day for lunch, and he plans and prepares an evening meal. Vicky has become dependent on her husband for meal preparation and set up as result of dementia.

John (Vicky's husband): She has a lot of days that she don't really feel good. And we eat out every day at noon. That's pretty much seven days a week, and so I only have to fix a little bit for breakfast which is very light for both of us. She doesn't like breakfast, and I don't need breakfast, so it's mostly an evening meal is all I try to come up with.

Ronald and Charlotte said they eat out with friends often during the afternoon and evening. Charlotte had concerns that if she did not prepare or plan food for Ronald, that he would not eat. Malnutrition and dehydration is often a concern with advancing cognitive impairment. Spouses embraced changes in behaviors to ensure their loved one had food to eat and remembered.

Caregiving was discussed by all care partner participants. Because all dyads were a spousal relationship, many discussed caregiving as a natural component of marriage.

John described his transition into caring for Vicky after her physical and cognitive decline:

John: It's been quite a change from ten years ago. She was in a lot better health. She didn't have any of the broken bones and surgeries that she has had in the last couple years, and she does have some dementia now. So I, uh, I take over, I do what little house cleaning and stuff, and cooking. I prepare the meals, and I do the laundry. And I try to baby her, she don't want me to, but I try to baby her because with her surgeries and everything. They told her she can't do heavy work like mopping or vacuuming. And she has knee problems, needs to be replaced and she don't want it. So I just try to get her to take it easy, so we try to enjoy life. She's not as sturdy and bouncy as she used to be so I take care of her. When we are out, I hold her arm, and at home I just watch out for her. I got wheelchairs and transporters in the car. If she gets tired I wheel her, but she likes to walk. If it doesn't hurt her back or legs, she will walk.

Simple reminders to overcome memory impairments were mentioned, such as putting in hearing aids or dentures, were expressed by several care partners. Ronald and Ricky both provide care for their wives in terms of medication retrieval and transportation. Alex, Pamela's husband also played an active role in providing care for her when she was upset or frustrated. Alex had a calm, quiet demeanor and would encourage her to use anxiety reduction techniques or allow her to cool off alone. Pamela said her frustration is better when she is able to talk through her thoughts.

Pamela: It's either fester then I'll probably kill you or let it out. Then, it's not so bad. My therapist, I've been seeing him for 20 years or more, and sometimes I get angry and I want to yell and scream...so I go there, and yell and curse and scream, kick his chair and all that. But I have this anxiety thing. I have some medicine for it but I'd rather not do that. I take too much medicine anyway so I just, I cry real hard and everything.

Alex: Yeah, I talk to her and help her chill out.

Karen, Chris's wife had the heaviest caregiving role. She assists him with lower body self-care, wound management, working through depression, and vigilant reminders to swallow while eating. Because of Parkinson's disease, Chris has choked several times, to the point of requiring the Heimlich maneuver three times. Karen discussed the highest levels of stress and burden.

For some dyads, both spouses take on caregiver roles for each other, despite their own ailments. When both spouses took on a caregiving role, there was increased reliance on environmental support. For example, Charlotte and Robert both have mild cognitive impairment, and so their daughters offered significant support for routine tasks which enable them to continue to reside in the community. Ricky and Janelle also discussed reliance on social environments for support as they faced impairments associated with cognitive dysfunction.

All care partners, except John described their own medical conditions. Samuel described limitations to what he could do because of a bad back and a heart condition. Janelle is living with Parkinson's disease and severe chronic back pain. Karen described challenges associated with her back problems, migraines, and difficulty coping with

stress at times. Ronald, himself, has increasing cognitive impairment and a recent history of a stroke, while Charlotte required oxygen, battles COPD, and chronic fatigue. Alex has diabetes and was careful to monitor and regulate blood sugars. Ellen faced challenges due to her diagnosis of multiple sclerosis. Laura also talked about having a bad back, feeling as though she was deteriorating.

Laura (Walter's wife): *It's hard for me to go up and down stairs. My back hurts sometimes. I get down stairs and I have to rest and by the time I come back up, I'm out of the desire to do whatever I was going to do and just want to sit down and rest.*

Because of the significant effects of caregiver burden associated with care for someone with dementia, care partner ailments can have costly effects on their safety and well-being, and too, the person with cognitive impairment. Behavioral adjustments to living with cognitive impairment, physical decline, and transitions into roles of care partners were prominent throughout the data. The dyads of this study had strong partnerships which supported adjustment and adaptation as they progressed through time and cognitive decline.

Living with Cognitive Impairment: "You just have to accept it." Living with cognitive impairment and dementia is a central component of this dissertation. Coping with and managing life with cognitive impairment seemed to permeate all other themes discussed and observed.

Participants described their previous exposure with dementia, their current situations, and anticipated changes in the future. Pamela and Betty both reported significant involvement with diagnosed dementia throughout their family, and they

expected to have some cognitive impairment as they aged. Participants talked about ways they worked with and around cognitive impairment. For example, Pamela attempts to wait for her thoughts to return when she is forgetful. Ricky works daily crossword puzzles and word jumbles from the new paper to help combat cognitive decline. And Betty continues to participate in volunteer activities for her church and neighborhood. They talked about these aspects in ways that helped them feel like they were coping with cognitive impairment and maintaining their personhood.

Betty: People haven't finished asking me to do things, but they start with, "You know, I know you have Alzheimer's but could you..." That's the phone call I got last night. You just have to accept it. I know I do react differently, but I have all my life probably. You just have to accept it go on, and that's the best you can. I haven't thought in terms of fighting it, there wasn't anything I could do about it so you accept it and go on and do as much as you can and I'm trying to do while I'm able physically to get as much done.

Some participants had relatives who died with Alzheimer's disease or dementia. Adam and Ricky discussed experiences in which their friends developed dementia. They seemed to have some prior experience with dementia and were informed on various changes that may lie ahead.

Memory loss was present for all participants with cognitive impairment. The participants discussed various difficulties, such as recalling names of streets, recognizing people in public, remembering words, spelling, short term memory deficits, and orientation to dates, places, and tasks at hand. Chris said, *"I can't remember, oh I, it's very frustrating, I get very frustrated at times how I can't recall simple things."*

Navigating healthcare systems and medications were frequently discussed by both partners of the dyad. These tasks were completed by the dyad unit, rather than independently by each member of the dyad. They talked about trying various medications for cognitive impairment and behavioral changes. Some worked, while some had significant side effects. Feeling comfortable with their doctors and neurologist was also important to the participants. Ellen discussed Adam's drug regime to help his mood.

Ellen (Adam's wife): *He gets irritated, but that's not his main mode of activities. He's usually a very, very calm person, but the last couple years he has gotten kind of an edge on him. He'll get irritated in certain situations which are frustrating. We talked to his neurologist, six months ago, no a year ago, and we decided to try him on a new drug. And, uh, it sort of takes the edge off your irritation level a little bit. And you're a much more in-charge person now.*

Others discussed changes in their behavior and mood with the onset of cognitive impairment. Laura said Walter *"has days when he's calm and can get along and not fussy, he has days when everything is an argument and he thinks people are trying to control him."* Of all the dyads, Walter and his wife seemed to have the most troublesome relationship and the greatest difficulty in coping. Charlotte expressed that she is more depressed now, and Ronald is quicker to become agitated. Ricky also said he becomes agitated but uses learned coping techniques. John added that Vicky has not had any increases in agitation or aggression, *"She is a gentle lamb, and she hasn't changed."* Vicky added, *"We just get along fine. Neither one of us ever give another a cross word."*

Discussion

This study sought to qualitatively explore behaviors in a community dwelling sample with cognitive impairment or dementia. Individuals with highest reports of ASD in the study explained in chapter 3 were unavailable for participation for reasons including a recent move into facility-based care or refusal to participate from care partners. This may be indicative of advanced cognitive impairment, presence of challenging behaviors, and increased caregiver fatigue or burden.

Of the participants with cognitive impairment in this study, three of nine were reported to have ASD behaviors frequent enough for GARS-2 classification as autism likely/probably (Gilliam, 2006). Findings identified all three of these participants to have behaviors consistent with ASD to an extent. For example, these participants showed signs of decreased empathy or turn taking in conversation, personal history of preference to be alone, and a need for routine and consistency. These behaviors do not appear pervasive enough to be able to confirm autism. Behaviors exhibited may be more appropriately labeled broad autism phenotype as described in Caselli (2018). Or, there may be undiagnosed personality disorders which also have behaviors comparable to autism spectrum disorders (Dudas et al., 2017).

An interesting finding was that of the length of environmental connection in both the social and physical context. All dyads had been married for at least ten years and in their current home environments for at least that long. Caregiving by a spouse often promotes longevity of community residence (Spijker et al., 2008). Length of time associated with these environmental contexts was likely supportive and prompted adaptive behaviors. Time was referred to frequently in terms of routines. Interestingly, habits and routine behavior can be protected despite mild cognitive impairment and

dementia. Storage of habit and routine information is in the striatum, an area of the basal ganglia that is rarely impacted by dementias, such as Alzheimer's disease (Duhigg, 2014; Graybiel & Grafton, 2015). Participants adapted and modified their home environment set up to be personalized and suitable to each person's behavioral needs and sensory preferences (Rowles, 2000; Rowles and Watkins, 2003). For example, Adam left the window blinds open at night so he could see the street light shine in. Frequent environmental changes can be degrading to behaviors for individuals with cognitive impairment.

Various behaviors, both normative and/or atypical, were evident throughout the data. Minimal challenging or adverse behaviors were observed during data collection. Individuals with cognitive impairment may have a tendency for improved behavioral performance around medical staff and/or researchers compared to that of being alone with their spouse indicating potential for Hawthorne effect (Franke & Kaul, 1978; McCarney et al., 2007). And so, an interview with care partners was imperative for a better understanding of the holistic situation (Jicha, 2011). Participants with cognitive impairment who were apt to display significant maladaptive behaviors may have care partners too burdened for participation in this study.

This study is not without limitations. The study used GARS-2 reports of behavior as classification of autism likely/probably or autism unlikely. As described in chapter 3, the GARS-2 is not validated in a geriatric population. GARS-2 reports are used in this study as exploratory and descriptive, not definitive or for diagnosis. Because of the small pool of potential participants, a diverse range along the cognitive impairment continuum was not achieved. A small number of participants volunteered who were considered

autism likely/probable according to the GARS-2. Despite these limitations, findings of this study offer description of the lived experiences for those with cognitive impairment and their care partners. Data can be applied toward emerging models describing experiences of the environmental interactions at play. Causation and ramifications of sensory processing impairment warrants further exploration and description than was afforded in the current study. Future research is needed to confirm behavior and the relationship to sensory stimulation and processing in later stages of cognitive impairment.

Conclusion

Onset and progression of cognitive impairment can have significant implications on behavior, environmental interaction, and care partner well-being. Enhanced understanding of behaviors in relation to environmental congruence and sensory experiences for those living with cognitive impairment may provide insight into avenues for improved quality of life for all individuals involved. Emergent themes place emphasis on behavioral adjustments over time even in steady and dependable environmental contexts for those living with cognitive impairment in the community. Involvement of sensory processing was apparent as all participants with cognitive impairment deviated from typical in at least one category compared to other adults of same age. Behaviors and psychological symptoms of dementia are troublesome to manage. Perhaps such behaviors and psychological symptoms may indicate incongruences with environment and sensory process abilities. And if so, environmental modifications and sensory processing awareness may have the potential to significantly improve quality of life for those living with progressive cognitive impairment.

CHAPTER 5. TOWARD A DYNAMIC MODEL OF THE RELATIONSHIP AMONG ENVIRONMENT, BEHAVIOR, SENSATION, AND COGNITIVE AGING

Introduction

Environmental gerontology has developed theories depicting the relationship between the environment and the older person. Such theories denote behavior as an outcome of this relationship. In situations or conditions where adverse and/or maladaptive behavior become problematic, the lens of environmental gerontology persuades one to further examine characteristics of the environment and the person.

In chapter 2, I described an array of theories from environmental gerontology. Here, I move on from these theories and focus on concepts of cognitive capacity and sensory processing as they relate to behavior. Available theories of environmental gerontology have increased in sophistication, but have notable shortcomings at the most basic biological levels. There is a lack of explanation of biological and neurological involvement to understand the person-environment relationship. Exploration of other disciplines, including neuroscience, psychology, and rehabilitation science offers some support to help fill holes when examining causal relationships among the person, environment, and behavior. But, among all these disciplines, there is a lack of theory exploring behavior as a result of biological, cognitive, and environmental interplay. Specifically, for older adults with dementia, there is no theory examining behavior as a bioenvironmental phenomenon.

Without the prospect of a cure for dementia in the near future, and with minimal established avenues for behavioral treatment for those with dementia, theoretical models are needed to help frame care options for both the care partner and the person with dementia. In this chapter, a theoretical model is introduced describing behavior as a

result of the environment and personal interactions with emphasis on biological and cognitive components of the person. This model illustrates relationships among environments and behavior of the person along a temporal continuum of cognitive impairment. The model provides a framework for understanding areas of potential intervention when addressing adverse behaviors in those with dementia.

Application of Theory to Cognitive Impairment

Environmental gerontology theories offer solid foundational understanding of the aging person's opportunities for interaction and experience within their environment. Lifetime affordances, competencies within the surrounding environment and feelings of belongingness create a personal history and trajectory of behavior and well-being.

Application of existing theories provokes questions in consideration of conditions that have become quite frequent in elder care. For example, what level of cognitive awareness is needed to form meaningful attachment to place? Or, what role does the environment have on behavior when cognitive functions are diminished? It is apparent that existing environmental theories do not illuminate intricacies involved in recognition of environmental features or the neurological processes which lead to behavior.

Environmental gerontology theories provide a framework to understanding key concepts in the relationship between the person and environment in a healthy functioning older adult. But appropriate application of these theories for older adults with cognitive impairment and dementia has received limited attention. A model with enhanced emphasis on biological functioning and the richness of influence from environmental elements is needed to better understand the aging experience with cognitive impairment and dementia.

A Systems Approach to the Relationship among Environment, Cognition, and Behavior

Gaps in existing theories and frameworks have encouraged exploration of the relationship among environment, sensation, and cognitive aging. Using a systems approach, I have illustrated processes involved in environmental stimulation, cognitive processing, and behavioral expression (Figure 5.1) which can be applied to all individuals across the lifespan with or without cognitive impairment. This is presented as an illustrative model depicting sensation and perception as a result of environmental stimulus and both of which precede behavioral expression (Gibson, 1966; Hurley, 1998). Temporality is employed in application of the model as it can be used to describe a specific point in time, throughout one's life. It is used in provided examples as a cross-sectional analysis of behavior for those with cognitive impairment in old age. Specifically, the model (figure 5.1) depicts the sequence of environmental and cognitive factors related to behavior with three categories and two transitions.

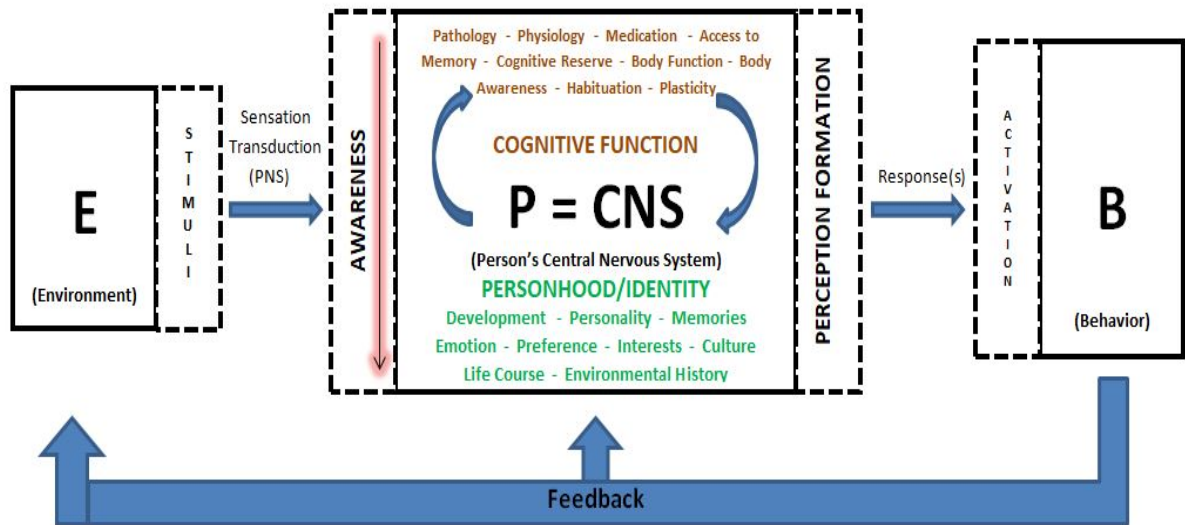


Figure 5.1 Systems model of environment-person relationship on behavior.

Five main components create the sequence. Environment leads to sensation transduction in which the sensory receptor cells throughout the person's peripheral nervous system (PNS) convert environmental stimuli to chemical messages sent to the central nervous system. Sensation is processed by the person's central nervous system. Processing allows for perception formation which promotes a response or thought inhibition. Finally, response to stimuli leads to motor activation and behavior.

Environment (E). The external environment, indicated by E in Figure 5.1 is all that surrounds the person's physical self. Components of natural and built environments, accessible tools, technology, social interactions, and nested layers of proximity as in Ecological Systems Theory are all considered within the external environment for the purposes of this diagram in Figure 5.1. These concepts will be later explained in more detail. The environment is a catalyst for the sequence offering sensory input to neural circuitry activation via sensory receptors.

Sensation transduction. In order for the individual to experience the environment, neural circuitry is activated via sensory receptors in the peripheral nervous system (PNS) throughout the person's body. Once peripheral sensory receptors are activated from environmental stimulus, this input is turned into a chemical-based message. This process is called sensation transduction. Sensory receptor cells are differentiated to collect specific sensory information, such as photoreceptors which allow for vision, thermoreceptors allow for perception of hot and cold, and chemoreceptors allow for taste and smell. Table 5.1 describes sensory receptors which are embedded throughout the body paired with environmental stimuli.

Table 5.1. Sensory receptors with corresponding stimuli to which they respond. (Gregory, 2013).

Receptor	Stimulus
Apmullae of Lorenzini (primarily function as electroreceptors)	Electric fields, salinity, and temperature
Baroreceptors	Pressure in blood vessels
Chemo receptors	Chemical stimuli
Electromagnetic radiation receptors	Electromagnetic radiation
Electroreceptors	Electrofields
Hydroreceptors	Humidity
Infrared receptors	Infrared radiation
Magnetoreceptors	Magnetic fields
Mechanoreceptors	Mechanical stress or strain
Nociceptors	Damage or threat of damage to body tissues (leads to pain perception)
Osmoreceptors	Osmolarity of fluids
Photoreceptors	Visible light
Proprioceptors	Sense of position
Thermoreceptors	Temperature
Ultraviolet receptors	Ultraviolet radiation

Sensory messages are carried via action potentials from the point of origin, through the periphery, and to the central nervous system (CNS) including the spinal cord and the associated area of the brain for processing. The action potential relays information regarding the modality (type of sensation), intensity, location, and duration of stimuli. In situations of continual stimulation, sensory receptors have the ability to adapt to the stimulus and provide decreased messaging to the central nervous system. For example, when a person first gets into cold water, they feel very cold. With time, the sensory receptors adapt to the cold water and decreased messages are sent to the CNS. Sensory adaptation occurs due to continual stimulation over a period of time. Exception to cerebellar processing of sensation is that of spinal reflex arcs in which the sensory signal is relayed through the spinal cord and back to the periphery for instantaneous reaction, such as the patellar (knee jerk) reflex.

Person's central nervous system (P = CNS). CNS sensory processing pathways have been hypothesized and examined via neural imaging. However, the exact pathways and neurochemical reactions of cerebral sensory processing continue to be investigated. It is known that several areas of the brain are used for sensory processing, including the thalamus, orbitofrontal cortex, limbic system, postcentral gyrus, occipital lobe, and cerebellum. Gregory (2013) has illustrated simplified sensory pathways in Figure 5.2.

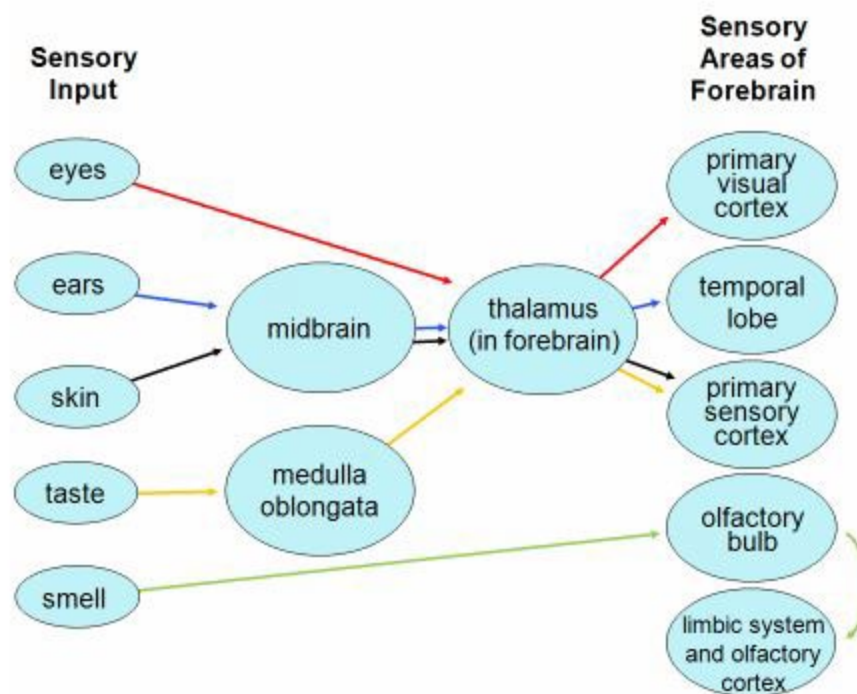


Figure 5.2. Sensory pathways. (Gregory, 2013).

Specific pathways are activated depending on the type of sensation, in addition to the area of sensation. For example, a drop of lemon juice on the hand will elicit a tactile sensation, while a drop of lemon juice on the tongue will provide both tactile and gustatory sensations.

I highlight the importance of processes involved in obtaining sensation from the external environment and, in turn, opportunity for awareness of the sensation. Aging

often alters sensory receptor cells in terms of degradation to quality and efficiency of transduction, such as seen with visual changes with age. Changes in peripheral sensory acquisition may distort or alter messages to the CNS for processing. Once the message, accurate or not, is received to the CNS for processing, numerous factors play a role in perception formation. Attention to the circuitry involved in perceiving one's environment is important for recognizing areas of influence and possible intervention.

Awareness of sensations can be placed along a continuum. As sensations are received to the CNS, the person may be fully aware, such as when a light is turned on in a dark room. Or, the person may be unaware of sensory messages, such as that of proprioceptive input for body positioning. However, selective attention and mindfulness to sensations can alter awareness. As a person eats a meal, if they are tuned into a television show while they eat, they will be less aware of tastes and swallowing as their selective attention is on the television. If the same person is eating a meal in a dim, quiet, calm environment and they are attending to the distinctive tastes of the meal, they will be more fully aware of gustatory sensations.

Cognitive processing via physiological means tends to go on without much conscious awareness. Through proprioceptive input, a person's body is able to maintain posture while sitting without awareness or thought. Conversely, personhood and identity lend towards increased awareness and complexity for thought formation. A person is more aware of decisions made based on interests or past memories than they are aware of neural cell growth. Once sensory messages enter the CNS, numerous factors create a filter to perception formation.

Cognitive functioning. Cognitive functioning in the older person is reliant on basic physiological processes, stable bodily functioning, and is enhanced with body schema (Pitron & de Vignemont, 2017). Habituation is a crucial factor for sensory processing and selective attention. For example, the CNS has ability to reduce awareness to habituated sensations, such as the sound of a humming fan or trickling water in the background.

Presence of pathology and/or medications may alter cognitive processing functioning, as well as access to memory. An example of altered cognitive processing due to pathology can be seen in dementias associated with AD compared to Parkinson's disease. Habitual movement and routines are diminished with pathology in the basal ganglia attributed to Parkinson's disease. Individuals with Parkinson's disease often forget to swallow or blink due to loss of cognitive processing in the areas of the brain which control these routine behaviors. Conversely, this area is not typically impacted in AD, and a person can continue to rely on procedural memory and routine formation despite diminished cerebral cortex functions.

Neuroplasticity is increasingly recognized across the lifespan as the ability of the brain to grow and adapt as a result of environmental stimulation and engagement (Carulli, Foscarin, & Rossi, 2011; Hurley & Noe, 2003; Neidl et al., 2016). Recent evidence suggests neuroplasticity can be seen in diseased brains, including those with cognitive impairment and dementia (Fischer, Sananbenesi, Wang, Dobbin, & Tsai, 2007). Neuroplasticity allows for development and growth of cognitive reserve (Whalley, Deary, Appleton, & Starr, 2004). Cognitive reserve is increased density of neurons and neural

cell growth as the result of an active, healthy, and fully engaged life, and can be observed in older adults.

Personhood. Gerontologists recognize the inherent value of personhood and identity, which must be considered in this model. Over one's life course, numerous influences impact development. Life course theory (Elder, 1998) provides grounding in the complexity of evolvment in personhood over the life span. Contextual influences including culture are vast as seen in ecological systems theory (Bronfenbrenner, 1979). Development throughout the life course plays a role in forming preferences, interests, and occupational opportunities. Moreover, a person's occupational history defines prior patterns of behavior and provides depth to an individual's experiences (Kielhofner, 2008). Innate personality characteristics, along with emotion, also provide a filter in coding sensation prior to perception formation. For example, a person who has a long history of depression and tends to have a pessimistic outlook may perceive sensations as more painful, than someone who has no signs or history of depression and is generally optimistic (Ramírez-Maestre, Esteve, & López, 2012). Memories have a similar role and can influence emotion, such as that seen in post-traumatic stress disorder or general anxiety disorder, when typical sensations may be paired with traumatic memories and illicit negative responses (Hannibal & Bishop, 2014).

These complexities of neural communication occur continually for the individual to process sensations from the environment. Rate of perception formation is dependent on the functioning of neural communication, but can be almost instantaneous in the typical adult. Degenerative cognitive impairments may also impact components involved in sensory processing and awareness. For example, a person with dementia can have

delayed auditory processing in which case their sensory receptors obtain auditory information, but there is a delay in messaging to the brain and/or to perception of the sound. Once the CNS is able to process sensory messaging, perception of the sensation is formed. Perception is the body's ability to interpret and respond to sensory stimulation (Gibson, 1966).

Response(s). If the perception elicits the need for behavior, a response is sent out from the CNS into the peripheral nervous system to prompt motor activation of the muscles and a behavior is completed. Through neural communication, the CNS also has the ability to inhibit continued communication of the perception, so that the thought or perception is no longer present.

Behavior (B). Simply put, behavior is a result of internal or external sensory stimulation (Pavlov, 1927). Behavior is precipitated by the need for activation after perceiving stimuli. Activation can take a variety of forms, including thoughts, memories, metacognition, emotion, and movement. A typically aging older adult has the ability to filter stimuli and activate desired patterns of thought and behavior. A person with dementia loses the ability to appropriately respond to stimuli through CNS integration and modulation. This person may also lose the ability to consider future consequences and alternative thoughts, as seen in theory of mind (Moreau, Rauzy, Viallet, & Champagne-Lavau, 2016).

I suggest description of behavior causation must consider environmental stimuli, sensory processing, and a filter of cognition and personality. When working with adults with dementia, these factors should be considered as they relate to behavioral expression. More specifically, during times of challenging and maladaptive behavior as seen with

BPSD, nonpharmacological intervention should target these areas for behavioral improvement.

Application of this model can be appropriate at any point in time for individuals across the lifespan. It is presented here as an explanation of cognitive and biological factors involved in person-environment interactions. With increased understanding of this process, utilization can promote increased validity and identification of areas for intervention when addressing behavioral concerns in those with cognitive impairment and dementia.

Dynamic Model of Environment Interaction for Those with Neurodegenerative Cognitive Impairment

Living with neurodegenerative cognitive impairment has significant consequences on interactions with the environment. Evolving abilities of the aging person also alter affordances of an environment. Neurodegenerative cognitive impairment decreases one's ability to function independently as they were able to at younger ages. This promotes the need for increased reliance and interaction within the social environment with increasing dependence on a primary caregiver. Additionally, degradation of the nervous system's ability to acquire and process incoming information from the environment alters perception formation and abilities to engage in meaningful and purposeful behaviors. Using evidence presented in this dissertation, as well as insights gained while practicing as an occupational therapist, I have created a model illustrating the environmental interactions for older adults living with cognitive impairment and their primary care partners as these evolve over time and the life course (Figure 5.3).

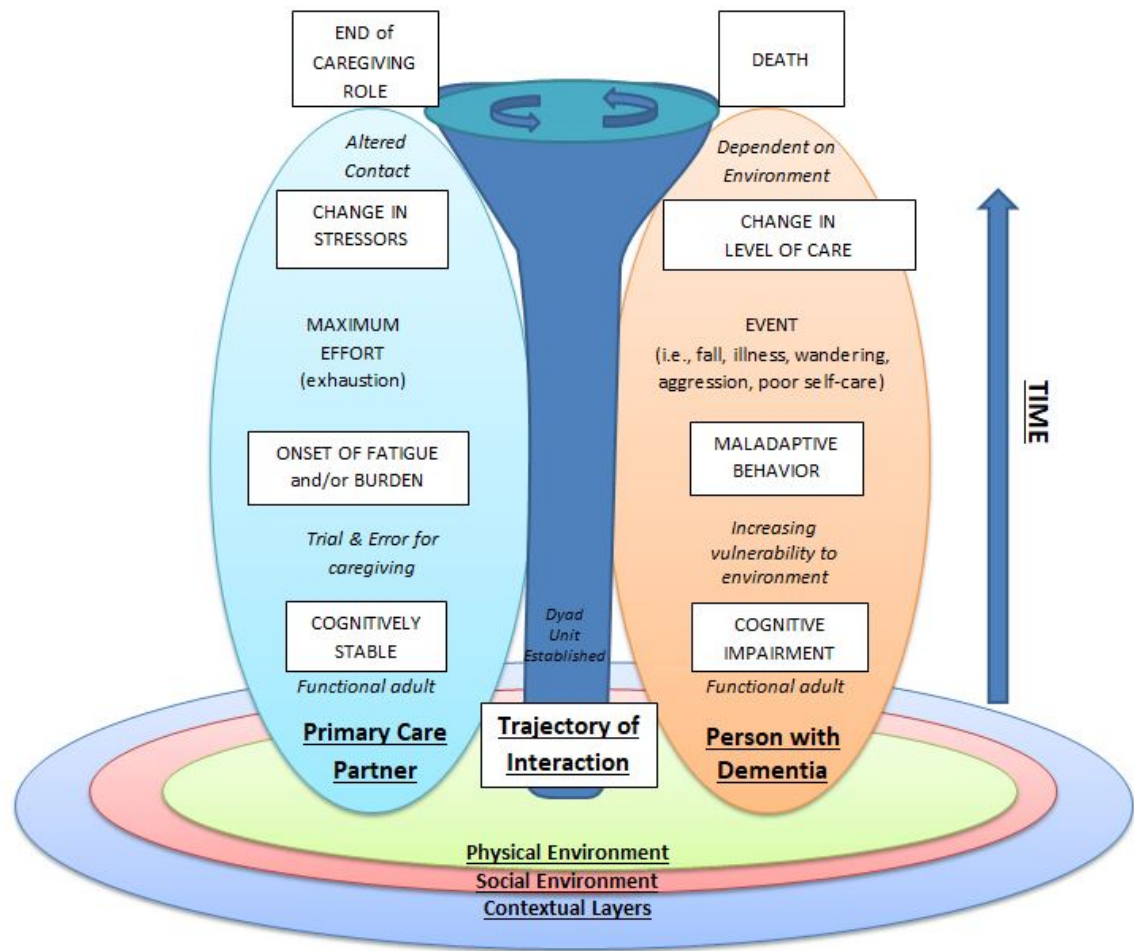


Figure 5.3. The ecological model of care: Aging with dementia behaviors.

The proposed model (Figure 5.3) is grounded in environmental layers and explores evolution of the interdependent dynamic among the social dyad between the person with cognitive impairment and their primary care partner over the course of time. This model has five major components: environment, time, person with dementia, primary care partner, and the trajectory of interaction.

Environment. The model in 5.3 uses environments as central underpinnings to experiences by adults with cognitive impairment and their care partners. Environmental

influences are depicted by overlapping ovals at the bottom of the model, but are implied to have a three-dimension spatial and temporal influence as people involved cannot be removed from environment. The physical environment provides structure and support for living. Individuals always have contact with the physical environment, and so, it is depicted as the foundational layer of this model (indicated in green in figure 5.3).

Natural and built environments offer affordances allowing for or disallowing access and engagement. But, with declining competencies due to aging and cognitive impairment, there is potential for evolving incongruences and maladaptive behavior, as described by environmental press (Chaudhury, Cooke, & Frazee, 2013; Lawton & Nahemow, 1973).

When considering environmental interactions for this population, the social environment must be acknowledged due to the nature of caregiving that is needed with advancing cognitive impairment. The red oval at the bottom of the model in figure 5.3 indicates social environments. The social environment includes the primary care partner, as well as an array of other social input and can be described as the social space (Wiles et al., 2009). Significant implications on the quality of life and well-being of both the care partner and the care recipient dyad have been identified (Sayer, Whitlatch, Lyons, & Zarit, 2002). Congruencies in perceptions of care, socialization, and personal need sway quality of life for those involved toward positive well-being, whereas incongruence in the social dyad can have grave negative ramifications (Kahana, 1982; Moon, Townsend, Whitlatch, & Dilworth-Anderson, 2017).

As seen in ecological systems theory, contextual layers are embedded into the trajectory of environmental interactions (Bronfenbrenner, 1979). Contexts, such as family, friends and laws and regulations, influence each circumstantial situation and are

participant to each individual function. For example, a person living in an assisted living facility is surrounded by the rules and regulation of the facility and should behave accordingly. Both the person with dementia and their primary care provider are impacted but such contextual surrounds of the setting and situation. The impact of such contextual layers is inseparable to any given moment in time or transaction with the environment.

Time. Temporality is a crucial element of the model, as neurodegenerative cognitive impairment worsens with time. The model is oriented with time as the vertical axis as indicated by the arrow on the right. As cognitive impairment worsens, multiple areas of environmental interaction are impacted. Cognitive function, including safety awareness, problem solving, sequencing of care tasks, and initiation of activities all face decline with time. Physical ailments of aging are increasingly present with time; including onset or increase in arthritis, declined vision and hearing, increasing weakness with aging (sarcopenia), and decline in coordination have potential to influence negotiability and access to physical environments. Because of these declining abilities, there is increasing vulnerability to environmental surroundings with time and increases in impairment (Wiles, 2011). There is also an increase in need for social support and care provision from others with time and increased impairment.

Primary care partner. Individuals who become primary care partners for someone with dementia may or may not have experience with such care. Roles prior to that of care partner vary, with spousal relationships being common (Braun et al., 2009). This was noted in the qualitative data described in chapter 4. Other care partners might have the role of child, sibling, distant family, friend, or paid care partner. The primary

care partner is the person who maintains continual contact with the person throughout the cognitive impairment continuum, often overseeing care until death.

Introduction of the trajectory of interaction does not begin until the care recipient has need for assistance in any areas of life, such as cooking, transportation, or scheduling appointments. The primary care partner needs to be cognitively stable enough to provide adequate assistance as needed. Often times, assistance in caregiving proceeds by trial and error and the primary care partner may not know exactly how to help the person with dementia as their condition worsens (Whitlatch, Femia, Judge, & Zarit, 2006). With time, continual adaptation to changes in care, as well as the demands of caregiving itself, creates perceptions of fatigue and possible burden for the primary care partner (Leven et al., 2013; Molnar & Frank, 2018). Care partners often suffer through this time silently, but get to a point of maximum effort in caregiver often accompanied by exhaustion. A shift in care is seen at this point, as increased social support is needed for the primary care partner and the person with dementia, leading to the transition to the therapeutic landscape for the person with dementia. With this transition, the care partner often feels a sense of relief as they are no longer solely responsible for care, but there are new worries. New worries might include training the new caregivers, oversight of acute medical needs, finances, and planning for future care of the person with dementia. As the person with dementia nears death, there is an increased presence by the primary care partner until death. Death of the person with dementia is the end of the caregiving role, and the primary care partner works through remaining affairs, grief, and recovery.

Person with dementia. Older adults with dementia often go through the first stage of the disease without notable recognition of changes at the neurobiological level.

They remain functional in adult roles and independent. With time, onset of cognitive impairment is felt through increasing lapses in memory, increasing disorientation, and difficulty with sequencing among other changes in cognitive function. As the ability to independently function declines, there is increasing vulnerability to environmental stimuli. The person is less able to adapt and problem solve in various situations, and competencies decrease in surrounding environments. Apathy may begin, as well as maladaptive or adverse behaviors as the person moves out of the zone of optimal performance as defined by Lawton and Nahemow (1973). With time, environmental demands become too much and the person often experiences a significant event requiring temporary or permanently increased care. Events are often related to caregiver burden and may include an injurious fall, serious illness, problematic wandering, BPSD with aggression, or difficulty with self-care (Afram et al., 2014). Increased need for assistance, need for skilled care, care partner health, and dementia-related behaviors often initiates movement towards higher levels of care (Buhr, Kuchibhatla, & Clipp, 2006; Wackerbarth, 1999, 2000).

Transitions in and out of facility-based care are often very taxing on function for the person with dementia. Decreasing competencies and limited ability to adapt to new environments prompts depression, apathy and decreased independence. For this, there is growing dependence on environmental supports for safety and well-being until death. If the environment (physical and/or social) is not congruent with the person's needs, wants, and preferences, declining quality of life and reduced well-being occurs prior to death (Kahana, 1982; Moon, Townsend, Whitlatch, and Dilworth-Anderson, 2017).

Trajectory of interaction. Acknowledging the continuum of cognitive decline, I suggest interactions begin with two healthy, functioning older adults, parallel, and not yet engaging in social exchange from a care provision stand point. The first stage of dementia is at the molecular level and not detectable from behavioral symptomology, so the person continues to function independently.

With progression of time and evolution of neuropathology, cognitive impairment begins to appear in terms of decreased executive functioning, memory lapse, and possible decreased safety awareness. Introduction of the care provision dyad begins at this point, as indicated in the model by the two-way arrow between the care provider and the person with dementia.

Continued worsening of cognitive abilities requires the need for regular interactions with the care provider and increasing vulnerability to the environment. Heterogeneity of the lived experience in aging, care partner dyads, and environmental affordances requires trial and error attempts provided by the care provider. For example, a shower chair may be introduced for increased safety while bathing. The person with dementia may positively respond and use the chair safely, or the person may become confused with the addition of the chair and insist on its removal. Specific adaptation techniques can be applied to allow for increased time prior to onset of adverse behavior

With the progression of neuropathology and decreasing congruence of the person-environment fit, there is decreased safety and functioning in the typical environment. The addition of physical environmental interactions is added to that of social interactions and is indicated in the model by an arrow with three points (the person, the primary care partner, and the environment). Increased dependence on the environment often facilitates

adverse and maladaptive behavior from the person with dementia. Their care provider attempts to manage behavioral outbursts and problems, but there is often an increasing sense of burden and pressure to maintain safety and functioning. Depression and stress of the care provider is often associated with this stage.

Despite care providers' maximum effort to provide adequate care for the person with dementia, there is a point in time that the typical community environment is no longer suitable for the person with dementia. This time is indicated by a multi-point arrow representing the complexity of environmental interactions and influences. An event occurs of some kind which facilitates a significant change in the level of care needed. Precipitating events may include a fall, illness (often pneumonia), unsafe wandering, severe agitation or aggression, and bowel and/or bladder concerns. These events indicate a need for increased support from an environmental and care provision stand point.

At this time, the person with dementia changes levels of care (Kearns and Andrews, 2005; Rowles & Teaster, 2016; Williams, 1999; Williams, 2002). Often times, there is an addition of paid caregivers or relocation to higher levels of care, such as in an assisted living or a nursing home. But, it may also include addition of paid care providers in the home, and increased home-based health and rehabilitative services. With these changes, the primary care provider experiences changes in stressors. There are other supports to provide care, but there are also new worries, such as with training new staff, aiding in transitions to new living situations, and a change in dynamic of care provided.

With time and neuropathology involvement, the person with dementia grows to be completely dependent on their surrounding environment. In the final stages of dementia,

the person is entirely dependent on others to assist with nutrition and hydration, self-care hygiene, and daily activities. There are intertwined interactions with environment for successful engagement, quality of life, and life maintenance. As their function declines and they near the end of their life, particularly for those in institutional settings, the primary care provider may have increased contact with them through more frequent visits and spending more time with their relative (High & Rowles, 1995). The contact allows for end of life preparation by primary care providers. In the suggested model, the trajectory of interactions ends with death of the individual with dementia. The role of primary care provider comes to an end.

Discussion and Implications

Environmental gerontology theories support the development of a model describing the relationship among behavior, environment, sensory processing, and cognitive aging. The suggested model incorporates and expands theories beginning with Lewin's (1936) equation of behavior as a function of the environment, Bronfenbrenner's (1979) contextual layers, Lawton and Nahemow's (1973) environmental press, and neuroscience-based sensory processing theories (Churchland & Sejnowski, 1988). These all offer key components within a dynamic interplay of concepts related to behaviors in those with dementia.

This conceptualization of experiences of those living with cognitive impairment offers a framework for understanding processes and trajectories involved in care. Embedded within physical, cultural, and social contextual layers, the person with dementia and their primary care partner create a dyadic relationship. As explained by Rowles (1983) and Cutchin (2001), the dyad works through time in continual attempts at

accommodation to be fully integrated within each person's surroundings. Cutchin (2001) termed *place interaction* as experiences of problem solving and negotiation of environments in order to maintain connectedness with one's surrounding place. The model presented above illustrates, first, the person's ability to understand the environment through sensation and in turn behavior, and second, the trajectory of interactions for problem solving and attempts to accommodate despite declining cognitive abilities.

It is important to note, that despite an increased dependence on the environment, vulnerability is not deemed to be necessarily a negative experience for the older person (Cutchin, 2003; Hammarström & Torres, 2012). Evidence of the subjective experiences of environmental vulnerability may be met with acceptance, passivity, and appreciation for support (Wiles, 2011). With vulnerability comes opportunity for incongruence and care burden. For the older person, as sensory systems and sensory processing abilities change, so do the experiences of interaction with the environment. When addressing behaviors of those with mild cognitive impairment and dementia, it is most consequential to orient assessment and intervention of behaviors to environmental congruence and sensory stimuli.

Application of the model provides numerous opportunities for improved understanding of the experience of aging with cognitive impairment, as well as for the potential for intervention. Long-term goals of this model are to recognize opportunities for decreased emotional and behavioral strain of aging with cognitive impairment, as well as decreased caregiver burden and distress. The model aligns with older adults' desire to remain in their home for as long as possible. Further work is needed to test and confirm

aspects involved in this model, as well as identification and/or creation of instrumentation for assessment.

Conclusion

Application of the proposed model provides numerous opportunities for intervention by various disciplines to improve experiences of those living with and around cognitive impairment. Gerontology offers an avenue for advocacy of this model and the trajectory of environmental interactions for those with cognitive impairment. Social sciences may use the model to better understand the roles of primary care partners, dynamics of burden throughout the continuum of impairment, and areas in which the person with dementia may need additional support from the social environment. And nursing staff can use the model to more empathetically understand environmental interactions and influences. A focus on congruence of person-environment fit, both socially and physically, and the trajectory of environmental interactions can have tremendous effects on quality of life and comfort throughout the end of life.

CHAPTER 6. SYNTHESIS

“I’ve learned that people will forget what you said,
people will forget what you did, but people will never forget how you made them feel.”

— Maya Angelou

During the process of aging, neural functioning, cognitive abilities, and sensory systems change (Humes, 2015; Gutman, 2008). While memories and experiences accumulate throughout the lifespan, access to and existence of neural pathways for cognitive reminiscence becomes compromised when a person is living with cognitive impairment and dementia. If concepts such as agency, independent function, and competency are stripped away (Wahl, Iwarsson & Oswald, 2012), then what is the interplay between behavior and environment? Exploration of the interplay has been a goal throughout this dissertation.

Clinical observations as an occupational therapist spawned a hypothesis that dementia often presents with ASD-like behaviors. Further, I found such behaviors positively responded to sensory-based interventions that are commonly used in ASD intervention. At the time of these observations, minimal evidence or literature existed to support this hypothesis. And so, research questions were posed and a study was designed and implemented to address this gap.

In specific aim 1, I demonstrated statistically significant findings to confirm that adults with neurodegenerative cognitive impairment exhibit behaviors similar to that of individuals with ASD using a cross-sectional design. Specifically, younger age of onset and advanced cognitive impairment were associated with higher reports of exhibited

ASD behaviors (Rossor, Fox, Mummery, Schott, & Warren, 2010; Savva, 2009). It is significant to note that this is the first study to identify such behaviors in a variety of dementia types, including Alzheimer's disease.

Specific aim 2 assessed behaviors, environmental features, care partner perceptions, and sensory processing preferences of community-dwelling adults with mild cognitive impairment or dementia. Findings revealed congruence among these aspects for the individuals who participated (Kahana, 1982; Iwarsson, 2005). For example, Pamela exhibited some challenging behaviors. But, she appeared to be in congruence with her environment, because she had access to emotional support services, she was engaged in hobbies and community events, and her primary care partner was in tune with supporting her needs. She was able to be active and engaged in her life as a community-dwelling adult with cognitive impairment because of these congruencies. Such compensating congruencies may have been a major factor promoting ability to continue to reside at home despite cognitive impairment for all participants.

Study two had a goal to observe behaviors of participants. Specifically, observations oriented toward behaviors characteristic of ASD was included in data collection. This goal was created following study one which found these behaviors to be prevalent in later stages of cognitive impairment and in those with early diagnosis. During recruitment, it was found that participants with advanced stages were no longer living in the community or their care partners declined participation. As a result, observations that were included were those of individuals with mild cognitive impairment and early-stage dementia. Behaviors characteristic of ASD were observed in a few participants who reported to have such behaviors throughout their adult lives. This may

lend to the notion that ASD behaviors in early stages of cognitive impairment may be due to underlying personality characteristics (Dudas et al., 2017). Observations of those with late-stage dementia are needed to add to the description of behaviors and sensory processing patterns throughout the continuum of cognitive impairment.

Of participants with cognitive impairment in study two, all had involvement of sensory processing patterns different than that of typical adults of the same age in at least one of the four categories of the Adult Sensory Profile (Brown, Tollefson, Dunn, Cromwell, & Fillion, 2001). Maladaptive behaviors were not observed in response to sensory processing patterns outside of the norm. As an example, Ronald was much more sensation avoiding than normative data provided by the Adult Sensory Profile. His behaviors lean toward this as he prefers alone time during the day and avoids large-store shopping. Similar to behaviors characteristic of ASD, maladaptive behaviors associated with sensory processing may not be prevalent until later stages of cognitive impairment.

Data to address specific aims 1 and 2 facilitated the development of a dynamic model explaining evolving relationships among the environment, the person, and behavior through a gerontological lens. With this model, environmental interactions that are common along the continuum of cognitive impairment were illustrated. Buckley and Toyozumi (2018) depict the closed loop system with environmental sensory stimulation promoting behavior. Yet, they fail to examine influences of cognition and personhood in terms of perception formation. And so, the current model adds depth to established system-based approaches.

The model presented and described in chapter 5 has two components. One component uses a systems approach to illustrate behavior in any given instant. This

system can then be applied in a second, more dynamic component, illustrating the trajectory of environmental interactions that a person experiences. Grounded in evidence gained in this dissertation, the trajectory of interactions model provides a framework to understand experiences of social and physical environments for people as they age with cognitive impairment and their primary care partners. The trajectory of interactions surrounding the dyadic relationship of these two people is a unique contribution to the field of environmental gerontology.

Findings of this dissertation begin to describe the relationship of behaviors observed in early-stage dementia and ASD, explore behaviors, environments, and sensory experiences of community-dwelling adults with cognitive impairment, as well as describe a hypothesis of the trajectory of environmental interactions. Additional exploration of behaviors in later stages of dementia, as well as in different living environments, will create a holistic picture of environmental interactions throughout the continuum of cognitive impairment.

Limitations of the Studies

Limitations of the studies need to be acknowledged. All participants of this study were predominately European American with high educational attainment living in one geographical region, thereby limiting generalizability of the study findings. Participants were enrolled in the University of Kentucky Alzheimer's Disease Center (UK ADC) longitudinal cohort, and accustomed to research participation and involvement. Participants lived in an urban region and were all of middle class socioeconomic status.

In study one (chapter 3), report of autism spectrum disorders (ASD) in a geriatric cohort was conducted using a cross-sectional approach. The survey used, the Gilliam

Autism Rating Scale, 2nd edition (GARS-2), (Gilliam, 2006) is a validated assessment categorizing behaviors as ‘autism likely/probable’ or ‘autism unlikely.’ The assessment is validated in persons aged 3-22 years of age. It is currently not validated for older adults. And so, the GARS-2 is used as an exploratory tool to described behaviors of older adults with mild cognitive impairment or dementia. This cross-sectional approach shows association but does not link causality of the behavioral relationships. Results from this study should be used with caution and offer an exploratory description to similarities in behaviors between ASD and dementia.

Study two (chapter 4) recruited from participants in study one who completed the GARS-2 assessment. GARS-2 results were used to support observation findings in the field. Again, the GARS-2 is not a validated tool with this population. Of those who were cognitively impaired in this study, eight had a diagnosis of MCI and only one had a diagnosis of dementia. Because of this, limited representation from those with advanced cognitive impairment was seen. Also, this study was focused on experiences of community-dwelling adults. But, environmental influence and behavioral disturbance may be at its highest in later stages of the disease, when people are typically placed in institutional care.

Finally, the ecological model of care: aging with dementia behaviors (chapter 5) was developed using data from studies one and two. Homogeneity in the sample and minimal involvement of those with advanced cognitive impairment are continued limitations. The model has not yet been tested for validity and reliability. Caution should be taken during application of this theory until it has been tested further. Despite these limitations, findings of this dissertation provide new insights and knowledge into

the relationship among behavior, environment, and sensation for those living with cognitive impairment.

Future Research

Work completed in this dissertation has allowed for recognition of numerous areas to move forward with additional research. Identification of ASD behaviors in a geriatric cohort with mild cognitive impairment or dementia is a substantial finding. Additional research is needed to identify causal relationships of these associated behaviors. Findings illuminate that early age of onset and advanced cognitive impairment significantly increase the frequency of these behaviors. This evidence is descriptive and does not yet answer why such overlap in ASD behaviors and dementia behaviors exist. I continue to question if this overlap is due to similarities in neuropathology, comparable sensory processing deficits or driven by environmental congruence. Behavioral life histories would also add description on whether these behaviors existed in the past. Several additional questions remain after concluding this study. At what stage in the continuum of cognitive impairment do symptoms/behaviors emerge, and do the behaviors terminate in late stages of dementia? What causes behaviors to increase, and what are care partners doing to help minimize such behaviors? Does emergence of ASD behaviors correlate with moves to institutional care? Do interventions, both pharmacological and nonpharmacological, overlap to effectively treat behaviors of ASD and dementia?

Additional research is needed examining neuropathology between both conditions. Access to the UK ADC database may allow for exploration of such findings for those with dementia. Partnership with researchers who have access to

neuropathology of ASD would likely identify areas of neuroanatomical overlap. Further definition of behaviors characteristic of ASD and dementia is needed. Comparison of assessment tools, such as the GARS-2 and the Neuropsychiatric Inventory, may strengthen results of this study and highlights additional areas for investigation.

Findings of the second study also foster continued research opportunities. Of those who participated, three participants had ASD behaviors frequent enough for classification as autism likely/unlikely. Upon observation, these individuals did not present as someone who has ASD. Instead, there may be underlying personality traits or undiagnosed personality disorders that are similar to ASD behaviors, such as broad autism phenotype. If this is so, what other personality traits are identifiable? How does this predict behaviors in later stages of cognitive impairment?

Also in question is the reliability of observation. It is known that individuals with cognitive impairment may act differently around primary care partners than around researchers. In moving forward with behavioral observation, additional variables may be considered in order to provoke potential circumstantial behavioral occurrence. Variables such as extreme fatigue, stress, time of observation, increasing the number of visits or length of stay may trigger ASD behaviors more so than what was afforded in study two.

Further, it is intriguing to question whether those with highest reports of ASD behaviors were not available for participation due to challenging behavior onset, environmental incongruence, sensory processing deficits, or a combination of these factors. Does this identify a window of time in which behavior characteristic of ASD emerge? And, does this possibly contribute to feelings of maximum effort and fatigue for

care partners? Additional work is needed to observe behaviors in various living environments and across the cognitive impairment continuum.

Further exploration of the relationship between sensory processing and behavior is warranted. Further, opportunities utilizing sensation and environmental stimuli should be considered for intervention approaches for such behaviors. Recent evidence supports use of multi-sensory exposure to specifically improve cognitive function and decrease Alzheimer's disease pathology in mouse models (Martorell et al., 2019). The research highlighted neural benefits of plaque and tau removal using visual and auditory stimuli. These benefits were magnified when sensory stimuli was simultaneous compared to one sensory input at a time. This new research lays out potential implications of sensory-based interventions for those with dementia. New directions toward understanding biological and behavioral changes as a result of specific multi-sensory exposure are intriguing.

Numerous areas for research arise from the model explaining the trajectory of environmental interactions in care for those with dementia. The model has been based on data collected in the community. Application of the model in various levels of care, including facility-based care, is needed. The model established here needs to be tested with participants throughout the cognitive impairment continuum. What level of cognitive awareness is needed to have active and meaningful interactions with the environment? What role does the environment have on behavior when cognitive functions are almost entirely diminished?

Several goals from the model lead continued research directions. A goal to further refine and operationalize the model is to create an assessment tool which

measures levels of congruence to environments, both physical and social. The tool could assess perceptions of those with dementia in regards to their actual and desired abilities to interact with the physical and social environments. As communication diminishes, the tool may transition to observation of environmental interaction success. A long-term goal for clinical intervention may be to develop strategies that prolong the time before adverse behaviors emerge and caregiver burden intensifies. Another goal of intervention may be to identify accommodation strategies and/or modifications of environments to best meet the needs and sensory preferences of the person living with cognitive impairment.

There are countless opportunities to build on findings of this dissertation. Specifically, I plan to investigate neuropathology involvement in those with dementia who were reported to have ASD behaviors. I also plan to measure the comparison of assessments between the GARS-2 and Neuropsychiatric Inventory. Given opportunities in the future, I plan to test the model presented here through interview and observation of the dyad unit. Analysis will refine the model for added reliability and validity. I also would like to move forward with sensory-based interventions for behavioral management of those with cognitive impairment.

Future directions also lend towards exploration of the trajectory of environmental interactions. Emphasis will be placed on diverse environmental pathways, rather than the linear movement along the long-term care continuum. The linearity of long-term care is not tailored to meet unique needs of older adults, especially those with the highest reliance on environmental supports. By focusing on individual traits and characteristics, the best trajectory of environmental interaction may not be linear, but a unique path

dependent on individuality while living with dementia. Ideally, I would like to work with community-dwelling dyads to assess and implement individualized interventions while promoting congruence along a unique environmental trajectory.

At this point, it is appropriate to take a step back and fully appreciate the essence of the lived experiences involved in environmental interactions and behavioral expression for those with cognitive impairment and their care partner. Environmental gerontologists have described components of place, the meaning of place, and contextual surrounds of the environment. Humanistic approaches have offered a philosophical explanation to meaning of place connected with the past and memory formation (Rowles, 1983). These ideas have been elaborated through application of Deweyan pragmatism (Cutchin, 2001). Cutchin (2001) explored ideas of action and problem resolution as embedded within constantly evolving situations; this enabled him to better explain place integration for older adults. He identified that problems continually arise while aging and actions are taken to overcome problems *in situ*. The alternative is relocation to a more accommodating place. Problem solving, action, and future orientation via planning and worry were seen in care partner participants of study two in this dissertation. But one is hard pressed to recognize these concepts and processes in someone with dementia, as future orientation may be fading or less immediate to their conscious.

A gap is identified in the understanding of how someone with dementia behaves when future orientation erodes and consequences of action are forgotten. Continuing to explore a pragmatic approach to the essence of the present moment in time as experienced by the person with dementia is needed. Future-oriented action and resolution may be instinctual for care partners. But care partners may then be too hurried

or consumed by worry to recognize subtle environmental cues of the situation which sway behavior, because, as cognitive abilities decline, vulnerability to environmental stimuli increases. Environmental stimuli and biological abilities surrounding awareness of and reaction to sensation may offer substantial information in terms of behavioral causation in those with dementia. The modern gerontologist is emboldened to embrace older adults who are fully situated within and dependent on surrounding environmental stimuli.

Conclusion

Maladaptive and challenging behaviors exhibited in those with neurodegenerative cognitive impairment cause significant distress for the individual and those involved in care. Findings presented in this dissertation begin to demonstrate relationships among the environment, sensory systems, and behavior for this population. These findings allow for new opportunities to develop environmental, sensory, and behavioral interventions. Intervention which may offer relief from distressing behaviors and caregiver burden can have significant impact on the quality of life, well-being, and independence of both members of the dyad.

The environment has a significant influence on sensation and perception of those with cognitive impairment. Congruence and interactions with the environment can promote adaptive behavioral responses. In a time of trial and error for treatment and care approaches, this dissertation may offer guidance to those struggling with maladaptive behaviors and environmental incongruence. As with any doctoral dissertation, these studies are an ongoing story with next the chapter yet to be written.

EPILOGUE

My journey throughout life has allowed tremendous opportunity to promote comfort and well-being for others. I truly value the human experience, which I believe is enabled through sensation and perception of environmental stimuli. It is my continued goal to encourage maximized human experiences and comfort by focusing on using sensation and deeper understanding of the nervous system as it influences older adults with cognitive impairment.

Developing deeper understanding of the research process through the doctoral program has taught me so much regarding evidence-based methods, data collection, and the presentation of findings. The knowledge and skills gained will allow me to competently and confidently pursue additional research opportunities to continue my research agenda with the eventual objective of changing and improving care for those with neurodegenerative cognitive impairment. In addition, I have gained leadership abilities and skills through employment experiences as a clinical occupational therapist focusing on interventions across the lifespan, a therapy team leader, an area clinical coordinator for multi-state therapy clinics, and a national clinical educator for all rehabilitation disciplines. These roles and acquired skills fuel my passion to provide a voice and advocacy for those who may not be able to advocate for themselves.

Sarah, who was introduced in the prologue continued to have success in her environment. Her daughter emailed me several months after her discharge from occupational therapy services. Sarah no longer stood alone in the corners of the halls. Her daughter sent pictures of Sarah with her family and grandchildren, fully engaged and participating in holiday celebrations with her entire family. The services and techniques

implemented using an environmental and sensory-based approach allowed Sarah to regain awareness and attention to her surroundings, connect with her family, and remain in her surroundings with increased comfort. By grounding these techniques in evidence, I hope to be a player in the transformation of care for those living with dementia. Sarah's daughter provides strong affirmation of this aspiration.

Elizabeth,

I can't begin to thank you enough for the huge, positive impact you have made in mom's life. I was visiting yesterday, and the aide was talking about the huge turn around in all respects. Aside from the ADL goals, mom is just in a happier and more peaceful state of mind. A true blessing for her and everyone she interacts with.

One of the aides did mention that she just let mom eat with her fingers, since mom was having gagging problems when she tried to use the utensils, even the red ones. It may just be a short-term thing, or part of the continued deterioration. Regardless, mom is eating very well and enjoying her meals immensely, which in no way was she doing before.

Thank you so very, very much for working with mom. Your work and care is so crucial. You are touching many precious lives with your insights and dedication to the people you serve every day. And we are all very grateful for that.

Blessings,

Signed by Sarah's daughter

APPENDICES

APPENDIX A. CAREGIVER SEMI-STRUCTURED INTERVIEW GUIDE

1. Describe your relationship with the person who you care.
 - a) How did you meet?
 - b) How do you provide care for this person?
2. Describe the living situation and daily routines or rituals that you do with the person who you are caring for.
3. Describe some examples of how this person acts that you think is happening because of the dementia.
 - a) Do they have aggression or violent behaviors?
 - b) Does their behavior change throughout the day?
4. How do you respond if the person becomes upset?
5. Are there any behaviors that the person you are caring for displays that happen regularly or are persistent?
 - a) How often do you observe behaviors such as repetition, staring, touching, difficulty with transitions, over-arousal, etc.?
 - b) How do you and the person you are caring for cope with these behaviors?
 - c) Is there anything that helps to decrease unwanted behaviors or anything that makes them worse?
 - d) What is the environment/situation like before, during, and after?

APPENDIX B. ADULT SENSORY PROFILE

Adolescent/Adult Sensory Profile Self-Questionnaire

Name: _____ Age: _____ Date: _____
Birthdate: _____ Gender: M F

Are there any aspects of daily life that are not satisfying to you? If yes, please explain.

Instructions: Please check the box that best describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

Please answer all of the statements. Use the following key to mark your responses:

Almost Never: When presented with the opportunity, you almost never respond in this manner (about 5% or less of the time).

Seldom: When presented with the opportunity, you seldom respond in this manner (about 25% of the time).

Occasionally: When presented with the opportunity, you occasionally respond in this manner (about 50% of the time).

Frequently: When presented with the opportunity, you frequently respond in this manner (about 75% of the time).

Almost Always: When presented with the opportunity, you almost always respond in this manner (about 95% or more of the time).

	A. Taste/Smell Processing	Almost Never	Seldom	Occas- ionally	Fre- quently	Almost Always
1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).					
2	I add spice to my food.					
3	I don't smell things that other people say they smell.					
4	I enjoy being close to people who wear perfume or cologne.					
5	I only eat familiar foods.					
6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).					
7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).					
8	I go over to smell fresh flowers when I see them.					

Comments:

	B. Movement Processing	Almost Never	Seldom	Occas- ionally	Fre- quently	Almost Always
9	I'm afraid of heights.					
10	I enjoy how it feels to move about (for example, dancing, running).					
11	I avoid elevators and/or escalators because I dislike the movement.					
12	I trip or bump into things.					
13	I dislike the movement of riding in a car.					
14	I choose to engage in physical activities.					
15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					
16	I become dizzy easily (for example, after bending over, getting up too fast).					

Comments:

	C. Visual Processing	Almost Never	Seldom	Occas- ionally	Fre- quently	Almost Always
17	I like to go to places that have bright lights and that are colorful.					
18	I keep the shades down during the day when I am at home.					
19	I like to wear colorful clothing.					
20	I become frustrated when trying to find something in a crowded drawer or messy room.					
21	I miss the street, building, or room signs when trying to go somewhere new.					
22	I am bothered by unsteady or fast moving visual images in movies or TV.					
23	I don't notice when people come into the room.					
24	I choose to shop in small stores because I'm overwhelmed in large stores.					
25	I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).					
26	I limit distractions when I am working (for example, I close the door, or turn off the TV).					

Comments:

	D. Touch Processing	Almost Never	Seldom	Occas- ionally	Fre- quently	Almost Always
27	I dislike having my back rubbed.					
28	I like how it feels to get my hair cut.					
29	I avoid or wear gloves during activities that will make my hands messy.					
30	I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					
31	I am bothered by the feeling in my mouth when I wake up in the					

	morning.					
32	I like to go barefoot.					
33	I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).					
34	I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).					
35	I move away when others get too close to me.					
36	I don't seem to notice when my face or hands are dirty.					
37	I get scrapes and bruises but don't remember how I got them.					
38	I avoid standing in lines or standing close to other people because I don't like to get too close to others.					
39	I don't seem to notice when someone touches my arm or back.					

Comments:

	E. Activity Level	Almost Never	Seldom	Occasionally	Frequently	Almost Always
40	I work on two or more tasks at the same time.					
41	It takes me more than other people to wake up in the morning.					
42	I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					
43	I find time to get away from my busy life and spend time by myself.					
44	I seem slower than others when trying to follow an activity or task.					
45	I don't get jokes as quickly as others.					
46	I stay away from crowds.					
47	I find activities to perform in front of others (for example, music,					

	sports, acting, public speaking, and answering questions in class).					
48	I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					
49	I avoid situations where unexpected thing might happen (for example, going to unfamiliar places or being around people I don't know).					

Comments:

	F. Auditory Processing	Almost Never	Seldom	Occasionally	Frequently	Almost Always
50	I hum, whistle, sing, or make other noises.					
51	I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					
52	I have trouble following what other people are saying when they talk fast or about unfamiliar topics.					
53	I leave the room when others are watching TV, or I ask them to turn it down.					
54	I am distracted if there is a lot of noise around.					
55	I don't notice when my name is called.					
56	I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).					
57	I stay away from noisy settings.					
58	I like to attend events with a lot of music.					
59	I have to ask people to repeat things.					
60	I find it difficult to work with background noise (for example, fan, radio).					

Comments:

APPENDIX C. GILLUM AUTISM RATING SCALE, 2nd EDITION

Behavior, Communication, and Social Interaction Questionnaire

Directions:

Rate the following items according to the frequency of occurrence. Use the following guidelines for your ratings:

- 0 Never Observed** – You have never seen the individual behave in this manner.
- 1 Seldom Observed** – Individual behaves in this manner 1-2 times per 6-hour period.
- 2 Sometimes Observed** – Individual behaves in this manner 3-4 times per 6-hour period.
- 3 Frequently Observed** – Individual behaves in this manner at least 5-6 times per 6-hour period.

Circle the number that best describes your observations of the individual's typical behavior under ordinary circumstances (i.e. in most places, with familiar people, and in usual daily activities). Remember to rate every item. If you are uncertain about how to rate an item, delay the rating and observe the individual for a 6-hour period to determine your rating. Remember, every item should receive a score.

	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
Behavior				
1. Avoids establishing eye contact; looks away when eye contact is made.	0	1	2	3
2. Stares at hands, objects, or items in the environment for at least 5 seconds.	0	1	2	3
3. Flicks fingers rapidly in front of eyes for periods of 5 seconds or more.	0	1	2	3
4. Eats specific foods and refuses to eat what most people will usually eat.	0	1	2	3
5. Licks, tastes, or attempts to eat inedible objects (e.g. person's hand, books).	0	1	2	3

6. Smells or sniffs objects (e.g. person's hand, hair).	0	1	2	3
7. Whirls, turns in circles	0	1	2	3
8. Spins objects not designed for spinning (e.g. saucers, cups, glasses).	0	1	2	3
9. Rocks back and forth while seated or standing.	0	1	2	3
10. Makes rapid lunging, darting movements when moving from place to place.	0	1	2	3
11. Prances (i.e. walks on tiptoes).	0	1	2	3
12. Flap hands or fingers in front of face or at sides.	0	1	2	3
13. Makes high-pitched sounds (e.g. eee-eee-eee-eee) or other vocalizations for self-stimulation.	0	1	2	3
14. Slaps, hits, or bites self or attempts to injure self in other ways.	0	1	2	3
<p>Communication</p> <p>How does the individual communicate? (Please check one)</p> <p><input type="checkbox"/> Talks</p> <p><input type="checkbox"/> Signs</p> <p><input type="checkbox"/> Does not talk or sign</p> <p>Have they always communicated in this way? (Please check one)</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
15. Repeats (echoes) words verbally or with signs.	0	1	2	3
16. Repeats words out of context (i.e. repeats words heard at an earlier time; e.g. repeats words heard more than 1 minute earlier).	0	1	2	3
17. Repeats words or phrases over and over.	0	1	2	3
18. Speaks or signs with flat tone, affect, or dysrhythmic patterns.	0	1	2	3
19. Responds inappropriately to simple commands (e.g. "sit down," "stand up").	0	1	2	3
20. Looks away or avoids looking at speaker when name is called.	0	1	2	3

21. Does not ask for things he or she wants.	0	1	2	3
22. Does not initiate conversation with peers or adults.	0	1	2	3
23. Uses “yes” and “no” inappropriately. Says “yes” when asked if he or she wants an aversive stimulus, or says “no” when asked if he or she wants a favorite toy or treat.	0	1	2	3
24. Uses pronouns inappropriately (e.g. refers to self as “he,” “you,” “she”).	0	1	2	3
25. Uses the word / inappropriately (e.g. does not say “I” to refer to self).	0	1	2	3
26. Repeats unintelligible sounds (babbling) over and over.	0	1	2	3
27. Uses gestures instead of speech or signs to obtain objects.	0	1	2	3
28. Inappropriately answers questions about a statement or brief story.	0	1	2	3
Social Interaction	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed
29. Avoids eye contact; looks away when someone looks at him or her.	0	1	2	3
30. Stares or looks unhappy or unexcited when praised, humored, or entertained.	0	1	2	3
31. Resists physical contact from others (e.g. hugs, pats, being held affectionately).	0	1	2	3
32. Does not imitate other people when imitation is required or desirable, such as in games or learning activities.	0	1	2	3
33. Withdraws, remains aloof, or acts standoffish in group situations.	0	1	2	3
34. Behaves in an unreasonably fearful, frightened manner.	0	1	2	3
35. Is unaffectionate; does not give affectionate responses (e.g. hugs and kisses).	0	1	2	3

36. Shows no recognition that a person is present (i.e. looks through people).	0	1	2	3
37. Laughs, giggles, cries inappropriately.	0	1	2	3
38. Uses toys or objects inappropriately (e.g. spins objects, takes objects apart).	0	1	2	3
39. Does certain things repetitively, ritualistically.	0	1	2	3
40. Becomes upset when routines are changed.	0	1	2	3
41. Responds negatively or with temper tantrums when given commands, requests, or directions.	0	1	2	3
42. Lines up objects in precise, orderly fashion and becomes upset when the order is disturbed.	0	1	2	3
	Never Observed	Seldom Observed	Sometimes Observed	Frequently Observed

APPENDIX D. RECRUITMENT FLYER

UNIVERSITY OF KENTUCKY RESEARCH

**Investigation of the Relationship between
Behaviors and Memory**

**Sanders Brown Center on Aging Participants Needed for
Observation-based Study**



Description:

This study is designed to explore behaviors related to memory and thinking. Participation involves:

- A study partner interview
- A brief survey
- Two in-home observations

Participants in this study will receive a Complimentary Home Safety Assessment.

You May Be Eligible To Participate:

- Enrolled as a Participant at Sanders Brown Center on Aging
- Have a primary study partner who is willing to participate
- Live in the Lexington area

For more information, contact:

Elizabeth Rhodus or Dr. Shani Bardach

Sanders-Brown Center on Aging

University of Kentucky Alzheimer's Disease Center

030 South Broadway, Suite 5

Lexington, KY 40504

Phone: (859) 323-1331

Elizabeth.Rhodus@uky.edu

APPROVED

By Mallory Powell at 3:08 pm, Sep 07, 2017



**Sanders-Brown
Center on Aging**

An Equal Opportunity University

For more information on research studies see: www.UKclinicalresearch.com

REFERENCES

- Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M. H., Suhonen, R., Sutcliffe, C., . . . Hamers, J. P. (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J Am Med Dir Assoc*, 15(2), 108-116. doi:10.1016/j.jamda.2013.09.012
- Alwin, D. F. (2012). Integrating Varieties of Life Course Concepts. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 67B(2), 206-220. doi:10.1093/geronb/gbr146
- Alzheimer's Association. (2016). 2016 Alzheimer's Disease Facts and Figures. Retrieved from https://www.alz.org/documents_custom/2016-facts-and-figures.pdf
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders : DSM-4*.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
- Ayres, J. (1989). *Sensory Integration and Praxis Tests*. Los Angeles, California Western Psychological Services.
- Ayalon, L., Gum, A. M., Feliciano, L., & Arean, P. A. (2006). Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. *Arch Intern Med*, 166(20), 2182-2188. doi:10.1001/archinte.166.20.2182
- Baez, S., & Ibanez, A. (2014). The effects of context processing on social cognition impairments in adults with Asperger's syndrome. *Front Neurosci*, 8, 270. doi:10.3389/fnins.2014.00270

- Bakker, R. (2003). Sensory Loss, Dementia, and Environments. *Generations*, 27, 46-51.
- Barker, D., Eriksson, J., Forsen, T., & Osmond, C. (2002). Fetal origins of adult disease: strength of effects and biological basis. *International Journal of Epidemiology*, 31(6), 1235-1239.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from Asperger Syndrome/high-functioning autism, males and females, scientists and mathematicians (vol 31, pg 5, 2001). *Journal of Autism and Developmental Disorders*, 31, 603-603.
- Behrman, S., Chouliaras, L., & Ebmeier, K. P. (2014). Considering the senses in the diagnosis and management of dementia. *Maturitas*, 77(4), 305-310.
doi:10.1016/j.maturitas.2014.01.003
- Boecker, H., Ceballos-Baumann, A., Bartenstein, P., Weindl, A., Siebner, H. R., Fassbender, T., . . . Conrad, B. (1999). Sensory processing in Parkinson's and Huntington's disease: investigations with 3D H(2)(15)O-PET. *Brain*, 122 (Pt 9), 1651-1665.
- Boyle, P. A., Malloy, P. F., Salloway, S., Cahn-Weiner, D. A., Cohen, R., & Cummings, J. L. (2003). Executive dysfunction and apathy predict functional impairment in Alzheimer disease. *Am J Geriatr Psychiatry*, 11(2), 214-221.
- Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: a dyadic perspective. *Aging Ment Health*, 13(3), 426-436. doi:10.1080/13607860902879441
- Briesacher, Limcango, Simoni-Wastila, Doshi, Levens, Shea, & Stuart. (2005). The quality of antipsychotic drug prescribing in nursing homes. *The Journal of the*

American Medical Association, 165(11), 1280-1285. doi:
10.1001/archinte.165.11.1280

- Brodsky, H. & Burns, K. (2012). Nonpharmacological management of apathy in dementia: A systematic review. *American Journal of Geriatric Psychiatry, 20(7), 549-564.*
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge, MA: Harvard University Press.
- Brorsson, A., Ohman, A., Lundberg, S., and Nygard, L. (2011). Accessibility in public space as perceived by people with Alzheimer's disease. *Dementia, 10(4), 587-602.*
- Brown, C., Tollefson, N., Dunn, W., Cromwell, R., & Filion, D. (2001). The Adult Sensory Profile: measuring patterns of sensory processing. *Am J Occup Ther, 55(1), 75-82.*
- Buckley, C., & Toyozumi, T. (2018). A theory of how active behavior stabilises neural activity: Neural gain modulation by closed-loop environmental feedback. *PLoS Computational Biology, 14(1), E1005926.*
- Calkins, M. (1988). *Design for dementia.* Baltimore, MD: National Health Pub.
- Buhr, G.T., Kuchibhatla, M., & Clipp, E.C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist, 46(1), 52-61.*
- Calkins, M. P. (2004). Articulating Environmental Press in Environments for People With Dementia. *Alzheimer's Care Today, 5(2), 165-172.*

- Carulli, D., Foscarin, S., & Rossi, F. (2011). Activity-Dependent Plasticity and Gene Expression Modifications in the Adult CNS. *Frontiers in Molecular Neuroscience*, 4(50). doi:10.3389/fnmol.2011.00050
- Caselli, R. J., Langlais, B. T., Dueck, A. C., Locke, D. E. C., & Woodruff, B. K. (2018). Subjective Cognitive Impairment and the Broad Autism Phenotype. *Alzheimer Disease & Associated Disorders*, 32(4), 284-290. doi:10.1097/wad.0000000000000273
- Caserta, M. S., Lund, D. A., & Wright, S. D. (1996). Exploring the Caregiver Burden Inventory (CBI): further evidence for a multidimensional view of burden. *Int J Aging Hum Dev*, 43(1), 21-34. doi:10.2190/2dkf-292p-a53w-w0a8
- Champagne, T., & Stromberg, N. (2004). Sensory approaches in inpatient psychiatric settings: Innovative alternatives to seclusion & restraint. *Journal of Psychological Nursing and Mental Health Services*, 42(9), 34-44. doi: 10.3928/02793695-20040301-01
- Chaudhury, H., Cooke, H., & Frazee, K. (2013). Developing a physical environmental evaluation component of the dementia care mapping (DCM) tool, in Rowles, G.D and Bernard, M. (eds) *Environmental Gerontology: Making Meaningful Places in Old Age*. New York, NY: Springer Publishing Company.
- Christiansen, C.H., Baum, C.M. & Bass-Haugen, J. (2015). *Occupational therapy: Performance, participation and well-being*. (4th edition). Thorofare, NJ: SLACK.
- Chung, J. (2006). Measuring sensory processing patterns of older Chinese people: Psychometric validation of the adult sensory profile. *Aging & Mental Health*, 10(6), 648-655. doi:10.1080/13607860600648080

- Chung, J. A., & Cummings, J. L. (2000). Neurobehavioral and neuropsychiatric symptoms in Alzheimer's disease: characteristics and treatment. *Neurol Clin*, 18(4), 829-846.
- Churchland, P. S., & Sejnowski, T. J. (1988). Perspectives on cognitive neuroscience. *Science*, 242(4879), 741-745.
- Cohen, U. & Weisman, G. (1991). *Holding on to home*. Baltimore, MD: John Hopkins University Press.
- Cohen-Mansfield, J. (1986). Agitated behaviors in the elderly. II. Preliminary results in the cognitively deteriorated. *J Am Geriatr Soc*, 34(10), 722-727.
- Cohen-Mansfield, J., Thein, K., Marx, M. S., Dakheel-Ali, M., & Freedman, L. (2012). Efficacy of nonpharmacologic interventions for agitation in advanced dementia: a randomized, placebo-controlled trial. *J Clin Psychiatry*, 73(9), 1255-1261. doi:10.4088/JCP.12m07918
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Res*, 228(1), 59-64. doi:10.1016/j.psychres.2015.03.043
- Collier, L., McPherson, K., Ellis-Hill, C., Staal, J., & Bucks, R. (2010). Multisensory stimulation to improve functional performance in moderate to severe dementia--interim results. *Am J Alzheimers Dis Other Demen*, 25(8), 698-703. doi:10.1177/1533317510387582
- Courchesne, E., Redcay, E., Morgan, J. T., & Kennedy, D. P. (2005). Autism at the beginning: microstructural and growth abnormalities underlying the cognitive and

behavioral phenotype of autism. *Dev Psychopathol*, 17(3), 577-597.

doi:10.1017/s0954579405050285

Creswell, J. W. (2013). *Qualitative Inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J.W. (2014). *Research design: Quantitative, qualitative, and mixed methods approaches*. Washington, D.C.: SAGE.

Crowe, J. (2014). Professional Reasoning and Occupational Therapist's Use of a Multi-Sensory Environment for Clients with Dementia. *Physical & Occupational Therapy In Geriatrics*, 32(3), 198-209. doi:10.3109/02703181.2014.927947

Cummings, J., Mega, M., Gray, K., Rosenberg-Thomson, S., Carusi, D., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology*, 44, 2308–2314.

Cummings, J., Mintzer, J., Brodaty, H., Sano, M., Banerjee, S., Devanand, D. P., . . .

Zhong, K. (2014). Agitation in cognitive disorders: International Psychogeriatric Association provisional consensus clinical and research definition. *Int Psychogeriatr*, 27(1), 7-17. doi:10.1017/S1041610214001963

Cutchin, M. P. (2001). Deweyan integration: Moving beyond place attachment in elderly migration theory. *The International Journal of Aging and Human Development*, 52(1), 29-44.

Cutchin, M. P. (2003). The process of mediated aging-in-place: a theoretically and empirically based model. *Social Science & Medicine*, 57(6), 1077-1090. doi:
[https://doi.org/10.1016/S0277-9536\(02\)00486-0](https://doi.org/10.1016/S0277-9536(02)00486-0)

- Cutchin, M. P. (2018). Active relationships of ageing people and places, in M.W. Skinner, G.J. Andrews, and M.P. Cutchin (eds), *Geographical gerontology: Perspectives, concepts, approaches* (pp. 203-215). New York, NY: Routledge.
- Dewing, J. (2002). From Ritual to Relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1(2), 157–171. <https://doi.org/10.1177/147130120200100204>
- Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10, 171-177.
doi:10.1192/apt.10.3.171
- Dudas, R.B., Lovejoy, C., Cassidy, S., Allison, C., Smith, P., Baron-Cohen, S. (2017). The overlap between autistic spectrum conditions and borderline personality disorder. *PLoS One*, 12(9):e0184447. Published 2017 Sep 8.
doi:10.1371/journal.pone.0184447
- Duhigg, C. (2014). *The power of habit: Why we do what we do in life and business*. New York: Random House.
- Dunn, W., & Bennett, D. (2002). Patterns of Sensory Processing in Children with Attention Deficit Hyperactivity Disorder. *OTJR: Occupation, Participation and Health*, 22(1), 4-15. doi:10.1177/153944920202200102
- Dunn, W., & Westman, K. (1997). The sensory profile: the performance of a national sample of children without disabilities. *Am J Occup Ther*, 51(1), 25-34.
- Ecerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and Psychological Symptoms of Dementia. *Frontiers in Neurology*, 3, 73.
doi:10.3389/fneur.2012.00073

- Elder, G. H. (1998). The life course and human development. In Handbook of child psychology: Theoretical models of human development, Volume 1, 5th ed. (pp. 939-991). Hoboken, NJ, US: John Wiley & Sons Inc.
- Eska, K., Graessel, E., Donath, C., Schwarzkopf, L., Lauterberg, J., & Holle, R. (2013). Predictors of Institutionalization of Dementia Patients in Mild and Moderate Stages: A 4-Year Prospective Analysis. *Dementia and Geriatric Cognitive Disorders Extra*, 3(1), 426-445. doi:10.1159/000355079
- Fazlıoğlu, Y., & Baran, G. (2008). A sensory integration therapy program on sensory problems for children with autism. *Perceptual and Motor Skills*, 106(2), 415-422.
- Finkel, S. I., Costa e Silva, J., Cohen, G., Miller, S., & Sartorius, N. (1996). Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *Int Psychogeriatr*, 8 Suppl 3, 497-500.
- Fischer, A., Sananbenesi, F., Wang, X., Dobbin, M., & Tsai, L.-H. (2007). Recovery of learning and memory is associated with chromatin remodelling. *Nature*, 447, 178. doi:10.1038/nature05772
- Fitzsimmons, S., Barba, B., & Stump, M. (2014). Sensory and nurturing nonpharmacological interventions for behavioral and psychological symptoms of dementia. *J Gerontol Nurs*, 40(11), 9-15. doi:10.3928/00989134-20140923-01
- Folstein, M., 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(3); 189-198

- Franke, R.H., & Kaul, J.D. (1978). The Hawthorne experiments: First statistical interpretation. *Am Sociol Rev*, 43, 623–643. doi: 10.2307/2094540.
- Geurts, H. M., & Vissers, M. E. (2012). Elderly with autism: executive functions and memory. *J Autism Dev Disord*, 42(5), 665-675. doi:10.1007/s10803-011-1291-0
- Gibson, J. J. (1966). The senses considered as perceptual systems. Boston: Boston, Houghton Mifflin.
- Gilliam, JW (2006) *GARS-2: Gilliam Autism Rating Scale–Second Edition*. , PRO-ED, Austin, TX.
- Gurvich, T., & Cunningham, J. A. (2000). Appropriate use of psychotropic drugs in nursing homes. *American family physician*, 61(5), 1437.
- Gitlin, L. N., Marx, K., Stanley, I. H., & Hodgson, N. (2015). Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps. *The Gerontologist*, 55(2), 210-226. doi:10.1093/geront/gnu123
- Gonzalez, M. T., & Kirkevold, M. (2015). Clinical use of sensory gardens and outdoor environments in norwegian nursing homes: a cross-sectional e-mail survey. *Issues Ment Health Nurs*, 36(1), 35-43. doi:10.3109/01612840.2014.932872
- Graybiel, A. M., & Grafton, S. T. (2015). The striatum: where skills and habits meet. *Cold Spring Harb Perspect Biol*, 7(8), a021691. doi:10.1101/cshperspect.a021691
- Green, S. A., & Ben-Sasson, A. (2010). Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There a Causal Relationship? *Journal of Autism and Developmental Disorders*, 40(12), 1495-1504. doi:10.1007/s10803-010-1007-x

- Gregory, M. (2013). *Sensory Systems*. Clinton Community College. Retrieved February 24, 2019, from:
<https://archive.is/20130625101331/http://faculty.clintoncc.suny.edu/faculty/michael.gregory/files/bio%20102/bio%20102%20lectures/sensory%20systems/sensory.htm>
- Guerriero Austrom, M., Damush, T. M., West Hartwell, C., Perkins, T., Unverzagt, F., Boustani, M., . . . Callahan, C. M. (2004). Development and Implementation of Nonpharmacologic Protocols for the Management of Patients With Alzheimer's Disease and Their Families in a Multiracial Primary Care Setting. *The Gerontologist, 44*(4), 548-553. doi:10.1093/geront/44.4.548
- Gurvich, T., & Cunningham, J. (2000). Appropriate use of psychotropic drugs in nursing homes. *American Family Physician, 61*(5), 1437-46.
- Iwarsson, S. (2005). A Long-Term Perspective on Person-Environment Fit and ADL Dependence among Older Swedish Adults. *Gerontologist, 45*(3), 327. doi:10.1093/geront/45.3.327
- Gutman, S. (2008). *Neuroscience for Rehabilitation Professionals*, 2nd ed. Thorofare, NJ: Slack Incorporated.
- Hammarström, G., & Torres, S. (2012). Variations in subjective well-being when 'aging in place' — A matter of acceptance, predictability and control. *Journal of Aging Studies, 26*(2), 192-203. doi:<https://doi.org/10.1016/j.jaging.2011.12.004>
- Hannibal, K.E., & Bishop, M.D. (2014). Chronic stress, cortisol dysfunction, and pain: a psychoneuroendocrine rationale for stress management in pain rehabilitation. *Physical therapy, 94*(12), 1816-1825.

- Happe, F., & Charlton, R. A. (2012). Aging in autism spectrum disorders: a mini-review. *Gerontology*, 58(1), 70-78. doi:10.1159/000329720
- Hebert, R., Levesque, L., Vezina, J., Lavoie, J. P., Ducharme, F., Gendron, C., . . .
Dubois, M. F. (2003). Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. *J Gerontol B Psychol Sci Soc Sci*, 58(1), S58-67.
- Heller, S. (2002). *Too loud, too bright, too fast, too tight: What to do if you are sensory defensive in an overstimulating world*. (1st ed.). New York: HarperCollins.
- Hepburn, K. W., Tornatore, J., Center, B., & Ostwald, S. W. (2001). Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *J Am Geriatr Soc*, 49(4), 450-457.
- High, D.M. & Rowles, G.D. (1995). Nursing home residents, families, and decision making: Toward a theory of progressive surrogacy. *Journal of Aging Studies*, 9(2), 101-117.
- Hodgson, N., & Craemer, G. (2013). *In sickness and in health: Coregulation of spousal caregivers' and dementia patients' cortisol levels, relationship quality and health outcomes* (Vol. 9).
- Hodgson, N.A., Gitlin, L.N., Winter, L., & Czekanski, K. (2011). Undiagnosed illness and neuropsychiatric behaviors in community residing older adults with dementia. *Alzheimer Dis Assoc Disord*, 25(2), 109-115. doi: 10.1097/WAD.0b013e3181f8520a

- Hornberger, M., Piguet, O., Kipps, C., & Hodges, J. R. (2008). Executive function in progressive and nonprogressive behavioral variant frontotemporal dementia. *Neurology*, 71(19), 1481-1488. doi:10.1212/01.wnl.0000334299.72023.c8
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *Br J Psychiatry*, 140, 566-572.
- Humes, L. (2015). Age-related changes in cognitive and sensory processing: Focus on middle-aged adults. *American Journal of Audiology*, 24(2). 94-97. doi: 10.1044/2015_AJA-14-0063
- Hurley, S. L. (1998). *Consciousness in action*. Cambridge, Mass.: Cambridge, Mass. : Harvard University Press.
- Hurley, S., & Noë, A. (2003). Neural Plasticity and Consciousness. *Biology and Philosophy*, 18(1), 131-168. doi:10.1023/A:1023308401356
- Inglis, F. M., & Fibiger, H. C. (1995). Increases in hippocampal and frontal cortical acetylcholine release associated with presentation of sensory stimuli. *Neuroscience*, 66(1), 81-86. doi:https://doi.org/10.1016/0306-4522(94)00578-S
- Iwarsson, S., Sixsmith, J., Oswald, F., Wahl, H-W., Nygren, C., Sixsmith, A., Széman, Z., & Tomsone, S. (2005). The ENABLE-AGE Project: Multi-dimensional methodology for European housing research. In: Vestbro, D. U., Hürol, Y. & Wilkinson, N. (Eds.), *Methodologies in housing research* (pp. 70-90) . Gateshead: The Urban International Press.
- Iwarsson, S., Stahl, A., & Lovquist, C. (2013). Mobility in outdoor environments in old age. In G.D. Rowles & M. Bernard (Eds.), *Environmental Gerontology: Making*

Meaningful Places in Old Age, (pp. 175-198), New York, NY: Springer Publishing Company.

James, I. A., Mukaetova-Ladinska, E., Reichelt, F. K., Briel, R., & Scully, A. (2006).

Diagnosing Aspergers syndrome in the elderly: a series of case presentations. *Int J Geriatr Psychiatry*, 21(10), 951-960. doi:10.1002/gps.1588

Jicha, G. (2011). Medical management of frontotemporal dementias: The importance of the caregiver in symptom assessment and guidance of treatment strategies.

Journal of Molecular Neuroscience, 45(3), 713-723. doi: 10.1007/s12031-011-9558-7

Kahana, E. (1982). A congruence model of person-environment interaction, in M.P.

Lawton, P. Windley and T. Byers (eds), *Aging and the environment: Theoretical approaches* (pp. 97-121), New York: Springer Publishing.

Kane, R. A. (2001). Long-Term Care and a Good Quality of LifeBringing Them Closer Together. *The Gerontologist*, 41(3), 293-304. doi:10.1093/geront/41.3.293

Kearns, R. and Andrews, G. (2005). Placing ageing, in G. Andrews and D. Phillips (eds.), *Ageing and place: Perspectives, policy and practice* (pp. 13-23). London: Routledge.

Kielhofner, G. (2008). Model of human occupation: Theory and application. Baltimore, MD: Lippincott Williams & Wilkins.

Kim, S. H., & Lord, C. (2013). Chapter 1.2 - The Behavioral Manifestations of Autism Spectrum Disorders A2 - Buxbaum, Joseph D. In P. R. Hof (Ed.), *The Neuroscience of Autism Spectrum Disorders* (pp. 25-37). San Diego: Academic Press.

- Kitwood, T., & Bredin, K. (1992). Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*, 12(3), 269-287.
doi:10.1017/S0144686X0000502X
- Kleemeier, R. W. (1959). Behavior and the organization of the bodily and external environment. In J. E. Birren (Ed.), *Handbook of aging and the individual* (pp. 400–451). Chicago: University of Chicago Press.
- Kong, E. H., Evans, L. K., & Guevara, J. P. (2009). Nonpharmacological intervention for agitation in dementia: a systematic review and meta-analysis. *Ageing Ment Health*, 13(4), 512-520. doi:10.1080/13607860902774394
- Koren, M. J. (2010). Person-centered care for nursing home residents: the culture-change movement. *Health Aff (Millwood)*, 29(2), 312-317.
doi:10.1377/hlthaff.2009.0966
- Kovach, C. R. (2000). Sensoristasis and imbalance in persons with dementia. *J Nurs Scholarsh*, 32(4), 379-384.
- Kvale, S. (1994). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Landes AM, Sperry SD, Strauss ME, et al. (2001). Apathy in Alzheimer's disease. *J Am Geriatr Soc*, 49, pp. 1700-1707.
- Lane, A. E., Young, R. L., Baker, A. E., & Angley, M. T. (2010). Sensory processing subtypes in autism: association with adaptive behavior. *J Autism Dev Disord*, 40(1), 112-122. doi:10.1007/s10803-009-0840-2

- Lang, R., O'Reilly, M., Healy, O., Rispoli, M., Lydon, H., Streusand, W., . . . Giesbers, S. (2012). Sensory integration therapy for autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 6*(3), 1004-1018.
- Lau, D.T., Kasper, J.D., Potter, D.E., et al. (2004). Potentially inappropriate medication prescriptions among elderly nursing home residents: their scope and associated resident and facility characteristics. *Health Services Research, 39*, pp. 1257-1276.
- Laviola, G., Hannan, A. J., Macri, S., Solinas, M., & Jaber, M. (2008). Effects of enriched environment on animal models of neurodegenerative diseases and psychiatric disorders. *Neurobiol Dis, 31*(2), 159-168.
doi:10.1016/j.nbd.2008.05.001
- Law, M. (1991). The Environment: A Focus for Occupational Therapy. *Canadian Journal of Occupational Therapy, 58*(4), 171-179.
doi:10.1177/000841749105800404
- Law, M., Cooper, B., Strong, S., Steward, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *American Journal of Occupational Therapy, 63*(1), 9-23.
- Lawton, MP. (1980). *Environment and aging*. Albany: Center for the Study of Aging.
- Lawton, MP & Nahemow L. (1973). Ecology and the aging process. In: *The psychology of adult development and aging*. (pp.619-674). Washington, DC, US: American Psychological Association.
- Lawton, MP & Simon, B (1968). The ecology of social relationships in housing for the elderly, *The Gerontologist, 8*(2), 108-115. <https://doi.org/10.1093/geront/8.2.108>

- Lee, M. (2008). Caregiver Stress and Elder Abuse among Korean Family Caregivers of Older Adults with Disabilities. *Journal of Family Violence, 23*(8), 707.
doi:10.1007/s10896-008-9195-2
- Letts, L., Minezes, J., Edwards, M., Berenyi, J., Moros, K., O'Neill, C., & O'Toole, C. (2011). Effectiveness of interventions designed to modify and maintain perceptual abilities in people with Alzheimer's disease and related dementias. *Am J Occup Ther, 65*(5), 505-513.
- Leven, N., Prick, A.-E., Groenewoud, J., Roelofs, P., De Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review (Vol. 25).
- Lewin, K. (1936). *Principles of Topological Psychology*. New York: McGraw-Hill.
- Lorusso, L. N., & Bosch, S. J. (2017). Impact of Multisensory Environments on Behavior for People With Dementia: A Systematic Literature Review. *The Gerontologist, gnw168-gnw168*. doi:10.1093/geront/gnw168
- Lüdecke, D. (2018). Sjstats: statistical functions for regression models. R package version 0.14. 0.
- Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. *JAMA, 288*(12), 1475-1483.
- McCarney, R., Warner, J., Iliffe, S., van Haselen, R., Griffin, M., & Fisher, P. (2007). The Hawthorne Effect: a randomised, controlled trial. *BMC medical research methodology, 7*, 30. doi:10.1186/1471-2288-7-30

- McGreevy, J. (2016). Implementing culture change in long-term dementia care settings. *Nurs Stand*, 30(19), 44-50. doi:10.7748/ns.30.19.44.s43
- McKeith, I. G., Dickson, D. W., Lowe, J., Emre, M., O'Brien, J. T., Feldman, H., . . . Yamada, M. (2005). Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. *Neurology*, 65(12), 1863-1872. doi:10.1212/01.wnl.0000187889.17253.b1
- McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology*, 34(7), 939-944.
- Marshall, A., Myers, C., & Pierce, D. (2017). A Century of Therapeutic Use of the Physical Environment. *Am J Occup Ther*, 71(1), 1-10. doi:10.5014/ajot.2017.023960
- Martorell, A. J., Paulson, A. L., Suk, H.-J., Abdurrob, F., Drummond, G. T., Guan, W., . . . Tsai, L.-H. (2019). Multi-sensory Gamma Stimulation Ameliorates Alzheimer's-Associated Pathology and Improves Cognition. *Cell*. doi:<https://doi.org/10.1016/j.cell.2019.02.014>
- May-Benson, T. (2009). Occupational therapy for adults with sensory processing disorder. *OT Practice*, 14(10), 15-19.
- Mendez, M. F., Shapira, J. S., & Miller, B. L. (2005). Stereotypical movements and frontotemporal dementia. *Mov Disord*, 20(6), 742-745. doi:10.1002/mds.20465

- Midorikawa, A., & Kawamura, M. (2012). The Relationship between Subclinical Asperger's Syndrome and Frontotemporal Lobar Degeneration. *Dementia and geriatric cognitive disorders extra*, 2, 180. doi:10.1159/000338174
- Miller, L. J., Coll, J. R., & Schoen, S. A. (2007). A Randomized Controlled Pilot Study of the Effectiveness of Occupational Therapy for Children With Sensory Modulation Disorder. *American Journal of Occupational Therapy*, 61(2), 228-238. doi:10.5014/ajot.61.2.228
- Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a Caregiver Intervention on Negative Caregiver Appraisals of Behavior Problems in Patients With Alzheimer's Disease: Results of a Randomized Trial. *The Journals of Gerontology: Series B*, 59(1), P27-P34. doi:10.1093/geronb/59.1.P27
- Molnar, F., & Frank, C. C. (2018). Support of caregivers of persons with dementia. *Canadian Family Physician*, 64(4), 294.
- Montgomery, J., Newton, B., & Smith, C. D. (2008). Test reviews: Gilliam, J. (2006). GARS-2: Gilliam Autism Rating Scale-Second Edition. Austin, TX: PRO-ED. *Journal of Psychoeducational Assessment*, 26(4), 395-401.
- Moon, H., Townsend, A. L., Whitlatch, C. J., & Dilworth-Anderson, P. (2017). Quality of Life for Dementia Caregiving Dyads: Effects of Incongruent Perceptions of Everyday Care and Values. *The Gerontologist*, 57(4), 657-666. doi:10.1093/geront/gnw055
- Moore, K.D. (2018). Environment and Aging. In M.W. Skinner, G.J. Andrews, & M.C. Cutchin (eds.). *Geographical Gerontology: Perspectives, Concepts Approaches*. (pp.80-90). London: Routledge.

- Moreau, N., Rauzy, S., Viallet, F., & Champagne-Lavau, M. (2016). Theory of mind in Alzheimer disease: Evidence of authentic impairment during social interaction. *Neuropsychology, 30*(3), 312-321. doi:10.1037/neu0000220
- Mori, A. (2015). Addressing sensory integration and sensory processing disorders across the lifespan: The role of occupational therapy. Retrieved from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwjexsfrqOHWAhUk3YMKHVfKBQMqFggrMAA&url=https%3A%2F%2Fwww.aota.org%2F-%2Fmedia%2FCorporate%2FFiles%2FAboutOT%2FProfessionals%2FWhatIsOT%2FCY%2FFact-Sheets%2FFactSheet_SensoryIntegration.pdf&usq=AOvVaw2GBExCYP9AAYxGkBYwf7Gw
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology, 43*(11), 2412-2414.
- Neary, D., Snowden, J. S., Gustafson, L., Passant, U., Stuss, D., Black, S., . . . Benson, D. F. (1998). Frontotemporal lobar degeneration: a consensus on clinical diagnostic criteria. *Neurology, 51*(6), 1546-1554.
- Neidl, R., Schneider, A., Bousiges, O., Majchrzak, M., Barbelivien, A., de Vasconcelos, A. P., . . . Boutillier, A. L. (2016). Late-Life Environmental Enrichment Induces Acetylation Events and Nuclear Factor kappaB-Dependent Regulations in the Hippocampus of Aged Rats Showing Improved Plasticity and Learning. *J Neurosci, 36*(15), 4351-4361. doi:10.1523/jneurosci.3239-15.2016
- Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., del Ser, T., . . . Muñoz, R. (2010). Nonpharmacological Therapies in Alzheimer's Disease: A Systematic

Review of Efficacy. *Dement Geriatr Cogn Disord*, 30(2), 161-178.

doi:10.1159/000316119

Onwuteaka-Philipsen, B. D., W. Pasman, H. R., van Gennip, I. E., Oosterveld-Vlug, M.

G., & Willems, D. L. (2014). How Dementia Affects Personal Dignity: A Qualitative Study on the Perspective of Individuals With Mild to Moderate Dementia. *The Journals of Gerontology: Series B*, 71(3), 491-501.

doi:10.1093/geronb/gbu137

Padilla, R. (2011). Effectiveness of environment-based interventions for people with

Alzheimer's disease and related dementias. *Am J Occup Ther*, 65(5), 514-522.

doi:10.5014/ajot.2011.002600

Parham, L. D., Cohn, E. S., Spitzer, S., Koomar, J. A., Miller, L. J., Burke, J. P., . . .

Summers, C. A. (2007). Fidelity in sensory integration intervention research. *Am J Occup Ther*, 61(2), 216-227. doi:10.5014/ajot.61.2.216

Pavlov P. I. (1927). Conditioned reflexes: An investigation of the physiological activity

of the cerebral cortex. *Ann Neurosci*. 2010;17(3):136-41.

Pernecky, R., Wagenpfeil, S., Komossa, K., Grimmer, T., Diehl, J., & Kurz, A. (2006).

Mapping scores onto stages: mini-mental state examination and clinical dementia rating. *Am J Geriatr Psychiatry*, 14(2), 139-144.

doi:10.1097/01.JGP.0000192478.82189.a8

Pfeiffer, B. A., Koenig, K., Kinnealey, M., Sheppard, M., & Henderson, L. (2011).

Effectiveness of Sensory Integration Interventions in Children With Autism Spectrum Disorders: A Pilot Study. *The American journal of occupational therapy*, 65(1), 76-85.

- Phoenix, C. (2018). Why Qualitative Research is Needed in Gerontology and How We Can Do It Better. *The Journals of Gerontology: Series B*, 73(7), e81-e85. doi:10.1093/geronb/gby079
- Picciotto, M. R., Higley, M. J., & Mineur, Y. S. (2012). Acetylcholine as a neuromodulator: cholinergic signaling shapes nervous system function and behavior. *Neuron*, 76(1), 116-129. doi:10.1016/j.neuron.2012.08.036
- Pitron, V., & de Vignemont, F. (2017). Beyond differences between the body schema and the body image: insights from body hallucinations. *Consciousness and Cognition*, 53, 115-121. doi:https://doi.org/10.1016/j.concog.2017.06.006
- Powell, P. S., Klinger, L. G., & Klinger, M. R. (2017). Patterns of Age-Related Cognitive Differences in Adults with Autism Spectrum Disorder. *J Autism Dev Disord*, 47(10), 3204-3219. doi:10.1007/s10803-017-3238-6
- Rabig, J., Thomas, W., Kane, R. A., Cutler, L. J., & McAlilly, S. (2006). Radical redesign of nursing homes: applying the green house concept in Tupelo, Mississippi. *Gerontologist*, 46(4), 533-539.
- Rahman, A. N., & Schnelle, J. F. (2008). The Nursing Home Culture-Change Movement: Recent Past, Present, and Future Directions for Research. *The Gerontologist*, 48(2), 142-148. doi:10.1093/geront/48.2.142
- Ramírez-Maestre, C., Esteve, R., & López, A. (2012). The Role of Optimism and Pessimism in Chronic Pain Patients Adjustment. *The Spanish Journal of Psychology*, 15(1), 286-294. doi:10.5209/rev_SJOP.2012.v15.n1.37335

- Raznahan, A., Toro, R., Daly, E., Robertson, D., Murphy, C., Deeley, Q., . . . Murphy, D. G. (2010). Cortical anatomy in autism spectrum disorder: an in vivo MRI study on the effect of age. *Cereb Cortex*, *20*(6), 1332-1340. doi:10.1093/cercor/bhp198
- Researchware, Inc. (2018). HyperRESEARCH 4.0.2. Computer Software.
- Reynolds, P. & Cronin, A. (2005). Aging. In A. Cronin & M. Mandich (Eds), *Human development & performance*. (pp. 306-331), Clifton Park, NY: Thomson Delmar Learning.
- Risco, E., Cabrera, E., Jolley, D., Stephan, A., Karlsson, S., Verbeek, H., . . . Zabalegui, A. (2015). The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: a prospective observational cohort study. *Int J Nurs Stud*, *52*(5), 980-987. doi:10.1016/j.ijnurstu.2015.02.013
- Rhodus, E., & Hunter, E. (2017). How are sensory-based interventions used in dementia care: A scoping review. [Manuscript in preparation].
- Roman, G. C., Tatemichi, T. K., Erkinjuntti, T., Cummings, J. L., Masdeu, J. C., Garcia, J. H., . . . et al. (1993). Vascular dementia: diagnostic criteria for research studies. Report of the NINDS-AIREN International Workshop. *Neurology*, *43*(2), 250-260.
- Rossignol, D. A., & Frye, R. E. (2014). The use of medications approved for Alzheimer's disease in autism spectrum disorder: a systematic review. *Front Pediatr*, *2*, 87. doi:10.3389/fped.2014.00087
- Rossor, Iversen, L. L., Reynolds, G. P., Mountjoy, C. Q., & Roth, M. (1984). Neurochemical characteristics of early and late onset types of Alzheimer's

disease. *British Medical Journal (Clinical research ed.)*, 288(6422), 961.

doi:10.1136/bmj.288.6422.961

Rossor, M., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young-onset dementia. *Lancet neurology*, 9(8), 793-806.

doi:10.1016/S1474-4422(10)70159-9

Rowles, G.D. (1978). *Prisoners of space? : Exploring the geographical experience of older people*. Boulder, Colorado: Westview Press.

Rowles, G.D. (1991). Beyond performance: Being in place as a component of occupational therapy. *American Journal of Occupational Therapy*, 45(3), 265-271.

Rowles, G.D. (2000). Habituation and being in place. *Occupational Therapy Journal of Research*, 20(1 Supplement), 52S-67S.

Rowles, G.D. (2018). Being in place: Identity and place attachment in late life, in M.W. Skinner, G.J. Andrews, and M.P. Cutchin (eds), *Geographical gerontology: Perspectives, concepts, approaches* (pp. 203-215). New York, NY: Routledge.

Rowles, G.D., & Bernard, M. (2013). The meaning and significance of place in old age, in G.D. Rowles and M. Bernard (eds), *Environmental gerontology: Making meaningful places in old age* (pp. 3-24). New York, NY: Springer Publishing Company.

Rowles, G.D., & Teaster, P. B. (2016). The long-term care continuum in an aging society. In G.D. Rowles & P.B. Teaster (eds.), *Long-term care in an aging society: Theory and practice*. New York, NY: Springer Publishing Company.

- Rowles, G.D., & Watkins, J.F. (2003). History, habit, heart and hearth: On making spaces into places. In K.W. Schaie, H.W. Wahl, H. Mollenkopf, & F. Oswald (eds.), *Aging independently: Living arrangements and mobility* (pp. 77-96). New York, NY: Springer Publishing Company.
- Savva, G. M., Wharton, S. B., Ince, P. G., Forster, G., Matthews, F. E., & Brayne, C. (2009). Age, neuropathology, and dementia. *N Engl J Med*, *360*(22), 2302-2309. doi:10.1056/NEJMoa0806142
- Sayer, A. G., Whitlatch, C. J., Lyons, K. S., & Zarit, S. H. (2002). Caregiving as a Dyadic Process: Perspectives From Caregiver and Receiver. *The Journals of Gerontology: Series B*, *57*(3), P195-P204. doi:10.1093/geronb/57.3.P195
- Schaaf, R. C., Miller, L. J., Seawell, D., & O'Keefe, S. (2003). Children with disturbances in sensory processing: a pilot study examining the role of the parasympathetic nervous system. *Am J Occup Ther*, *57*(4), 442-449.
- Schanberg, S. M., & Field, T. M. (1987). Sensory deprivation stress and supplemental stimulation in the rat pup and preterm human neonate. *Child Dev*, *58*(6), 1431-1447.
- Schmitt, F. A., Nelson, P. T., Abner, E., Scheff, S., Jicha, G. A., Smith, C., . . . Kryscio, R. J. (2012). University of Kentucky Sanders-Brown healthy brain aging volunteers: donor characteristics, procedures and neuropathology. *Curr Alzheimer Res*, *9*(6), 724-733.
- Shelton, E. G., Orsulic-Jeras, S., Whitlatch, C. J., & Szabo, S. M. (2017). Does it Matter if We Disagree? The Impact of Incongruent Care Preferences on Persons with

Dementia and Their Care Partners. *The Gerontologist*, gnw202-gnw202.

doi:10.1093/geront/gnw202

Sokol, D. K., Chen, D., Farlow, M. R., Dunn, D. W., Maloney, B., Zimmer, J. A., & Lahiri, D. K. (2006). High levels of Alzheimer beta-amyloid precursor protein (APP) in children with severely autistic behavior and aggression. *J Child Neurol*, 21(6), 444-449. doi:10.1177/08830738060210062201

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *J Am Geriatr Soc*, 56(6), 1116-1128. doi:10.1111/j.1532-5415.2008.01705.x

Stark, S., Somerville, E., & Morris, J. (2010). In home occupational performance evaluation (I-HOPE). *American Journal of Occupational Therapy*, 64(4), 580-589.

Strom, B. S., Ytrehus, S., & Grov, E. K. (2016). Sensory stimulation for persons with dementia: a review of the literature. *J Clin Nurs*, 25(13-14), 1805-1834. doi:10.1111/jocn.13169

Teri, L., McCurry, S. M., Logsdon, R., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. *Gerontologist*, 45(6), 802-811.

United States Food and Drug Administration. (2013). Information for healthcare professionals: Conventional antipsychotics. Retrieved from <https://www.fda.gov/Drugs/DrugSafety/ucm124830.htm>

- Van Vracem, M., Spruytte, N., Declercq, A., & Van Audenhove, C. (2016). Agitation in dementia and the role of spatial and sensory interventions: experiences of professional and family caregivers. *Scand J Caring Sci*, 30(2), 281-289. doi:10.1111/scs.12240
- Verkaik, R., van Weert, J. C., & Francke, A. L. (2005). The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: a systematic review. *Int J Geriatr Psychiatry*, 20(4), 301-314. doi:10.1002/gps.1279
- Vozzella, S. (2007). *Sensory stimulation in dementia care: Why it is important and how to implement it* (Vol. 23).
- Wackerbarth, S.B. (1999). What Decisions are made by family caregivers? *American Journal of Alzheimer's Disease*, 14(2), 1-9.
- Wackerbarth, S.B. (2000). Caregivers of family members with dementia were involved in a dynamic decision making process to maintain tolerable situations. *Evidence-Based Nursing*. 3(1), 32.
- Wahl, H.-W., Iwarsson, S., & Oswald, F. (2012). Aging Well and the Environment: Toward an Integrative Model and Research Agenda for the Future. *The Gerontologist*, 52(3), 306-316. doi:10.1093/geront/gnr154
- Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin, A. (2016). Real-World Executive Functions in Adults with Autism Spectrum Disorder: Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid Anxiety and Depression. *J Autism Dev Disord*, 46(3), 1071-1083. doi:10.1007/s10803-015-2655-7

- Whalley, L. J., Deary, I. J., Appleton, C. L., & Starr, J. M. (2004). Cognitive reserve and the neurobiology of cognitive aging. *Ageing Research Reviews*, 3(4), 369-382. doi:<https://doi.org/10.1016/j.arr.2004.05.001>
- Wheatley, V. J., & Baker, J. I. (2007). "Please, I want to go home": ethical issues raised when considering choice of place of care in palliative care. *Postgraduate Medical Journal*, 83(984), 643-648. doi:10.1136/pgmj.2007.058487
- Whitlatch, C. J., Femia, E., Judge, K., & Zarit, S. H. (2006). Dyadic Intervention for Family Caregivers and Care Receivers in Early-Stage Dementia. *The Gerontologist*, 46(5), 688-694. doi:10.1093/geront/46.5.688
- Wilbarger, P. (1984). Planning a "sensory diet": Application of sensory processing theory during the first year of life. *Zero to Three*, 5(1), 7-12.
- Wilbarger, P. (1997). *Sensory defensiveness: A comprehensive treatment approach*. Chicago, IL: Avanti Educational Programs, Inc.
- Wilbarger, J., Gunnar, M., Schneider, M., & Pollak, S. (2010). Sensory processing in internationally adopted, post-institutionalized children. *J Child Psychol Psychiatry*, 51(10), 1105-1114. doi:10.1111/j.1469-7610.2010.02255.x
- Wiles, J.L. (2011). Reflections on being a recipient of care: The vexing concept of vulnerability. *Social and Cultural Geography*, 12(6), 573-588.
- Wiles, J. L., Allen, R.E.S., Palmer, A.J., Hayman, K.J., Keeling, S. and Kerse, N. (2009). Older people and their social spaces: A study of well-being and attachment to place in Aotearoa New Zealand. *Social Science and Medicine*, 68(4), 664-671.
- Wilkes, L., Fleming, A., Wilkes, B. L., Cioffi, J. M., & Le Miere, J. (2005). Environmental approach to reducing agitation in older persons with dementia in a

nursing home. *Australasian Journal on Ageing*, 24(3), 141-145.

doi:10.1111/j.1741-6612.2005.00105.x

Wilks, S. E., Boyd, P. A., Bates, S. M., Cain, D. S., & Geiger, J. R. (2017). Montessori-based activities among persons with late-stage dementia: Evaluation of mental and behavioral health outcomes. *Dementia (London)*, 1471301217703242.

doi:10.1177/1471301217703242

Williams, A. (1999). *Therapeutic landscapes: The dynamic between place and wellness*. Lanham, MD: University Press of America.

Williams, A. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*, 55(1), 141-151.

Winblad, B., Palmer, K., Kivipelto, M., Jelic, V., Fratiglioni, L., Wahlund, L.-O., . . . Petersen, R. (2004). *Mild cognitive impairment - Beyond controversies, towards a consensus: Report of the International Working Group on Mild Cognitive Impairment (Vol. 256)*.

Witucki, J. M., & Twibell, R. S. (1997). The effect of sensory stimulation activities on the psychological well being of patients with advanced Alzheimer's disease.

American Journal of Alzheimer's Disease, 12(1), 10-15.

doi:10.1177/153331759701200103

Woo, C. C., & Leon, M. (2013). Environmental enrichment as an effective treatment for autism: a randomized controlled trial. *Behav Neurosci*, 127(4), 487-497.

doi:10.1037/a0033010

- Woodbury-Smith, M. R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for Asperger Syndrome using the AQ: a preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders, 35*(3), 331-335.
- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1983). Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res, 17*(1), 37-49.
- Zeidan-Chulia, F., de Oliveira, B. H., Salmina, A. B., Casanova, M. F., Gelain, D. P., Noda, M., . . . Moreira, J. C. (2014). Altered expression of Alzheimer's disease-related genes in the cerebellum of autistic patients: a model for disrupted brain connectome and therapy. *Cell Death Dis, 5*, e1250. doi:10.1038/cddis.2014.227
- Zeisel, J., Silverstein, N. M., Hyde, J., Levkoff, S., Lawton, M. P., & Holmes, W. (2003). Environmental Correlates to Behavioral Health Outcomes in Alzheimer's Special Care Units. *The Gerontologist, 43*(5), 697-711. doi:10.1093/geront/43.5.697
- Zhao, Q. F., Tan, L., Wang, H. F., Jiang, T., Tan, M. S., Tan, L., . . . Yu, J. T. (2016). The prevalence of neuropsychiatric symptoms in Alzheimer's disease: Systematic review and meta-analysis. *J Affect Disord, 190*, 264-271. doi:10.1016/j.jad.2015.09.069
- Zuidema, S. U., de Jonghe, J. F., Verhey, F. R., & Koopmans, R. T. (2010). Environmental correlates of neuropsychiatric symptoms in nursing home patients with dementia. *Int J Geriatr Psychiatry, 25*(1), 14-22. doi:10.1002/gps.2292
- Zuidema, S. U., de Jonghe, J. F., Verhey, F. R., & Koopmans, R. T. (2011). Psychotropic drug prescription in nursing home patients with dementia: influence of

environmental correlates and staff distress on physicians' prescription behavior.

Int Psychogeriatr, 23(10), 1632-1639. doi:10.1017/s1041610211001438

VITA
Elizabeth K. Rhodus

Educational Institutions

Master of Science in Occupational Therapy

Eastern Kentucky University, Richmond, Kentucky
August, 2010-August, 2012

Bachelor of Science in Occupational Science

Minor in Psychology

Eastern Kentucky University, Richmond, Kentucky
August, 2006- May, 2010

Professional Positions

Adjunct Professor

Nova Southeastern University
Occupational Therapy Department, Tampa, Florida
January-May, 2019

Adjunct Professor

Eastern Kentucky University, Department of Occupational Science
and Occupational Therapy, Richmond, Kentucky
January-May, 2019

National Clinical Trainer

The Weston Group, Inc.
January, 2018—October, 2018

Area Clinical Coordinator

The Weston Group, Inc., Lexington, Kentucky
August, 2017—January, 2018

Occupational Therapist, Therapy Team Lead

The Weston Group, Inc., Lexington, Kentucky
May, 2016—August, 2017

Private Consultant in Dementia Care

Central Kentucky
March, 2016—December, 2017

Occupational Therapist

Brookdale Senior Living, Lexington, Kentucky
PRN, September, 2015—January, 2017
Full-Time, October, 2015—May, 2016

Occupational Therapist, Lead OT

Premier Home Care, Inc., Richmond, Kentucky
October, 2013—November, 2015

Occupational Therapist

New Beginnings Therapy Services, Inc., Richmond, Kentucky
October, 2013—April, 2014

Occupational Therapist

Riviera Palms Rehab Center, Palmetto, Florida
November, 2012—October, 2013

Occupational Therapist

Pediatric Therapy Services, Lakeland, Florida

July, 2012—November, 2012

Scholastic and Professional Honors

- ◆ Donovan Scholarship in Gerontology, 2018
- ◆ University of Kentucky College of Public Health Research Day Poster Presentations, First Place, 2017
- ◆ Online Course Development and Teaching Certification, Eastern Kentucky University, 2016
- ◆ Deep Physical Agent Modality Certification issued by KBLOT, 2014
- ◆ Physical Agent Modalities Credentialing Certificate, Nashville, TN, 2014
- ◆ Kentucky Board of Licensure for Occupational Therapy License, 2013—Present
- ◆ Florida Department of Health Occupational Therapy License, 2012—Present
- ◆ National Board for Certification in Occupational Therapy, 2012—Present
- ◆ Certified through American Red Cross in First Aid, Adult CPR and AED 2011—Present
- ◆ Eastern Kentucky University President's List Fall, 2006—2010
- ◆ Eastern Kentucky University Dean's List Fall, 2006—2010
- ◆ Eastern Kentucky University Presidential Scholarship, 2006—2010
- ◆ Eastern Kentucky University Honors Program Scholarship, 2006--2012
- ◆ College of Health Sciences Dean's Award, 2010
- ◆ Outstanding Occupational Science Senior Award, 2010
- ◆ Bert Gallicchio Scholarship, 2006

Professional Publications

Rhodus, E., Barber, J., Abner, E., Duff, D., Bardach, S., Caban-Hold, A., Lightner, D., Rowles, G., Schmitt, F., & Jicha, G. (Under Review). Behaviors characteristic of Autism spectrum disorder in a geriatric cohort with mild cognitive impairment or early dementia. *Alzheimer's Disease and Associated Disorders*.

Rhodus, E., & Hunter, E. (2018). How are sensory-based interventions used in dementia care: A scoping review. [Manuscript in preparation].

Bryden, P., Bhandari, M., & **Miller, E.*** (2011). Breaking through the time barrier: Changing the path to healthy behaviors. *Kentucky Association of Health, Physical Education, Recreation and Dance*, 48(2), 27-34.

*Miller is author's maiden name, Rhodus is current surname.