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APATHY AND CARE ENVIRONMENTS IN DEMENTIA AND MEASURES OF ACTIVITY

by

Ying-Ling Jao

A thesis submitted in partial fulfillment of the
requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
The University of Iowa

May 2014

Thesis Supervisor: Professor Janet K. Specht

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Graduate College
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Iowa City, Iowa

CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph. D. thesis of

Ying-Ling Jao

has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
degree in Nursing at the May 2014 graduation.

Thesis Committee: ___________________________________
Janet P. Specht, Thesis Supervisor

____
Sue E. Gardner

____
Donna L. Algase

____
Kristine Williams

____
Lucas J. Carr

ACKNOWLEDGMENTS

I would like thank the Wound, Ostomy, and Continence Nurses Foundation (WOCN®), the Sigma Theta Tau (STT) International, and Gamma Chapter for funding this dissertation. I would also like to thank my research team members, including Christine Haedtke, I-Chi Liang, Lisa Pruitt, and Jennifer Laheta for the WBA activity project, as well as Elizabeth Edleman, Jung Min Lee, and Cathy Antonakos for the PEAR apathy project. Their great work helped this dissertation generate rigorous and fruitful findings. I also want to thank two NIH/NINR-funded studies—"Wandering: Background and Proximal Factors" (PI: Algase) and "Bioburden Predictors of Diabetic Ulcer Complications" (PI: Gardner)—for providing access to research samples and resources.

I am extremely grateful for my dissertation committee, Drs. Janet Specht, Sue Grdner, Donna Algase, Kristine Williams, and Lucas Carr. They have devoted considerable time to support this dissertation. I want to give special thanks to my advisor, Dr. Janet Specht. She has mentored me for the past seven years in my graduate education. She has always believed in me and our mentorship has made this journey enjoyable. I am also grateful to have worked on Dr. Gardner's research team for more than six years and have led multiple research projects, which have established my research skills and inspired me to continue my education in the doctoral program at the University of Iowa.

Finally, I want to thank all my family in Taiwan for their unconditional love and support, which gave me courage to pursue my passion in the U.S. I especially want to thank my grandparents. They have been my motivation to pursue gerontological nursing as my long-term career.

ABSTRACT

Objective: This dissertation includes three projects that study care environments and apathy in dementia as well as measures of activity. Project 1 developed the Person-Environment Apathy Rating (PEAR) scale to measure environmental stimulation and apathy, and tested its psychometrics. Project 2 examined the association between care environments and apathy in persons with dementia. Project 3 tested the accuracy of ActiGraph and activPAL^{TM} activity monitors in measuring weight-bearing activities among persons with previous diabetic foot ulcers.

Methods: The PEAR consists of environment (PEAR-Environment) and apathy (PEAR-Apathy) subscales. The validity and reliability of the PEAR was examined through video observation of 24 participants. Project 2 selected 40 participants with dementia in order to examine the association between apathy and environmental stimulation, ambiance, crowding, staff familiarity, and light and sound. Study procedures involved video observation and data extraction. Project 3 enrolled 31 participants to test the accuracy of ActiGraph and activPAL^{TM} in measuring number of steps taken and duration of walking, standing, sitting, and lying.

Results: The PEAR-Environment subscale had significant but fair correlation with the Crowding Index (ρ=.27, p<.01), suggesting fair validity. The PEAR-Apathy highly correlated with the Passivity in Dementia Scale (ρ=.81) and Neuropsychiatry Inventory (NPI)-Apathy subscale (ρ=.266), and moderately correlated with the NPI-Depression subscale (ρ=.46), indicating good convergent validity and moderate discriminate validity. The PEAR also demonstrated good internal consistency (Cronbach's α= .84 -.85) and moderate to good inter-rater (Weighted Kappa=.47-.94) and

intra-rater (Weighted Kappa=.47-.94) reliability. Project 2 revealed that stimulation clarity and strength were significantly associated with a low apathy level (p<.001). An increase of 1 point on stimulation clarity and strength corresponded to a decrease on apathy score of 1.3 and 1.9 points, respectively. Project 3 revealed that ActiGraph had widely varied accuracy in measuring duration of standing, walking, sitting, and lying (0-100%) and in measuring number of steps taken (43-81%). In contrast, activPAL™ showed consistently high accuracy in measuring duration of standing, walking, sitting, and lying (97-100%) and in measuring number of steps of taken (91-99%).

Discussion: The PEAR is a valid and reliable measure of care environment and apathy in long-term care residents with dementia. Care environments that contain clear and sufficiently strong environmental stimulation are significantly associated with lower apathy levels, providing a foundation for interventions targeting apathy. ActivPAL™ is a valid tool to measure weight-bearing activity in persons with diabetes in order to examine the role of weight-bearing activity in foot ulceration. This monitor may also be useful as a supplemental measure for apathy in persons with dementia.

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CHAPTER I

OVERVIEW

Overview of the Problem

This dissertation addresses two different problems: 1) apathy in dementia, and 2) weight-bearing activity in diabetic foot ulcers. In this chapter, these two problems are reviewed individually.

Apathy in Dementia

Prevalence and Significance of Apathy in Dementia

Apathy is one of the most prevalent neuropsychiatric and behavioral problems in persons with dementia (Starkstein, Jorge, & Mizrahi, 2006). Most studies describe lack of motivation as the core problem of apathy, and it is often clinically demonstrated as diminished goal-directed activities in cognitive, behavioral, and emotional/affective dimensions, including lack of interest, lack of initiatives, social withdrawal, and flat emotional response (Starkstein & Leentjens, 2008). It can occur in all types and all stages of dementia but shows higher prevalence in late-stage dementia (Marin, 1996; Starkstein et al., 2006).

Apathy can be problematic for both patients and their family caregivers. Studies have reported that apathy is associated with patients' deterioration of dementia, declined function in activities of daily living, and decreased quality of life (Burns, 1996; Landes, Sperry, Strauss, & Geldmacher, 2001). Apathy is also associated with an increase of caregiver burden and a higher incidence of depression for those caregivers (Landes, Sperry, Strauss, & Geldmacher, 2001). Moreover, patients with apathy tend to exhibit less compliance with treatment, require aggressive behavioral treatment, need more support, require home care or institutional care, require increased cost of treatment, and have poor treatment outcomes (Landes et al., 2001; Starkstein et al., 2006).

Gaps in Apathy Management

Despite the negative impact of apathy on patients and their family caregivers, people with apathy are often undiagnosed and often do not receive appropriate care (Landes et al., 2001). Several issues have risen in apathy assessment and management, including ill-defined criteria, lack of standardized measures, and lack of consensus on the pathological mechanism of apathy (Robert et al., 2009; Starkstein & Leentjens, 2008).

Moreover, due to the nature of dementia and apathy, it can be challenging to administer apathy instruments. Marin (1991) suggests that a self-report instrument can acquire more accurate data on apathy because apathy is a subjective feeling; however, self-report information is difficult to obtain in people who have both advanced dementia and apathy. In addition, studies have revealed that persons with dementia and apathy tend to show lack of awareness, and rate their own apathy level significantly lower than their family caregivers/informants do (Robert et al., 2002). However, assessment based on informants' reports may also be problematic, because their reports are often not available for many people, especially for long-term care residents. Therefore, a clinician-administered apathy instrument that does not overly rely on patient- or informant- reports is needed for apathy assessment.

Additionally, although part of the definition of apathy refers to a lack of responsiveness to surrounding stimuli (Strauss & Sperry, 2002), none of the apathy instruments considers socio-environmental stimuli in apathy assessment. In environments with very limited stimuli or incentive, persons who appear apathetic may be doing so because of a lack of motivational stimulus in their immediate environment rather than true apathy.

Moreover, an increasing body of literature has revealed that brain lesions involving motivation correlates with apathy (Levy & Bubois, 2006). This finding further supports the conception that lack of motivation is the core problem of apathy. However, very few studies have examined the association between environmental stimuli or motivators and apathy in people with dementia. The understanding of external factors of apathy can guide clinicians to focus on the preventable or modifiable factors and therefore more effectively target apathy in prevention and treatment. In order to improve the quality of care for persons with dementia and apathy, it is necessary to develop an observational scale to accurately quantify apathy, and identify environmental correlates of apathy to accurately measure and manage apathy. In this way, the enormous physical, emotional, and financial burden on sufferers and their caregivers can be decreased.

Weight-bearing Activity in Diabetic Foot Ulceration

Diabetic Foot Ulceration (DFU)

Among the 19 million people with diabetes in the United States (Centers for Disease Control and Prevention, 2011), three million will develop at least one DFU during their lifetime and one out of four of those persons who develop a DFU will require an amputation (Lott, Maluf, Sinacore, & Mueller, 2005). In addition, DFUs are associated with depression, decreased mobility, and poor quality of life (Vileikyte, 2001). Medicare costs for treatment of DFUs rose from $1.5 billion in 1995 to $10.9 billion in 2001 (Powell, Carnegie, & Burke, 2004), indicating DFUs are becoming more common and the cost of treatment is increasing. These findings show the need to develop interventions that prevent DFUs.

It is difficult to identify persons at risk for DFU and to provide individualized preventive interventions. Although there are several DFU prediction models proposed in the literature, (Monteiro-Soares, Boyko, Ribeiro, Ribeiro, & Dinnis-Ribeiro, 2011; Monteiro-Soares & Dinnis-Ribeiro, 2010), their clinical usefulness for ulcer prevention is questionable. Most of the risk factors included in the models are difficult to modify (e.g., neuropathy and vascular disease), and they only serve as "proxies" for mechanisms that are more directly involved in the ulceration pathway. Accordingly, there is a need to identify mechanistic risk factors that are modifiable, more proximal to the ulceration pathway, and that are amendable to direct measurement.

The Role of Weight-bearing Activity in Foot Ulceration

Weight-bearing activity is defined as any activity where individuals are supporting their body weight on their feet. These activities primarily include standing and walking (Mueller, Zou, Bohnert, Tuttle, & Sinacore, 2008). Weight-bearing activity plays an important role in foot ulceration because it creates high plantar pressures, which account for 90% of plantar foot ulcers (Mueller et al., 2008; Orsted et al., 2007). According to the Physical Stress Theory, three components determine plantar pressure: direction, magnitude, and time (Mueller et al., 2008).

To date, there is no commercially available device to measure the "direction" of pressure (e.g., shear stresses) (Meuller et al., 2008). Therefore, magnitude and time are the only components of plantar pressure that can be measured in order to improve DFU prevention. The "magnitude" of pressure refers to the extent of the pressure applied on the foot at the moment of weight-bearing activity, and can be measured using force plates. Evidence shows that the magnitude of pressure for ulceration varies from person to person, suggesting that the “magnitude” of pressure alone is insufficient to explain the impact of plantar pressure on DFU recurrence (Mueller et al., 2008).

The “time” of pressure refers to the duration of the weight-bearing activity (Mueller et al., 2008). Therefore, the level of activity determines the cumulative and repetitive plantar pressure that theoretically increases the risk of foot ulceration and recurrence (Orsted et al., 2007). The American Diabetes Association (ADA) (1999) recommends that people with diabetes and peripheral neuropathy should decrease weight-bearing activity in order to minimize risk of foot ulceration. However, only one case study has demonstrated that the risk for DFU increases when level of activity increases (LeMaster et al., 2003). Others have found that weight-bearing activity is not directly related to DFU (LeMaster, Reiber, Smith, Heagerty, & Wallace, 2003; Maluf & Mueller, 2003).

These conflicting results suggest that more studies with better approaches are needed in order to identify the role of activity level on DFU (LeMaster et al., 2003). Compared to other risk factors for DFU (e.g., neuropathy and deformity), weight-bearing activity is one of the very few factors that is modifiable. If the role of weight-bearing activity can be better understood, less costly and less invasive interventions may be more effectively implemented for DFU prevention.

Measurement Issues of Weight-bearing Activity in

People with Risk of DFU

Four studies have investigated the relationship between weight-bearing activity and foot ulceration (LeMaster et al., 2003; LeMaster et al., 2008, Lott et al., 2005; Maluf & Mueller, 2003). Three of the four studies used steps taken during walking as the measure of activity level using two dimensional activity monitors (LeMaster et al., 2003; Lott et al., 2005; Maluf & Mueller, 2003). The problem with using walking as the sole indicator of weight-bearing activity is that this measure can only capture the impact of dynamic plantar pressure and entirely misses the impact of static plantar pressure that occurs during standing. Only one study used both standing and walking as measures of activity level using a 24-hour activity questionnaire to inquire about activity once every 17 weeks (LeMaster et al., 2003). Although this measure of activity includes both dynamic and static components, the psychometric properties of the tool, including construct validity and reliability, have not been well evaluated.

In 2010, Najafi and colleagues (Najafi, Crewsm, & Wrobel, 2010) examined both dynamic and static weight-bearing activity in patients using a three-dimensional monitor. Compared to two-dimensional monitors, three-dimensional monitors have an additional inclinometer function to measure anatomical postures. That is, these types of monitors can measure movement (i.e., walking) and can also distinguish different postures (including lying, sitting, and standing) so that standing can be quantitatively measured. This study reported that people with diabetes spent a significantly higher proportion of time standing than walking (Najafi et al., 2010). Although this study did not examine the relationship between standing and DFU occurrence and recurrence, this was the very first study pointing out the importance of including static weight-bearing activity in activity assessment of persons with diabetes. A valid three-dimensional activity monitor is necessary to more comprehensively examine the impact of weight-bearing activity (both dynamic and static) on foot ulceration.

Specific Aims

This dissertation includes three papers. Each paper is guided by the following specific aims.

- Aim 1: Develop and evaluate the psychometric properties of the Person-Environment Apathy Rating (PEAR) that measures apathy and the environmental stimulation concurrently.
- Aim 2: Evaluate the association between care environments and apathy in long-term care residents with dementia.
- Aim 3: Describe the accuracy of ActiGraph and activPAL^{TM} in measuring static and dynamic weight-bearing activities among person with a previous DFU.

Three Papers Proposed

Three independent papers (Chapters 2, 3, and 4) address the aims described above. Each paper addresses one aim and includes a description of the method and findings associated with that aim. Although the third aim (i.e. Chapter 4) does not appear to be directly linked to the first two aims, it was included as one of the three aims of this dissertation for several pertinent reasons.

First, my participation as a team member on Dr. Sue Gardner’s DFU study has been a major part of my research training in addition to the training received while participating on dementia research studies. I have been working in Dr. Gardner's DFU research team for more than six years and have led several secondary projects related to that study. The topic of the third aim built on my previous research work regarding assessment of risk factors associated with DFU.

Second, findings from this activity measurement study will inform my work on the measurement of apathy as well. A recent study reported that apathy is correlated with reduced activity as measured by activity monitors (Kuhlmei, Walther, Becker, Muller, & Nikolaus, 2011). The authors suggest that activity measurement may be useful for quantifying apathy. The two activity monitors tested in aim 3 were updated models of devices that include the inclinometer function. The inclinometer function allows these monitors to distinguish between different positions (e.g., sitting and lying). Therefore, these activity monitor may provide a better picture of individuals' activity patterns that may be important in the measurement of apathy. Most measures of apathy rely on rater judgments. A valid activity monitor can be used as a supplemental measure to more objectively quantify apathy and can help assess apathy and evaluate treatment outcomes.

Overview of Paper 1: Developing the Person-Environment Apathy Rating for Persons with Dementia

Purpose and Scope

The purpose of the first paper (Chapter 2) was to develop an instrument that measures care environment and apathy level in persons with dementia and establish its validity and reliability. The ultimate goal was to more accurately capture apathy and also to identify features of environmental stimulation relevant to apathy. These may in turn provide a foundation to develop interventions targeting apathy in persons with dementia, and improve health outcomes and quality of life for both the patient and their caregivers.

Methods

The PEAR scale was constructed through literature reviews of the concept of environments, motivation, and apathy in dementia. The PEAR includes environment (PEAR-Environment) and apathy (PEAR-Apathy) subscales, each of which has six items. The PEAR was field-tested to determine the usefulness and feasibility of the initial items by rating six nursing home residents with dementia. The items were refined accordingly.

The modified version of the PEAR was reviewed by three senior scientists with expertise in dementia research. They commented on the PEAR rating items and rating manual regarding how well they fit the concept of apathy and how feasible these items could be measured through observation. The PEAR was refined based on the comments. Through this process, the panel confirmed the content validity of the refined PEAR. The refined PEAR was pilot-tested using a cross-sectional design and 30 videotaped observations selected from a repository obtained from a parent study, which is a larger R01study on institutionalized residents with dementia.

Next, the construct validity was examined through video observation. Samples were selected from a parent study, which enrolled 185 participants from 23 long-term-care facilities, each participant having a minimum of 9 recorded videos. For this study, the sample size was 96 video observations selected from 24 participants; for each participant four videos over two days were selected. In each video, a segment of 1-2 minutes was selected for coding.

The PEAR-Environment was validated using the Ambiance Scale (Algase et al., 2007) and the Crowding Index (Algase et al., 2011). The PEAR-Apathy was validated using the Neuropsychiatric Inventory (NPI)-Apathy (Cummings et al., 1994; Sajatovic & Ramirez, 2003; Wood et al., 2000), Passivity in Dementia Scale (PDS; Colling, 2000), and NPI-Depression (Cummings et al., 1994; Sajatovic & Ramirez, 2003). Two trained researchers separately viewed each of the 96 videos and coded each video using the PEAR scale. Then, each rater rated 48 of the videos using the PEAR for a second time to test its intra-rater reliability. Finally, each rater rated the same 48 videos using the NPI-Apathy, PDS, and NPI-depression to evaluate the validity of the PEAR-Apathy. The measures of the Ambiance Scale and Crowding Index were extracted from the parent study database.

To analyze the validity of the PEAR, Spearman rank order correlations were used to examine the association for ratings between PEAR-Environment subscale and both the Ambiance Scale and Crowding Index. The same analysis was used to examine the individual association of ratings between the PEAR-Apathy and the NPI-Apathy, PDS, and NPI-Depression. To determine intra- and inter-rater reliability, percent agreements and Weighted Kappa were analyzed for the PEAR environment subscale using two observations from the same rater and from two different raters. Cronbach's α values were also analyzed to evaluate internal consistency of the environment and apathy subscales.

Overview of Paper 2: Association between Care Environments and Apathy in Persons with Dementia

Purpose and Scope

The purpose of this paper (Chapter 3) was to examine the relationship between environmental characteristics and apathy levels in long-term care residents with dementia. This study was guided by the Need-Driven Dementia-Compromised Behavior (NDB) model (Algase et al., 1996; Algase et al., 2011).

Method

This was a descriptive, repeated-observation study. All samples were selected from a large R01 parent study in which 185 residents with dementia were recruited from 23 long-term care facilities. Each participant had at least 9 twenty-minute videos recorded. For this study, 40 participants were randomly selected from the parent study and three videos per participant were purposefully selected: one during mealtime, one involving social interactions with staff, and one containing random environmental stimulation. From each video, three segments were selected to assess apathy and environmental stimulation.

The dependent variable was apathy level. The independent variables were environmental characteristics, including environmental stimulation, environmental ambiance, crowding, staff familiarity, light and sound. Apathy and environmental stimulation were assessed by two trained raters using the PEAR. Two trained researchers individually reviewed the video and coded the apathy and environmental stimulation. Other data were extracted from the parent study.

Descriptive statistics were summarized to describe participants' demographics and baseline conditions. A generalized linear mixed (GLM) model was used to account for the correlation among video on the same person and among segments within the same video. Each set of independent variables was fit to one GLM model to analyze their relationship with apathy. Then, a further model selection was performed.

Overview of Paper 3: Accuracy of ActiGraph and ActivPAL™ in Measuring Weight-bearing Activities

Purpose and Scope

The purpose of this paper (Chapter 4) was to evaluate the accuracy of ActiGraph and activPAL™ in measuring weight-bearing activity for persons with prior DFUs. The ultimate goal was to identify a valid measure to assess weight–bearing activity so that future research can accurately examine the impact of weight-bearing activity on foot ulceration.

Method

This was a cross-sectional descriptive study to evaluate the accuracy of using ActiGraph and activPAL™ to measure weight-bearing activity. Participants were recruited from an ongoing parent study that examined predictors of diabetic ulcers complications. For this study, 31 participants were enrolled from the parent study. Inclusion criteria of the present study included the capability to walk and perform different postures for at least 5 minutes with no assistance and no particular restriction on any activity.

The primary study variables were measures of duration of different postures for weight-bearing and non-weight-bearing activities and numbers of steps taken during dynamic weight-bearing activity (i.e., walking). The percentage accuracy of ActiGraph and activPAL™ was evaluated in terms of measuring the duration of particular postures (i.e., walking, standing, sitting, and lying) and number of steps taken as compared to the measurement of duration based on direct observation (criterion standard).

Summary

The three studies collectively provide an important overview of the measurement of apathy in dementia and the measurement of weight-bearing activities in persons with prior diabetic foot ulcers, which may have important implications for the measurement of apathy as well. Chapter 2, 3, and 4 reports detailed study procedures and finding for each of the three aims described above. Finally, Chapter 5 summarizes the findings and discusses the implications of the finding of all three aims collectively.

CHAPTER II

DEVELOPING THE PERSON-ENVIRONMENT APATHY RATING FOR PERSONS WITH DEMENTIA

Introduction and Overview

Apathy is a highly prevalent neuropsychiatric and behavioral syndrome occurring in all types and all stages of dementia, but is especially common in the late stage (Marin, 1996; Starkstein et al., 2006). Apathy is a disorder of motivation, and clinically manifests as lack of interest, lack of initiative, social withdrawal, and flat emotional responses (Marin, 1996; Starkstein & Leentjens, 2008). Apathy is associated with a variety of factors, including patients' advancing dementia, decreased functioning in activities of daily living, decreased quality of life, increased needs for home or institutional care, increased treatment costs, and poorer treatment outcomes (Landes et al., 2001; Starkstein et al., 2006). The patients' family caregivers tend to have an increased burden and incidence of depression (Burns, 1996; Landes et al., 2001). Despite the negative impact of apathy on patients and their family caregivers, persons with apathy are often either largely ignored or misdiagnosed with depression, and consequently do not receive appropriate care (Landes et al., 2001).

Assessment is a major challenge of apathy management (Clarke et al., 2011). Currently-available apathy assessments are of limited usefulness in institutionalized residents with moderate to advanced dementia, who cannot provide self-report and may not have family informants available. Identifying apathy in persons with moderate to advanced dementia is important because this population is at much greater risk of apathy than, for example, persons with mild dementia (Starkstein et al., 2006). Moreover, none of current instruments consider environmental stimulation in apathy assessment, despite the fact that a lack of response to environmental stimulation is an important criterion for apathy diagnosis (Robert et al., 2009). Without a measure of the care environment, it is unclear whether individuals in low-stimulus environments who appear apathetic are truly apathetic or simply have fewer stimuli to which they can respond.

Environmental stimulation provided through multisensory stimulation (Baker et al., 2001), social interaction (Dettmore, Kolanowski, & Boustani, 2009), and music therapy (Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006) has been shown to reduce apathy in patients with dementia; however, the underlying mechanisms are understudied. An instrument to examine both apathy and environment is necessary to understand the impact of care environments on apathy and to develop environmental interventions for dementia. Limitations in existing apathy scales highlight the need for a scale that 1) accurately quantifies apathy and the care environment for persons with moderate to advanced dementia, and2) allows for an examination of the association between apathy and environmental stimulation. Thus, this study aimed to:

1. Develop the Person-Environment Apathy Rating (PEAR) to measure care environments and apathy.
2. Evaluate the validity and reliability of the PEAR-Environment subscale.
3. Evaluate the validity and reliability of the PEAR-Apathy subscale.

Development of the PEAR

The PEAR consists of two subscales: environment (PEAR-Environment) and apathy (PEAR-Apathy). To establish content validity, the PEAR was developed through the following four-step process.

Item and Scale Development

The PEAR-Environment subscale was designed to capture features of individual's immediate physical and social environment that potentially influence apathy level. The items of the environment subscale were developed via a literature review of environmental factors relevant to aging, dementia, apathy, and motivation. According to Levy and Dubois (2006), a goal-directed behavior is achieved through a cyclic process from internal or external determinants, intention, planning, and carrying out an action, to outcome evaluation. Based on this model, internal or external determinants trigger one's intention and start the cycle of the goal-directed behavior. Environmental stimulation can be considered the external determinant in this model. In the PEAR, environmental stimulation is operationally defined as events, active objects, and people that are present within three feet of the participant's visual field. It includes, but is not limited to, sensory, physical, and social stimulation, such as a meal, music, TV shows, activity programs, and interpersonal interaction and conversation.

For the PEAR-Apathy, the constructs were developed based on literature reviews on the concept of apathy and the most recent diagnostic criteria for apathy (Robert et al., 2009). The diagnostic criteria define apathy as a disorder of lack of motivation, demonstrated as lack of goal-directed activities in cognitive, behavioral, and affective dimensions and lack of responses to internal or external stimuli (Robert et al., 2009). Other landmark conceptual definitions of apathy were also incorporated into this scale, including lack of interest (Cummings et al., 1994), lack of initiative and responsiveness to internal or external stimuli (Strauss & Sperry, 2002), and lack of voluntary and purposeful behaviors (Levy & Dubois, 2006). Next, because the PEAR was intended to be an observational scale, it was designed to measure these constructs by using rating items that are observable via patients' verbal and non-verbal expressions. For example, lack of affective response was quantified by three observational items: facial expression (no facial expression vs. laughing), verbal expression (expressing not care vs. pleasure or anger) and verbal tone (flat vs. high).

Field Testing: The PEAR was field-tested by rating six nursing home residents with dementia to determine the usefulness and feasibility of the initial items. The items were refined as described below. Through constant observation, the investigator noticed that some residents, who appeared apathetic most of time, occasionally became talkative and smiled when someone friendly interacted with them. One resident had no facial expressions the entire afternoon, but then suddenly smiled and asked to kiss the volunteer after she accompanied him to an activity session. Another newly admitted resident often looked blank without engaging in any activity, but when someone engaged her in conversation, she energetically expressed how she enjoyed her career in journalism and stated that she often was bored living in the nursing home and felt the only things she could do were merely sit in the living room or sleep. These observations reinforced the need to incorporate environmental stimulation in apathy measurement. Also, the observation findings suggested that the quality of environmental stimulation might be more important than the specific activity in which residents are participating. As a result, activity type was dropped and environmental feedback was added to the PEAR-Environment.

Expert Review: A modified version of the PEAR was reviewed by three senior scientists with expertise in dementia research. They commented on the PEAR rating items and rating manual regarding how well they fit the concept of apathy and how feasible it would be to observe these items. Based on their comments, the items were condensed, and the labels and instruction for using the scale were further modified. After these revisions, the panel confirmed the content validity of the PEAR.

Pilot Testing: The revised PEAR was pilot-tested using 30 videotaped observations selected from a large repository obtained from a parent study, a R01 study on institutionalized residents with dementia (funded by the National Institutes of Nursing and Aging, Grant# NR04569, PI: Algase). Details about the parent study are described in a later section. For the pilot testing, two trained individuals separately viewed residents on the videos and rated their environment and apathy levels. Their ratings were compared. Next, the two raters discussed their rationales for ratings on which they disagreed and they reconciled these discrepancies. The rating manual was refined by providing clearer instruction and examples. After these changes, percentage agreement between two raters was improved to at least 80% for all items.

Scale Description

The resulting version of the PEAR can be found in Appendix A. The PEAR scale consists of an environment subscale (PEAR-Environment) and an apathy subscale (PEAR-Apathy). Each subscale has six items and each item is rated on a 1-4 scale; higher ratings indicate better environment and greater apathy in the patient, respectively. For each subscale, the total score ranges from 4 to 24 and the ratings of the two subscales are not summed. PEAR-Environment items reflect stimulation clarity, stimulation strength, stimulation specificity, social involvement, physical accessibility, and environmental feedback within the participant's immediate social and physical environment. PEAR-

Apathy items encompass facial expression, eye contact, physical engagement, purposeful activity, and verbal tone and expression capturing the symptoms of apathy in cognitive, behavioral, and affective domains.

Construct Validity and Reliability Tests

Design, Samples, and Settings

This study used a cross-sectional correlational design. The construct validity and reliability of the PEAR were evaluated using videos from the same parent study used for the pilot testing. The videos were newly coded for the PEAR and compared to criterion measures for this study to evaluate validity and reliability.

The parent study was conducted in 16 nursing homes and 6 assisted living facilities in Michigan and Pennsylvania from 2000 to 2004. Facilities were selected for convenience, and to assure gender and racial diversity. Inclusion criteria of each participant included: 1) English-speaking, 2) DSM-IV diagnostic criteria of dementia, 3) score of less than 24 for Mini-Mental State Examination (MMSE), 4) being ambulatory, and 5) a stable regime of psychotropic medications. For each participant, twelve videos randomly distributed over two days were taken to capture behavior symptoms every hour between 0800 and 2000, including mealtimes and non-mealtimes; two additional videos captured one randomly selected period during hours of high activity and one care event (e.g., dressing in the morning). Each video was approximately 20 minutes in length and observation days were separated by a minimum of 48 hours. A total of 185 participants constituted the sample. Study procedures of the parent study were described elsewhere (Algase, et al., 2011).

For this study, the sample size was 96 video observations selected from 24 participants; for each participant four videos over two days were selected. In each video, a segment of 1-2 minutes was selected for coding. To assure there was adequate variance for psychometric tests, the four videos from each participant included one during mealtime, one containing interpersonal interactions between staff and participant, one containing no interpersonal interaction, and one was random selection.

Sampling Procedures

The sampling procedure is depicted in Figure 2.1. First, using a random sequence generator, 24 participants were randomly selected. Of the 185 participants in the parent study, only 172 with a minimum of 9 videos available were considered as potential participants and were placed in the selection pool for this study. Then, for each participant, available videos were screened and four qualified videos were selected to include the required environmental contexts and to ensure high recording quality. To assure recording quality, each eligible video had to contain at least 1 minute that clearly recorded: 1) participant’s facial expression, voice, and the front of the upper body, and 2) images and sounds of the participant’s immediate environment within 3 feet from the participant.

From each video of the four videos, one segment was selected to assess apathy and environments. Each selected segment lasted one to two minutes with constant environmental context. A change in environmental context was defined as: 1) the participant newly joining or leaving the room; 2) anyone newly joining or leaving the room, presenting in the participant’s visual field within three feet and staying for at least one minute, or 3) any person initiating an interpersonal conversation and remaining for at least one minute. The pilot study suggested that, if participants respond at all, their responses often come within one minute and do not change after one minute. To be eligible, each participant was required to have four videos that met the criteria. Of the 24 initially-selected participants, 6 were ineligible and were replaced by additional randomly-selected participants that met the criteria.

Instruments

Three instruments were used to evaluate the validity of the PEAR. The Ambiance Scale and the Crowding Index were used to evaluate the concurrent validity of the PEAR-Environment. The Neuropsychiatric Inventory (nursing home version), Apathy subscale (NPI-Apathy; Cumming et al., 1994) and the Passivity in Dementia Scale (PDS, Colling, 2000) were used as criterion measures to evaluate the convergent validity of the PEAR Apathy subscale. The NPI Depression subscale was used to evaluate discriminate validity of the PEAR-Apathy.

Ambiance Scale

Ambiance was measured in the parent study using the modified Ambiance Scale (Appendix B). The Ambiance Scale is used to assess the emotional attractiveness of long-term care environments and their capacity to trigger behavioral and affective symptoms in residents with dementia. Reliability tests of the Ambiance Scale revealed good internal consistency and inter-rater and intra-rater reliability (Algase et al., 2007). The Ambiance Scale includes soothing and engaging subscales. The engaging subscale includes 6 adjective pairs: stimulating-custodial, warm-cold, embellished-stark, welcoming-impersonal, colorful-drab, and novel-boring. The soothing subscale includes 3 adjective pairs: informal-formal, unpretentious-pretentious, and peaceful-chaotic. Each item was rated on a -2 to +2 scale (Algase et al., 2007).

At the end of the video recordings, the researchers rated each of the nine items of the Ambiance Scale based on their impression of the environments through direct observation. This study analyzed the participant's average score of the soothing and engaging subscales, separately.

Crowding Index

The Crowding Index was used to evaluate the concurrent validity of the PEAR-Environment particularly the stimulation specificity, social involvement, and physical accessibility. It is expected that the more people in close proximity to the participant, the more likely it is that the stimulation will be more specific, better involve the participants, and be more accessible for the participant.

The Crowding Index was developed in the parent study to assess "the density and proximity of people present in the area where a given study participant was at a specific point in time" (P.65, Algase et al., 2011). The Crowding Index was measured on a set of five concentric circles centering on the participant (Appendix C). From the inside (zone 1) to the outside (zone 5) of the circle, each circle represents a radius of 1 feet, 2 feet, 4 feet, 6 feet, and 8 feet, respectively, as indicated in Figure 2. Because it is challenging to reach or respond to stimuli beyond 8 feet, this study only analyzed crowing within 8 feet.

First, within each circle, trained researchers marked an X to indicate each person who was present around the participant at the corresponding distance. Then the crowding index was calculated by the following formula: 9 * number of people at zone 1 & 2 (within 2ft) + 3* number of people at zone 3 & 4 (within 4ft) + number of people at zone

5 (within 8ft). A higher Crowding Index score indicates a higher density of crowding; in other words, meaning more people and/or a greater proximity of those people to the participant.

The Crowding Index data were collected through the parent study. Data were collected at three different times for each videotaped observation: 1) the beginning of the observation, 2) at the 10-minute mark, and 3) at the 20-minute mark (the end of the video recording). The data measured at three different measurement points were matched to each video sample of this study using the following rule: data at the beginning observation was used if the selected video segment started at 5 minutes or before, data at the 10- minute mark was used if the segment started after 5 minutes, and data at the 20-minute mark was used if the segment started after 15 minutes. In this way, the Crowding Index data was always within 5 minutes of the video used for the PEAR-Apathy coding.

Passivity in Dementia Scale (PDS)

The PDS was selected to evaluate the convergent validity of the PEAR, because some disciplines, including nursing, often use passivity and apathy interchangeably (Kolanowski, Litaker, & Buettner, 2005). The PDS is an observational scale that consists of 32 items to assess passive behaviors through observation in nursing home residents with dementia (Colling, 2000, Appendix D). These 32 items are clustered into five categories (with 3-10 items in each category): thinking, emotions, interaction with environment, interaction with people, and activities. This scale describes passivity as a decrease in motor movement accompanied with apathy, and lack of interaction with environment (Colling, 1999, & Colling, 2000). Each item was rated either 0 (not present/not observed) or 1 (present). The PDS had fair to good inter-rater reliability with Kappa 0.55-0.81 (Colling, 2000).

NPI-Apathy Subscale

The NPI-Apathy subscale (nursing home version) was selected because the NPI (Cumming et al., 1994) is the most widely used scale measuring behavioral symptoms in persons with dementia (Sajatovic, & Ramirez, 2003). The NPI is also the most commonly used apathy scale. The NPI- Apathy (Appendix E) is one of the 10 subscales of the NPI. The NPI-Apathy includes seven items, with each item receiving a rating for severity and a rating for frequency. For this study, only severity was assessed for each video, rated on a 0-3 scale (0=not at all, 1=mild, 2=moderate, and 3=severe). The total score ranges from 0 to 21, with a higher rating indicating more advanced apathy (Cummings et al., 1994; Sajatovic & Ramirez, 2003).

Overall, the psychometrics of the NPI-Apathy have been well-established for content validity, inter-rater reliability (97.9%), and test-retest reliability (Kappa=.68) (Cummings et al., 1994; Sajatovic & Ramirez, 2003). Because this study rated apathy through video observation, the scale was slightly modified to make each item observable through a brief video segment and be more focused on the participant’s presentation during the video. To enhance rating consistency, this study added examples for some items. For example, before modification, item 7 asked if there are any other signs indicating the participant does not care about doing new things, but no examples were provided. Based on the diagnostic criteria for apathy (Robert et al., 2009), this study included additional examples for items 7: lack of self-initiated or purposeful behaviors, lack of spontaneous ideas or curiosity for new events, not starting or expanding conversation, and not seeking social activities.

NPI-Depression

The NPI-Depression subscale was selected to evaluate discriminate validity of the PEAR because the NPI is widely used in dementia research (Cummings et al., 1994, Appendix E). The rules of rating are the same as the NPI-Apathy described previously. Overall, the psychometrics of the NPI-Depression have been well established for content validity, inter-rater reliability (97.9%) and test-retest reliability (Kappa=.84) (Cummings et al., 1994). Similar to the NPI-Apathy, the NPI-Depression was slightly modified for this study to make each item observable in a brief video and more focused on the participant's presentation at the moment of observation. No examples were provided in the scale for item 8, which asks about other signs of depression or sadness, so this study reviewed the DSM-V (American Psychiatric Association, 2013) symptoms of depression and added lack of interest as an example.

Data Collection Procedure

The participants' demographics and baseline cognitive impairment and functional levels were extracted from the parent study data files. Coding for validity and reliability were completed by two trained raters. First, the raters separately viewed each video for all 96 videos and coded each video using the PEAR scale. Then, each rater rated 48 of the videos using the PEAR for a second time to test their intra-rater reliability. Finally, each rater rated the same 48 videos using the NPI-Apathy, PDS, and NPI-Depression to evaluate the validity of the PEAR-Apathy. Data from the Ambiance Scale and the Crowding Index were extracted from the parent study data files to evaluate the validity of the PEAR-Environment. Ratings on the same videos were separated by a minimum of one week. No communication or comparison within or between raters was allowed during the rating process. The study procedure was approved by the relevant Institutional Review Boards (IRBs).

For each video, the raters gave only one rating for every item. If a participant's environmental stimulation or apathy level changed over the observation period during the video observation, the raters rated the lowest score that was present for the PEAR-Apathy scale, and rated the highest score that lasted for at least one-quarter of the observation time for the PEAR-Environment scale. The raters were allowed to watch the videos as many times as needed but not allowed to discuss the ratings or revisit previous ratings during the procedure.

Data Analysis

Data analysis was conducted using the Statistical Package for the Social Science version 21 (SPSS 21; IBM Corporation, New York, NY). Descriptive statistics were generated to describe the participants' baseline characteristics and the ratings of environment stimulation, apathy, and depression measured by the four different instruments.

For validity, Spearman rank order correlations were used to analyze the rating between the PEAR-Apathy subscale and the other three scales (i.e., NPI-Apathy, PDS, and NPI-Depression) to determine the convergent and discriminate validity of the PEAR apathy subscale.

For reliability, percent agreement and weighted Kappa values for two ratings within the same rater and from two different raters were computed to test the intra- and inter-rater reliability, respectively. The Kappa values were then weighted, instead of using traditional Cohen Kappa values. This is because all PEAR items were rated on a 1-4 scale. The disagreement between scores of 1 and 4 is more serious than the disagreement between scores of 1 and 2. Weighted Kappa allows distinguishing different levels of disagreement (Cohen 1968, Sim & Wright, 2005). The weighted Kappa was calculated for each item of the PEAR for both the environment and apathy subscales.

Results

Demographics and Baseline Cognitive Function

This study included a total of 24 participants, whose baseline characteristics are summarized in Table 2.1. Two thirds of the participants lived in a nursing home and the rest of them lived in an assisted living facility. Participants' average age was 82.38 years and most of them were female (78.83%). Regarding cognitive function, 8 out of 22 demonstrated sufficiently severe cognitive impairment to have MMSE. Of the 14 participants who completed the MMSE test, the average MMSE score was 10.29, while the scores ranged widely from 2 to 20. Only 3 participants had mild cognitive impairment (MMSE: 17-23). The majority of participants showed advanced cognitive impairment evidenced by a score of less than 10 for the MMSE (80%). The majority of participants had deficits in learning, executing complex tasks, and reasoning.

Descriptive Ratings of Environments, Apathy, and Depression

Overall ratings of each measure are summarized in Table 2.2. The average rating of the total PEAR-Environment was 12.29 (±3.51), indicating moderate environmental stimulation. Of individual items of the PEAR-Environment, the individual-item averages ranged from 2.53 to 3.44 on the 1-4 scale. Stimulation clarity had the highest rating and environmental feedback had the lowest rating. For the PEAR-Environment, A higher score indicates a better environmental stimulation. The average rating of total PEAR-Apathy subscale was 14.48 (±4.44). Of the individual items of the PEAR-Apathy, the average rating was 1.60-3.01 on the 1-4 scale. The item with the highest rating was verbal tone and the item with the lowest rating was eye contact. For the PEAR-Apathy, a higher score indicates a higher level of apathy.

For the criterion measures, the average passivity was 13.53 (±5.82) on a scale of 0 to 32, suggesting a moderate level of passivity (Colling, 2000). For the NPI-Apathy, the average rating was 8.04 (±3.60) on a scale of 0-21, indicating moderate apathy (Cumming et al., 1994). The average NPI-Depression rating was 1.52 (±1.54) on a scale of 0-24, indicating no depression (Cumming et al., 1994).

Construct Validity of PEAR

The PEAR-Environment was validated using the Crowding Index. Study results revealed that the Crowding Index score had a low but significant correlation with the total PEAR-Environment score (ρ=.266, p=.009). Regarding validity of individual items, the Crowding Index had a significant correlation with stimulation specificity (ρ=.301, p=.003), social involvement (ρ=.322, p=.001), and physical accessibility (ρ=.348, p=.001), but not with stimulation clarity (ρ=.110, p=.290), stimulation strength (ρ=.129, p=.212), or environmental feedback (ρ=.133, p=.299).

The Ambiance score subscales were not correlated with the individual items or total score of the PEAR-Environment rating for either the Engaging score (ρ=-.002 -.083) or Soothing score (ρ=.009-.206). The lack of correlation may be due to the fact that measurements of the Ambiance Scale were not specific to the segments utilized to rate the PEAR-Environment for this study.

The PEAR-Apathy was validated using the PDS, the NPI-Apathy, and the NPI-Depression as criterion measures. The results are summarized in the Table 3. The PEAR-Apathy was highly correlated with the PDS (ρ=.814, p<.001) and the NPI-Apathy (ρ=.710, p<.001), suggesting good convergent validity. The PEAR-Apathy was not highly correlated with the NPI-Depression (ρ=.462, p<.001), suggesting fair discriminate validity. Notably, the results also showed that the NPI-Depression had a lower correlation with the PEAR-Apathy than the PDS (ρ=.581, p<.001) or NPI-Apathy (ρ=.614, p<.001), suggesting that PEAR-Apathy had a better discriminate validity than the PDS and the NPI-Apathy.

Internal Consistency

The total Cronbach's α was 0.84 for the PEAR-Environment and 0.85 for the PEAR-Apathy, suggesting good internal consistency for both subscales. The findings also showed that eliminating any of the items would not significantly increase the Cronbach's α value. Therefore, no items were removed from the PEAR.

Inter-Rater and Intra-Rater Reliability

The inter-rater and intra-rater reliability of the PEAR are demonstrated in Table 2.3. For the PEAR-Environment, the inter-rater reliability was 73.96-89.58% for percent agreement and 0.49-0.94 for weighted Kappa, also suggesting good to excellent reliability. The intra-rater reliability of the PEAR-Environment was 79.17-92.71% for percent agreement and 0.63-0.94 for weighted Kappa, suggesting good to excellent reliability. Although stimulation strength and physical accessibility showed a fair weighted Kappa (0.55 and 0.49 respectively) for inter-rater reliability, their high percent agreement (80.21% and 87.50% respectively) evidenced their good reliability. Their Kappa values were likely to be underestimated because there was not much rating variance on these two items as the selected videos were highly homogeneous for these two environmental characteristics.

For the PEAR-Apathy, except facial expression and eye contact, the inter-rater reliability was 63.54-85.42% for percent agreement and 0.66-0.86 for weighted Kappa, suggesting good to excellent reliability. The intra-rater reliability of the PEAR environment subscale showed 75.00-89.58% for percent agreement and 0.74-0.89 for weighted Kappa, suggesting excellent reliability. The inter-rater reliability was fair, but relatively lower than on other items, such as facial expression and eye contact with 51.04% and 56.25% for percent agreement and 0.60 and 0.47 for weighted Kappa, respectively.

Discussion

This study developed the PEAR and established its content validity for both environment and apathy subscales. Results on the construct validity demonstrated that the environment subscale had a modest validity for the total score. It also had a modest validity for subscale scores on stimulation specificity, social involvement, and physical accessibility, but not on stimulation clarity, stimulation strength, or environmental feedback. This was not unexpected. Crowding is more relevant to social involvement and stimulation clarity and strength. Even if crowding is relevant to the other three items, it only covers a partial construct of the environment subscale. This is because the environment subscale captures stimulation not only from people but also from ongoing events or activities and objects, Also, too much crowding could lead to chaos and overstimulation.

Results on construct validity demonstrated that the total score of the PEAR-Apathy subscale had good validity, as evaluated by the NPI-Apathy and PDS. Additionally, the findings also demonstrated a moderate correlation between the PEAR-Apathy and the NPI-Depression, indicating moderate discriminate validity to distinguish apathy from depression. Given the overlap between apathy and depression in the literature (Starkstein et al., 2005), this is not unexpected. However, this study demonstrated that the discriminate validity of the PEAR was better than the NPI and PDS. That is, the PEAR can better distinguish apathy from depression. The validity in discrimination of apathy from depression is important for an apathy instrument because clinical, apathy is often misdiagnosed as depression.

For reliability, all items in the PEAR, except for facial expression and eye contact in the apathy subscale, demonstrated good to excellent reliability in measuring the effect of the environment on the apathy level in residents with dementia in long-term care facilities. The modest inter-rater reliability of facial expression and eye contact was mainly due to the limitations of the videos that did not clearly capture participants' facial expression and eye contact status. It is expected that the reliability will be enhanced by using videos that are recorded specifically to evaluate apathy or direct observation. Based on the findings, the PEAR is suggested for use in measuring care environment and apathy via video observation in long-term care residents with dementia.

In summary, the PEAR is the very first instrument that measures apathy and care environments concurrently for persons with dementia. With established psychometrics, the PEAR is recommended for assessment of apathy and care environments related to apathy. This scale not only brings the awareness of environmental stimulation to apathy assessment, but also enables a study of the relationship between care environment and apathy. Consequently, the findings will guide environment-based interventions targeting apathy. Finally, another advantage of this scale is the ability, through observation, to measure apathy for long-term care residents with advanced dementia, especially for the cases in which assessment via self-report and family informants is not possible.

Limitations or Potential Difficulties

As of yet, there is no optimal criterion measure that will allow a full evaluation of the construct validity of the PEAR-Environment. While the Ambiance Scale conceptually captures similar environmental characteristics, results did not show clear correlation with the PEAR-Environment rating, possibly because those ratings were not specific to the segments utilized to rate the PEAR-Environment for this study. Future studies may duplicate this validity test scale by matching the exact measurement time. The lack of correlation may also due to the fact that the Ambiance Scale is a more global measure of the environment, while the PEAR-Environment looks at the participants' immediate environment and how it interacts with individual participants. As an alternative, this study used the Crowding Index to evaluate partial constructs of the PEAR-Environment. Once a proper criterion measure is identified, validity can be further evaluated.

While testing the psychometrics using video observation allowed repeated reviewing and observations by multiple raters, the videos of the parent study were not designed for this study, and did not always offer the best angle to observe the participants' apathy level and their immediate environment. Consequently, the validity and reliability of the PEAR may be underestimated. To minimize this limitation, the investigator used a selective video screening procedure to assure the quality of videos for the purposes of this study.

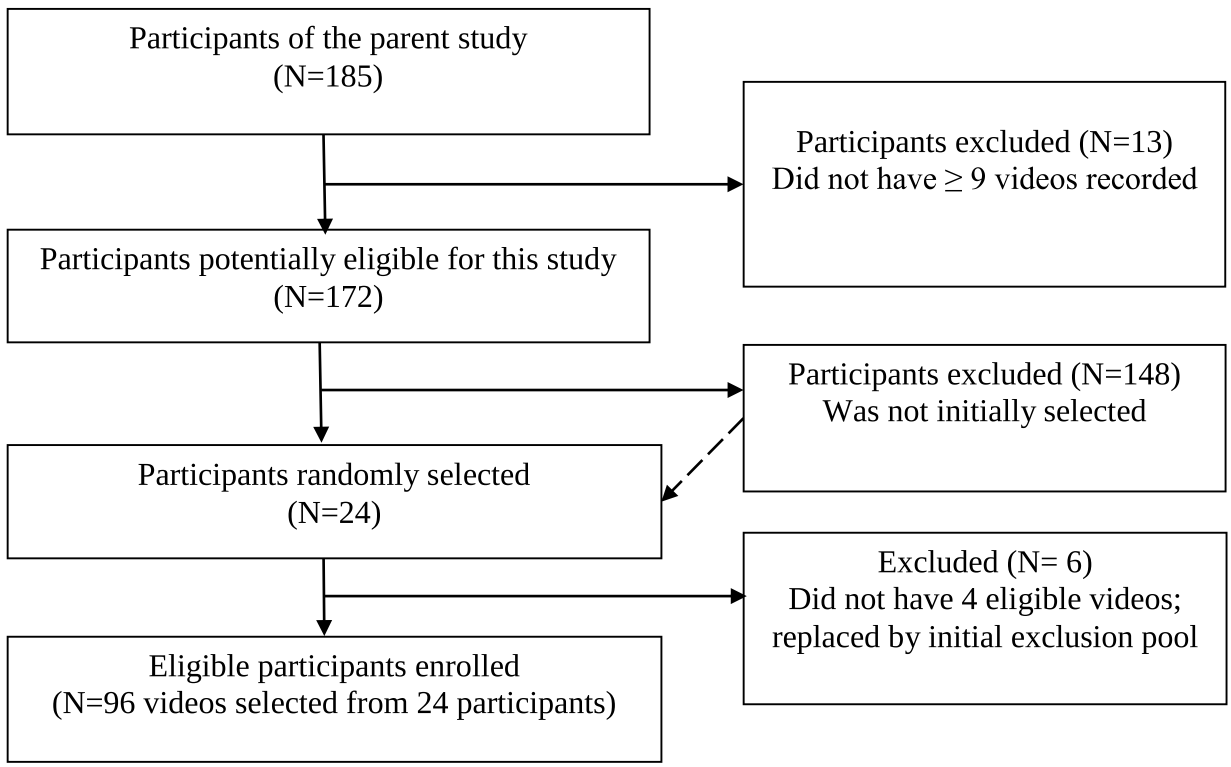


Figure 2.1. Sampling Process

Table 2.1. Demographics and Baseline Cognitive Function

(N=24 Participants)

Characteristic	*n (%)*
Age (years), mean ± SD (range)	82.38±6.95 (68-94)
Gender, Female, n (%)	17 (78.83%)
Race, Caucasian, n (%)	22 (91.67%)
Facility Type(N=22)	
Nursing Home, n (%)	14 (63.63%)
Assisted Living, n (%)	8 (36.36%)
MMSE (N=14\`), mean ± SD (range)	10.29 ± 6.24 (2-20)
Cognitive Impairment Level (N=22)	
Mild Impairment (MMSE=17-23), n (%)	3 (13.64%)
Moderate Impairment (MMSE=11-16), n (%)	3 (13.64%)
Severe Impairment (MMSE=0-10), n (%)	8 (36.36%)
Too Severe to Complete Test, n (%)	8 (36.36%)
Dementia-related Deficits	
Learning and Retaining New Information	21 (100.00%)
Handling Complex Tasks	19 (90.48%)
Reasoning Ability	21 (100.00%)
Spatial Ability and Orientation	14 (66.67%)
Language	10 (47.62%)
Behavior	5 (23.81%)

Table 2.2. Description of Ratings

(N=96 Videos)

Measurement	*Mean ± SD (range)*
PEAR	
Environment Total	11.96±3.51 (10-24)
Stimulation Clarity	3.44±.89
Stimulation Strength	2.91±.50
Stimulation Specificity	2.60±.85
Social Involvement	2.75±1.10
Physical Accessibility	3.81±.49
Environmental Feedback	2.53±.72
Apathy Total	14.48 ± 4.44 (6-23)
Facial Expression	2.55±.77
Eye Contact	1.60±.75
Physical Engagement	2.47±.87
Purposeful Activity	2.16±1.10
Verbal Tone	3.01±.96
Verbal Expression	2.69±1.31
Crowding Index	12.92 ±11.48 (0-66)
Passivity Total	13.53±5.82 (1-19)
NPI-Apathy Total	8.04±3.60 (0-17)
NPI-Depression Total	1.52±1.54(0-6)

Table 2.3. Inter-Rater and Intra-Rater Reliability of the PEAR

(N=96 Videos)

	Inter-Rater Reliability		*Intra-Rater Reliability*	
Coding item	Percent Agreement	Weighted Kappa	Percent Agreement	Weighted Kappa
Environment				
Stimulation Clarity	80.21	0.70	82.29	0.70
Stimulation Strength	80.21	0.55	85.42	0.69
Stimulation Specificity	73.96	0.78	79.17	0.86
Social Involvement	89.58	0.94	91.67	0.94
Physical Accessibility	87.50	0.49	92.71	0.63
Environmental Feedback	80.21	0.70	89.58	0.81
Apathy				
Facial Expression	51.04	0.60	75.00	0.75
Eye Contact	56.25	0.47	79.17	0.74
Physical Engagement	63.54	0.71	84.38	0.86
Purposeful Activity	68.75	0.66	78.13	0.75
Verbal Tone	85.42	0.86	89.58	0.89
Verbal Expression	71.88	0.85	79.17	0.86

CHAPTER III

THE ASSOCIATION BETWEEN CARE ENVIRONMENTS AND APATHY IN LONG-TERM CARE RESIDENTS WITH DEMENTIA

Introduction and Overview

Apathy is the most prevalent neuropsychiatric and behavioral symptom in persons with dementia. It can occur in all types and all stages of dementia (Starkstein et al., 2005). Conceptually, Marin (1996) first defined apathy as primarily a motivation deficit demonstrated by a lack of goal-directed activities in cognitive, behavioral, and affective dimensions. Clinically, apathy manifests as lack of interest, lack of initiative, social withdrawal, and flat emotional response (Starkstein & Leentjens, 2008).

Apathy can lead to adverse consequences in persons with dementia, including advancement of dementia, reduced function in activities of daily life, and decreased quality of life (Starkstein, Ingram, Garau, & Mizrahi, 2005). Moreover, persons with apathy tend not to adhere to treatment plans, and also need aggressive behavioral treatment, have poor treatment outcomes, and need more support and institutional care, resulting in higher treatment costs. In addition to reflecting suffering in patients, apathy is also associated with increased burden and depression in their family caregivers. Despite the negative impact of apathy on patients and family caregivers, persons with apathy are often not well-identified and mostly do not receive appropriate care for their medical and mental health conditions (Starkstein et al., 2005). A challenge to apathy management in persons with dementia is a lack of evidence of possible modifiable environmental factors for treating apathy (Robert et al., 2009). Environmental stimulation provided through multisensory stimulation (Baker et al., 2001), social interaction (Dettmore et al., 2009), and music therapy (Holmes et al., 2006) have shown to reduce apathy in patients with dementia; however, the underlying mechanisms are understudied.

The importance of the environmental factors in understanding apathy was pointed out by two major pioneer researchers in apathy. Marin (1996) suggested that environmental events, such as institutionalization, which lead to loss of incentive, reward, or control, are a precursor of apathy. Additionally, Strauss and Sperry (2002) described apathy as lack of responsiveness to internal or external stimuli demonstrated by a lack of self-initiated activity. The diagnostic criteria of apathy, proposed in a panel of experts, include patients' responses to environmental stimulation (Robert et al., 2009). This suggests that environmental stimulation plays an important role in the assessment of apathy.

Physical and social environments play a crucial role for behavioral symptoms and are suggested to be important treatment interventions for behavioral symptoms in dementia (Algase, Beattie, Antonakos, & Yao, 2010). For example, multisensory stimulation (Baker et al., 2001) and social networks (Dettmore et al., 2009) both involve components of the physical or social environments that have been shown to reduce adverse behavioral symptoms in dementia, including apathy. However, we know little about the key effective components of physical and social environments that influence apathy. Environmental factors are especially important given they are often modifiable factors which can effectively prevent or manage apathy.

Theoretic Framework

This study is guided by the Need-Driven Dementia-Compromised Behavior (NDB) model as depicted in Figure 3.1 (Algase et al., 2012). In the NDB model, behavioral symptoms in dementia are conceptualized as need-driven behaviors because they are an expression of needs (Algase et al., 1996; Algase et al., 2012; Whall & Kolanowski, 2004). This model also suggests that need-driven behaviors are a reflection of the collective effect of individuals' background and proximal factors. According to this model, background factors that potentially affect behavioral symptoms include underlying neurological, cognitive, and psychosocial factors as well as general health. The proximal factors involve individuals' need states (e.g., physiological and psychological needs) and their immediate environments (e.g., physical and social environments) (Algase et al., 1996). Both background and proximal factors can separately affect behavioral symptoms of dementia, and, according to the recent update of this model, background factors can also affect the relationship between proximal factors and behavioral symptoms (Algase et al., 1996; Algase et al., 2012; Whall & Kolanowski, 2004).

Although the NDB model has not been explicitly examined for apathy, this model fits nicely with the concept and mechanism of apathy in the literature. For background factors, the literature suggests that apathy results from the brain lesions that involve the mechanisms for motivation and plans for actions (Starkstein et al., 2006). Specifically, the cingulate circuit may be involved in the process of linking motivation to action, and limbic areas involved in conveying emotional experience into action (Habib, 2004; Starkstein et al., 2006).

Taking a slightly different conceptual approach, Levy and Dubois (2006) conceptualized apathy as the reduction of self-initiated and purposeful behaviors, and suggest that apathy is associated with the dysfunction of the goal-directed behaviors mechanism. This dysfunction is hypothesized to affect three mechanisms of processing: emotions-affective, cognitive, and auto-activation. As a result, individuals tend to have difficulty in connecting emotion/affect to behaviors, elaborating plan of action, and/or initiating thought or behaviors, and they consequently become apathetic (Levy & Dubois, 2006). Brain lesions that are involved in these mechanisms and associated with apathy include prefrontal lesions, basal ganglia, and limbic territories. These notions and evidence support the links between background factors and apathy as indicated in the NDB model.

For proximal factors, the link between apathy and personal needs and environments has not been clearly examined in the literature. However, Marin (1990) suggests that environmental events which can lead to loss of incentive, reward, or control can be the precursors of apathy, supporting the association between apathy and environment, and matching the NDB model. Additionally, according to Levy and Dubois (2006), the process of goal-directed behaviors is initiated with internal and external determinants, which parallel the personal need and environmental factors in the NDB model. Finally, the NDB model also suggests that background factors influence the relationship between proximal factors and behavioral symptoms of dementia. While this might be true for apathy, this notion has not been thoroughly discussed in the literature and needs further evaluation.

The focus of this study is to comprehensively explore the relationship between environmental factors and apathy, including the magnitude, direction, and statistical significance of the relationship.

Research Aims

The purposes of this study are to examine the relationship between apathy level and environment characteristics in long-term care residents with dementia. The environmental factors selected in this study include:

1) Environmental stimulation: stimulation clarity, strength, and specificity, social involvement, physical accessibility, and environmental feedback
2) Ambiance: engaging and soothing
3) Crowding: number of people within 2 feet, 4 feet, 6 feet, and 8 feet
4) Staff familiarity: how well the caregiver knew the participant, how long the caregiver had known the participant, and how often the caregiver had directly cared for the participant
5) Light and sounds: low, moderate, and high level.

In this study, we hypothesize that an engaging ambiance level and staff familiarity are associated with a lower apathy level, while a soothing ambiance level is associated with a higher apathy level. We also hypothesize that levels of crowding, light, and sound will have a curvilinear association with apathy level; a moderate level of crowding, light, and sound are associated with a reduced apathy level but a low or high level of these environmental factors are associated with an increased apathy level.

Methods

Design

This study employed a descriptive and repeated observation design to examine the relationship between apathy and physical and social environments in persons with dementia.

Setting/Sample

The sample was selected from a large observational parent study of dementia (Algase et al., 1996). The sample for the parent study was recruited from 16 nursing homes and 6 assisted living facilities in Michigan and Pennsylvania from 2000 to 2004. The parent study selected study facilities based on convenience, and gender and racial diversity.

Sample for the Parent Study

A total of 185 participants were enrolled in the parent study. Participants were included in the parent study if they: 1) were English speaking, 2) met DSM-IV diagnostic criteria of dementia, 3) scored < 24 for Mini-Mental State Examination (MMSE), 4) were ambulatory, and 5) maintained a stable regime of psychotropic medications. For each participant, 14 video observations were made to capture their dementia-related behavioral symptoms. Twelve of the videos were recorded between 8:00am and 8:00pm during non-mealtime periods on at least two different days separated by 48 hours. The other two videos were made to observe specific events: one mealtime and one care event (e.g., bathing or dressing). Each observation lasted 20 minutes. In total, there were 2,520 observations in the parent study.

Sample for this Study

For this study, a total of 40 participants were selected from the parent study. This is an exploratory study and there were no data for effect size established from previous studies. The desired sample size of 40 participants was calculated using the following parameters: anticipated effect size (f2) = 0.41, observed R^2=0.29, desired power level=0.8, and number of predictors= 6, and P=.05. The sample size was originally determined based on linear regression analysis. Additionally, using six predictors as a parameter was motivated by a conservative approach.

Sampling Procedures

The sampling procedure is summarized in Figure 3.2. First, 40 participants were randomly selected using a random sequence generator. Of the 185 participants in the parent study, 13 participants were excluded from the selection pool for the present study because they had less than 9 videos available, which left 172 potential participants. For each of the 40 randomly selected participants, 3 eligible videos and 3 segments from each video were selected to be measured for apathy levels and environmental characteristics.

For each participant, videos were screened for eligibility to assure that each video contained three specific environmental contexts with high video quality. The three environmental contexts included one mealtime, one interpersonal interaction between participant and staff, and one randomly selected video. A variety of observation samples for each participant allowed more representative data regarding participants' apathy and their exposure to their physical and social environments. In addition, each selected video segment had to contain high quality recordings of the participant's facial expression, voice, and front of the upper body, as well as the images and sounds of their immediate environment.

Each video segment lasted from one to two minutes with stable environmental context. Changes in environmental stimulation were defined when: 1) the participant newly entering or leaving the room; 2) anyone who was newly present coming into the participant's visual field within three feet and staying for at least one minute, or 3) anyone initiating an interpersonal conversation/interaction and staying for at least one minute. The minimum observation time was one minute because the findings of the pilot study suggested that participants often respond within one minute post-stimulation, if they respond at all. Their responses often do not change after one minute. Videos recorded during bedtime or nap time were eliminated.

To be enrolled, a participant required three eligible videos. If an initially-selected participant was ineligible, a replacement participant and videos were randomly reselected from the previously unselected pool until all eligible samples were identified.

Study Variables

Baseline Variables

Participants' demographic data and underlying conditions included age, gender, race, facility type, cognitive function, and dementia-related deficits. The level of care for this sample was either assisted living or nursing homes. Cognitive function was measured using MMSE levels. All baseline data were collected once for each participant in the parent study. Dementia-related deficits included: learning and retaining information, handling complex tasks, reasoning ability, spatial ability and orientation, language, and behaviors.

Dependent Variables

The dependent variable was apathy level measured using the Person-Environment Apathy Rating (PEAR)–Apathy (Jao et al., 2013, Appendix A). The PEAR-Apathy is a part of the PEAR scale recently developed by the first author (Jao). This scale aims to assess apathy level through observation in persons with dementia across different stages. Its psychometrics has been established. The PEAR-Apathy demonstrated good convergent validity as evaluated by the Neuropsychiatric Inventory (NPI)-Apathy subscale (Cumming et al., 1994) and the Passivity in Dementia Scale (Colling, 2000) with correlation of ρ=.710 (p<.001) and ρ=.814 (p<.001), respectively. For reliability, its Cronbach's α was 0.85, suggesting good internal consistency. The weighted Kappa of individual items ranged 0.47 to 0.86 and 0.74 to 0.89 for inter-rater and intra-rater reliability, respectively. This scale measures apathy level through six items: facial expression, eye contact, physical engagement, purposeful activity, verbal tone, and verbal expression. Each item is rated on a 1 to 4 scale with a higher score indicating a higher apathy level (Jao et al., 2013). Coding for the PEAR-Apathy was conducted in the present study. All video segments were randomly divided into two groups, and one researcher coded the first half while the other researcher coded the second half.

Independent Variables

Independent variables included: environmental stimulation, ambiance, crowding, staff familiarity as well as light and sound.

Environmental Stimulation: Environmental stimulation was measured using the Environment subscale of the PEAR scale (The PEAR-Environment; Appendix A). The PEAR-Environment scale was developed by the first author, and aims to examine the environmental stimulation relevant to apathy in persons with dementia. The content validity was established by a panel of dementia researchers. Its concurrent validity was supported by the Crowding Index (Algase et al., 2011) with a significant correlation with the total score (ρ=.266, p=.009), stimulation specificity (ρ=.301, p=.003), social involvement (ρ=.322, p=.001), and physical accessibility (ρ=.348, p=.001), but not with stimulation clarity, stimulation strength, and environmental feedback (Jao et al., 2014).

For reliability, results revealed that the total score for the PEAR-Environment had a low but significant correlation with the Crowding Index (ρ=.266, p=.009). Its weighted Kappa for inter-rater reliability was 0.49-0.94 (73.96-89.58% percent agreement) and for intra-rater reliability was 0.63-0.94 (79.17-92.71% percent agreement) suggesting good to excellent reliability. The total Cronbach's α was 0.84 suggesting good internal consistency. The PEAR-Environment included six items: stimulation clarity, stimulation strength, stimulation clarity, social involvement, physical accessibility, and environmental feedback. Each item was rated on a 1-4 scale with a higher rating indicating a better environment (Jao et al., 2013).

Similar to measures for the PEAR-Apathy, coding for the PEAR-Environment was conducted in this study by two trained researchers. However, the measures of apathy and environment subscales for the same video were coded by different researchers. For example, if the PEAR-Apathy for video segment 1 was measured by rater 1, then PEAR-Environment for the same video segment will be conducted by rater 2.

Ambiance: Ambiance was measured in the parent study using the modified Ambiance Scale (Appendix B). Based on observers' intuitive responses, the Ambiance Scale aims to assess long-term care facilities to be more homelike or institutional-like and consequently to assess the capacity of care environments for triggering behavioral and affective symptoms in residents with dementia. The psychometrics of the Ambiance Scale was examined in the parent study and reported elsewhere (Algase et al., 2007).

The Ambiance Scale includes 9 adjective pairs, categorized into two soothing and engaging subscales. The engaging subscale includes 6 items: stimulating-custodial, warm-cold, embellished-stark, welcoming-impersonal, colorful-drab, and novel-boring.

The soothing subscale includes 3 items: informal-formal, unpretentious-pretentious, and peaceful-chaotic. The AS was rated in the parent study by trained researchers at the end of each video recording. At the end of the video recording, the researchers rated each item based on their impression for the environments through direct observation. Each item was rated on a -2 to +2 scale (Algase et al., 2007). This study analyzed the average soothing and engaging score (ranged -2 to +2) separately.

Crowding: The measure of crowding was developed in the parent study to assess the density and proximity of people surrounding the participant (Algase et al., 2011). The crowding was measured using a set of five concentric circles as Appendix C. The center circle represents the participant. The five circles, from inside (zone 1) to outside (zone 5), indicate a radius of 1 feet, 2 feet, 4 feet, 6, feet, and 8 feet from the participant, respectively. The researchers marked every person within 8 feet from the participant to indicate their relative location and then calculated the total number of people in each zone.

The crowding data were collected in the parent study during each video recording at three measure points: 1) at the beginning, 2) immediately after 10 minutes, and 3) immediately after 20 minutes. This study used the measure closest to the selected segment for analysis. The data were matched to each video sample using the following rule: data point 1 was used if the video segment started at 5 minutes or before, data point 2 was used if the video segment started after 5 minutes, and data point 3 was used if the video segment started after 15 minutes. This way, the data were within 5 minutes from the beginning of the observation segment for all video samples. The number of people in zone 1 and 2 (within 2 feet), zone 1 to 3 (within 4 feet), zone 1 to 4 (within 6 feet), and zone 1 to 5 (within 8 feet) were calculated for analysis.

Staff Familiarity: Staff familiarity is described as how well the direct caregivers (those who provide care for the participant during observation) knew the participant (Kolanowski et al., 1994). Staff familiarity was measured in the parent study using three staff-reported indicators: 1) how well the caregiver knew the participant, 2) how long the caregiver had known the participant, and 3) how often the direct caregiver had cared for the participant (Appendix G). The researchers collected information from the direct caregivers and documented it once per video recording. Each item was rated on a Likert scale; a higher index indicates a higher familiarity.

Light and sound: The light and sound levels were measured in the parent study using Gossen Color Pro 3F Meter® (Bogen Photo Corp, Ramsey, NJ) and the Quest Sound Meter® (Quest Technologies, Oconomowoc, WI), respectively. Data were collected three times for each video: 1) at the beginning of the observation, 2) immediately after 10 minutes, and 3) immediately after 20 minutes of the video recording. The data were matched to selected video samples using the same rule as the data for crowding described earlier. Because the light and sound data were in a skew pattern and had outliers, the data were collapsed into three groups based on percentiles (≤33.3%, >33.3% - ≤66.6%, and >66.6%) to separately indicate from the lowest to the highest light and sound level. For light, the cut off points for the three groups were: ≤74, 75 to ≤170, and >170. For sound the groups are: ≤62, 62.1 to ≤68.1, and >68.1.

Data Collection Procedures

Data were collected via two methods: 1) extracting data from the parent study, and 2) coding data in this study through observing videos from the parent study. Data extracted from the parent study included: demographic and baseline variables (age, gender, race, facility type, and cognitive level) and environmental variables (ambiance, crowding, staff familiarity, and light and sound).

Data coded in this study included: apathy levels and environmental stimulation using PEAR-Apathy and Environment subscales, respectively. Coding was conducted by two trained researchers and was guided by the rating manuals. Data were coded specifically for each selected video segment. To avoid selection bias, the researchers were different from the screener. The rating order was prearranged and observations from the same participant were not arranged in sequence.

Data Analysis

Data analysis was conducted using the Statistical Package for the Social Science (SPSS 21, IBM Corporation, New York, NY) and Statistical Analysis Software (SAS 9, SAS Institute Inc., Cary, NC).

The dependent variable was the total score of the PEAR-Apathy. Independent variables included: 1) the total score of the PEAR-Environment, 2) average Engaging score and average Soothing score of the Ambiance Scale, 3) number of people (crowding) within 2 feet, 4 feet, 6 feet, and 8 feet from the participant, 4) three separate scores on Staff Familiarity (how well the caregiver knew the participant and how long and how often the caregiver had known the participant) and 5) light lux and decibels of sound. Because the light and sound data were in a skewed pattern and had outliers, the data were collapsed into three groups based on percentiles.

Descriptive statistics were summarized to describe participants' demographics and baseline conditions. Because this is a repeated-measure study and there were nine video segments purposefully selected from three different videos for each participant, a generalized linear mixed (GLM) model was used to account for the correlation among video on the same person and among segments within the same video. For the three videos, video 1 was at mealtime, video 2 contained interactions between staff and participant, and video 3 was a randomly selected video. Each set of independent variables was put in one GLM model to analyze their relationship with apathy. Because crowding data were drawn from a pool of people from within 2 feet to within 8 feet of the participant, the data began to overlap. Thus, each individual level of data was analyzed in a separate GLM model rather than combined.

Model selection was performed by using AIC as a criterion for forward selection. To avoid collinearity, the environmental variables were separately analyzed in two groups: 1) environmental stimulation, and 2) ambiance, crowding, staff familiarity, and light and sounds. In each group, the model was checked for collinearity before interpretation. In the case that multicollinearity was encountered, variables were removed to alleviate the problem. Interaction models were also explored through introducing interaction terms between levels of cognitive impairment and each environmental variable.

Results

This study included a total of 40 participants. Participants' demographics and baseline cognitive function data are summarized in Table 3.1. Participants' average age was 82 years, and 30 (75%) of them were female. Approximately two thirds of the participants were institutionalized in nursing homes and the remainder of them resided in assisted living facilities. In terms of cognitive function, based on MMSE results, approximately three fourths of the participants (73%) were severely impaired or were too severely impaired to complete the MMSE test. The majority of participants showed cognitive deficits in learning, executive capacity to complete complex tasks, and reasoning.

Association between Apathy and Care Environments

Results are discussed individually on the relationship between apathy and each set of environmental factors while accounting for the effect of different video observations. For the effect of different videos, this study revealed that difference in the environmental context of the video samples explained apathy level. As compared to the randomly selected contexts, participants in the mealtime or interacting with staff videos corresponded to a higher apathy score (a 0.39-062 and 0.23-0.68 higher score, respectively). Although the effects were small and not statistically significant, the effect size and direction were consistent across analyses on different environmental features, including environmental stimulation, ambiance, crowding, staff familiarity, and light and sound.

Environmental Stimulation

Results regarding the relationship between care environments and apathy are summarized in the Table 3.2. Findings demonstrated that observations from different videos did not significantly differ on apathy levels. Stimulation clarity and stimulation strength are significant factors for apathy score. On average, an increase of 1 point on stimulation clarity corresponded to a decrease of 1.3 points on apathy score. Similarly, an increase of 1 point on stimulation strength corresponded to a decrease of 1.9 points on apathy score. For the other four factors, stimulation specificity and physical accessibility were associated with a higher apathy level, while social involvement and environmental feedback were associated with a lower apathy level.

The model selection that examined the main effect of the environmental stimulation yielded a model with environmental clarity, strength, and specificity (Table 3.2.2). Environmental clarity and strength were associated with a lower apathy level, with an increase of 1 point corresponding to a decrease of 1.5 and 2.0 points on apathy score, respectively. The interaction model that introduced the interaction between levels of cognitive impairment and each factor of environmental stimulation revealed similar results, and did not generate compelling evidence for preferring them over simpler main effects models. Notably, the results concerning environmental clarity, strength, and specificity appeared to be quite robust for modeling selection. That is, they were stable and did not change greatly in effect or evidence when different models were fit.

Ambiance

Results on the relationship between apathy and ambiance engaging and soothing scores are summarized in Table 3.3. The data showed that the Engaging score was associated with a lower apathy level while the soothing score was associated with a higher apathy level. However, this effect was small and not statistically significant. The model selection that explored ambiance, crowding, staff familiarity, as well as light and sounds did not yield any significant main effect model or interaction model.

Crowding

Results on the relationship between apathy and crowding are summarized from Table 3.4-3.7to Table 4-8 for data on crowding within 2 feet, 4 feet, 6 feet, and 8 feet respectively. Results indicated that crowding in 2 feet was associated with a higher apathy level. Specifically, an increase of one person present within the 2 feet radius from the participant corresponded to an increase of 0.5 score on the total apathy score and the effect approached statistical significance (p=.06). However, the effect gradually decreased as the crowding distance extended. In fact, as the distance extended to 4feet, 6 feet, and 8 feet, the effect decreased to 0.3, 0.2 and 0.1 score on apathy, respectively and became less statistically significant. Therefore, the number of people who were close to the participant contributed to a higher apathy level but this effect became lower as the persons were further away from the participant.

Staff Familiarity

Results concerning the relationship between apathy and staff familiarity are summarized in Table 3.8. Staff familiarity was described using three indicators: 1) how well the caregiver knew the participant, 2) how long the caregiver had known the participant, and 3) how often the direct caregiver had cared for the participant. In examining the trend of the relationship, how well the caregiver knew the participant was associated with a lower apathy level while how long and how often had the caregiver cared for the participant tended to contribute to a higher apathy level. However, the effects were small and did not reach statistically significance.

Light and Sounds

Results concerning the relationship between apathy and staff familiarity are summarized in the Table 3.9. Data on light and sounds were collapsed into three levels, ≤ 33.3%, >33.3- ≤66.6%, and >66.6%, to indicate low, moderate, and high levels for light and sound. Overall, the total effects across levels were not statistically associated with apathy level for both light (p=.02) and sounds (p=.04). In examining the trend of their effect at the individual level, although the data did not reach statistical significance, the results showed that, as compared to the moderate level, the low and high levels of light were associated with a higher apathy level. In fact, as the light level decreased from moderate to low, apathy score increased 1.07 points (p=0.11). Similarly, when the light level increased from moderate to high, participants' apathy level increased 0.94 point (p=.17).

In contrast, results on sounds showed that the higher sound level was associated with the lower apathy level, but the effect size was small and not statistically significant. As compared to the moderate level of sound the lower sound level is associated with a 0.58 higher point higher on apathy level while the higher sound level was associated with a 0.28 lower point on apathy level.

Discussion

Overall, among all environmental factors tested in this study, clarity and strength of environmental stimulation were two factors significantly associated with apathy level. Specifically, an increase of 1 point on stimulation clarity was associated with a decrease of 1.3 points on apathy score. Similarly, an increase of 1 point on stimulation strength was associated with a decrease of 1.9 points on apathy score. These findings suggest that residents with dementia living in care environments with clear and sufficient stimulation tend to have lower apathy levels.

The effects on apathy of the other four features of environmental stimulation were small and not statistically significant. In terms of the direction of their effects, social involvement and environmental feedback were associated with lower levels of apathy while stimulation specificity and physical accessibility were associated with higher levels of apathy. This suggests that persons with dementia living in environments that actively involve individuals with social interactions and prompt their engagement tend to have lower apathy levels. These were unexpected but interesting findings. It is worthwhile to further explore these results in future studies.

The effects of other environmental characteristics were also small and not statistically significant. The characteristics corresponding to a lower apathy level include: an engaging level of environmental ambiance, how well the caregiver knows the residents, and a high level of sound. In contrast, environmental characteristics that corresponded to a higher apathy level include: a soothing level of environmental ambiance, crowding (the closer the person, the stronger the effect), the frequency and duration of caregivers’ care for the residents, a high or low level of light (versus moderate level), and a low level of sound.

Although most of the environmental factors examined in this study did not show a significant relationship with apathy, it might be premature to eliminate these factors as potential correlates of apathy. The absence of a significant relationship might be explained by some methodological limitations of this study. Firstly, the sample size of this study was relatively small. This prevented the combination of several environmental factors in the same model to examine individual factors while controlling the other factors.

Secondly, there were gaps of measure timing between apathy and most of the environmental factors. Except for the environmental stimulation measured using the same method and same video segments as apathy, the other environmental factors were measured in the parent study through direct observation of the environment one or three times each video, which did not necessary match to the selected video segments. Specifically, crowding, light, and sounds were measured three times each video, at the beginning, the middle and the end of video recording. The approach this study used to match data helped minimize the timing gap to within 5 minutes from the data were measured to the selected video segment for apathy measures.

However, because crowding, light and sounds are dynamic conditions that constantly vary, the brief gap of 5 minutes could still introduce measurement errors. The gapping was even greater in ambiance measure. The ambiance was measured at the end of video recording, so the measure gap could be up to 18 minutes. Not only could the environment climate change during that period, but the participant also could be in a different place and have experienced totally a different ambiance. For example, the selected video segments for apathy coding could be at the beginning of the video in which the participant was in a non-engaging environment such as their room, but by the time ambiance was measured, the participant could had moved to the living room to participate in an activity program where the environment was much more engaging.

The comprehensibility of environmental stimulation could be largely influenced by individuals' cognitive and sensory functions, e.g., vision and hearing. It is necessary to further examine these factors and the relationship between apathy and environmental stimulation. Because the participants in this study were mostly persons with moderate to advanced dementia, it would also be helpful to duplicate this study with participants with a mild stage of dementia. These results will help inform future intervention studies that tailor and tail environmental stimulation based on individuals' cognitive and functional levels.

This study also suggests that people under different environmental context show slightly different apathy levels, although the difference was not statistically significant. Interestingly, as compared to randomly selected videos, residents in the mealtime or interaction with staff show slightly higher apathy levels. One possible reason is that the stimulation during the mealtime and the interaction is with staff was not in high quality in terms of environmental stimulation. Additionally, if participants are apathetic, their apathy symptoms are prominent and are rated at a high level when exposed to environmental stimulation clearly and specifically toward them. For example, one person who does not respond to clear environmental stimulation will be rated at a higher level of apathy than those who appear to have the same response but to unclear stimulation. Future studies may compare apathy levels for people under these environmental stimulations versus no stimulations. This will require further analysis in larger studies in the future.

While there is literature about care environment for neuropsychiatric symptoms of dementia (Algase et al., 2010), there are no studies that investigate relevant environmental factors influencing apathy in dementia. Several studies have revealed a positive effect of environment-based interventions on apathy, supporting the role the care environment plays on apathy in dementia (Barker et al., 2003, Brodaty & Burns, 2011, Dettmore et al., 2009). However, influential components of the environment were not been specified. The present study is the very first study to explicitly explore the association between care environments and apathy, which limits the comparison of its results with other studies.

Overall, this study sheds light on our understanding of the effect of environmental stimulation on apathy. Findings on environmental factors can help inform future intervention research on apathy. The findings also support the NDB model for apathy, specifically the link between physical and social environments (proximal factors) to apathy (need-driven behavior). The NDB model is a well-established nursing theory for dementia care and has been used to guide interventions development for apathy in dementia (Kolanowski et al., 2005). However, this model has not been thoroughly examined for apathy. Findings of this study have helped fill this gap.

Limitations

Using data and videotaped observations collected in the parent study made this study more feasible and efficient. However, it is possible that that the observation may not always offer the best angle to observe the participant’s apathy level and the care environment. To overcome this limitation, we included three observations for each participant and clear inclusion criteria for each observation. In future studies, we will duplicate this study with real time observations in real life environments.

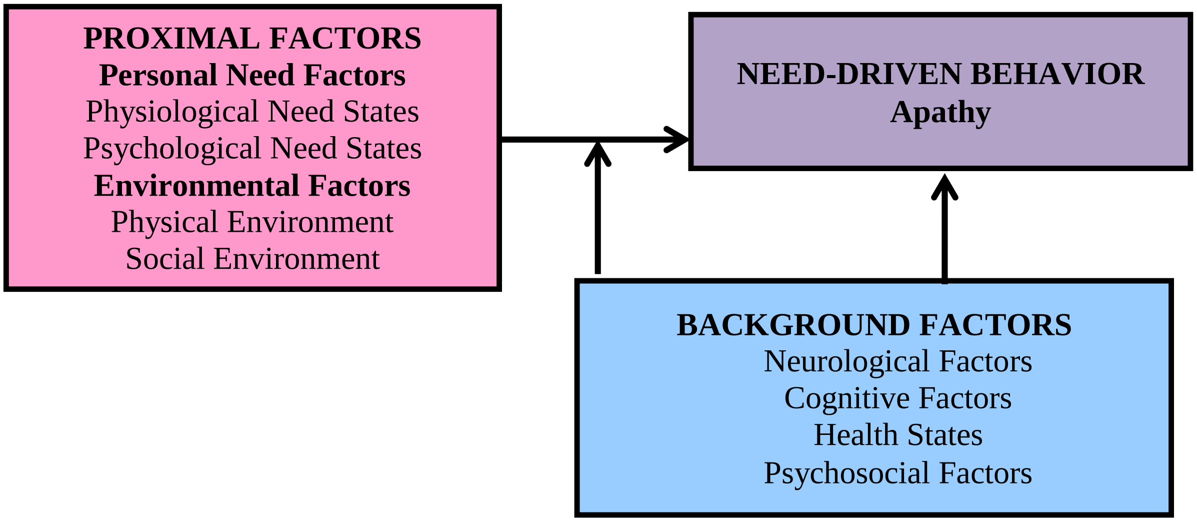


Figure 3.1. Modified Need-Driven Dementia-Compromised Behavior Model

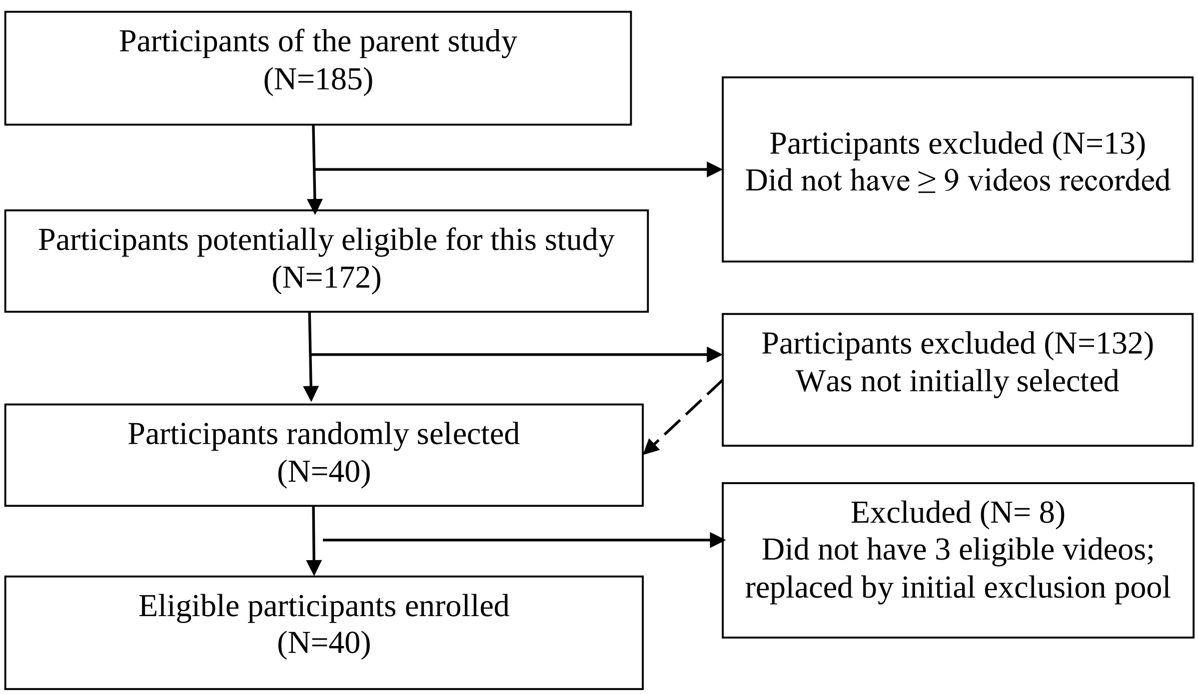


Figure 3.2. Sample Selection Procedures

Table 3.1. Demographics and Baseline Cognitive Function

(N=40 Participants)

Characteristic	*Frequency (%)*
Age, years, mean ± SD (range)	82.7±6.3 years (68-94 years)
Gender, Female, (N=38) n (%)	29 (76.3%)
Race, Caucasian, (N=38) n (%)	32 (84.2%)
Facility Type (N=38)	
Nursing Home	24 (63.2%)
Assisted Living	14 (36.8%)
MMSE (N=26) mean ± SD (range)	12.9 ± 6.5 (2-23)
Cognitive Impairment Level (N=37) n (%)	
Mild Impairment (MMSE:17-23)	9 (24.3%)
Moderate Impairment (MMSE:11-16)	7 (18.9%)
Severe Impairment (MMSE:0-10)	10 (27.0%)
Too Severe to Complete MMSE	11 (29.7%)
Dementia-related Deficits (N=35)	
Learning and Retaining New Information	33 (94.3%)
Handling Complex Tasks	19 (90.5%)
Reasoning Ability	21 (100.0%)
Spatial Ability and Orientation	19 (54.3%)
Language	14 (40.0%)
Behavior	9 (25.7%)

Table 3.2. Relationship between Environmental Stimulation and Apathy

(N=96 videos)

Effect	Estimate	P
Intercept	22.7634	<.0001
Video 1	0.4830	0.3064
Video 2	0.2324	0.4115
Video 3	0	.
Stimulation Clarity	-1.3491	<.0001
Stimulation Strength	-1.8743	0.0009
Stimulation Specificity	0.7014	0.1847
Social Involvement	-0.3681	0.2442
Physical Accessibility	0.2236	0.7505
Environmental Feedback	-0.4060	0.2218

Table 3.3. Relationship between Ambiance and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		13.9577	<.0001
VideoID	V1	0.5377	0.4444
VideoID	V2	0.4101	0.5738
VideoID	V3	0	.
Ambiance Engaging score		-0.3028	0.5276
Ambiance Soothing score		0.4859	0.4104

Table 3.4. Relationship between Crowding in 2 Feet and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		13.5457	.0001
VideoID	V1	0.4116	.5435
VideoID	V2	0.5985	.3878
VideoID	V3	0	.
Crowding in 2 feet		0.5346	.0645

Table 3.5. Relationship between Crowding in 4 Feet and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		13.4901	<.0001
VideoID	V1	0.4087	0.5581
VideoID	V2	0.5913	0.4045
VideoID	V3	0	.
Crowding in 4 feet		0.2517	0.1421

Table 3.6. Relationship between Crowding in 6 Feet and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		13.2983	<.0001
VideoID	V1	0.4363	0.5264
VideoID	V2	0.6872	0.3340
VideoID	V3	0	.
Crowding in 6 feet		0.1484	0.1252

Table 3.7. Relationship between Crowding in 8 Feet and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		13.9502	<.0001
VideoID	V1	0.5635	0.4306
VideoID	V2	0.5215	0.4612
VideoID	V3	0	.
Crowding in 8 feet		0.004685	0.8522

Table 3.8. Relationship between Staff Familiarity and Apathy

(N=96 videos)

Effect	VideoID	Estimate	P
Intercept		12.1734	<.0001
VideoID	V1	0.6812	0.3213
VideoID	V2	0.5398	0.4452
VideoID	V3	0	
Dcknow*		-0.1336	0.7948
Dcknown**		0.3853	0.1752
Dcoften***		0.1104	0.6567

*Dcknow=how well did the direct caregiver know the participant
**Dcknown=how long had the caregiver known the participant
***Dcoften=how often did the caregiver know the participant

Table 3.9. Relationship between Light and Sound and Apathy

(N=96 videos)

Effect	VideoID	Light	Sound	Estimate	P
Intercept				13.9436	<.0001
VideoID	V1			0.5968	0.33
VideoID	V2			0.4700	0.5172
VideoID	V3			0	.
Light		Low		-0.7216	0.2331
Light		High		0.7292	0.2460
Light		Moderate		0	.
Sound			Low	-0.6575	0.2441
Sound			High	-0.7381	0.2026
Sound			Moderate	0	

CHAPTER IV

ACCURACY OF ACTIGRAPH AND ACTIVPAL^{TM} IN MEASURING WEIGHT-BEARING ACTIVITIES

Introduction and Overview

Significance of Diabetic Foot Ulcers

Among the 19 million people in the United States with diabetes (Centers for Disease Control and Prevention, 2011), three million will develop at least one diabetic foot ulcer (DFU) during their lifetime and 720,000 of those who develop a DFU will require an amputation (Lott, et al., 2005). In addition, DFUs are associated with depression, decreased mobility, poor quality of life (Vileikyte, 2001) and increased mortality. Medicare costs for treatment of DFUs rose from $1.5 billion in 1995 to $10.9 billion in 2001 (Powell et al., 2004), a trend that indicates DFUs are becoming more common and the cost of treatment is increasing. Therefore, interest in preventing DFUs is growing.

Although the American Diabetes Association (ADA, 2012) suggests that 85% of DFUs are preventable; however, it is difficult to target persons at risk of ulceration for preventive interventions based on their specific risk factors. Several DFU prediction models have been published (Monteiro-Soares et al., 2011; Monteiro-Soares & Dinnis-Ribeiro, 2010), but their clinical utility is limited. Most of the risk factors in these prediction models are not modifiable (e.g., neuropathy and vascular disease) and serve as "proxies" for mechanisms that are more directly involved in the ulceration pathway. Moreover, these models do not identify patient-specific risk factors so that prevention interventions could target those factors. A model that includes modifiable risk factors that are more directly involved in the ulceration pathway would provide information that could be used to guide the clinical management of persons with previous DFUs.

Weight-bearing activity (i.e., standing and walking) is a preventable and modifiable factor that needs to be considered in a risk model for ulceration. However, studies examining the role of weight-bearing activity in DFUs have produced mixed results leading to confusion in the clinical management of risk. A better understanding of the role of weight-bearing activity in foot ulceration may lead to the timely identification of persons at risk, as well as less costly and more effective preventive interventions.

The study of weight-bearing activity on foot ulceration and recurrence has important clinical implications. For example, despite the lack of evidence, the American Diabetes Association (ADA, 1999) recommends that people with diabetes and peripheral neuropathy decrease weight-bearing activity in order to decrease risk of foot ulceration. Decreasing physical activity may affect overall health and quality of life; thus recommendations to reduce weight-bearing activity need to be based on solid evidence and/or weighed against the adverse impact of reduced activity. Second, compared to other risk factors (e.g., neuropathy and deformity), weight-bearing activity is one of the very few risk factors for foot ulceration and DFU recurrence that is modifiable. That is, weight-bearing activity is a potentially useful factor not only for DFU prediction but also for prevention. This is supported by the fact that pressure off-loading devices (e.g., diabetic shoes) are a widely used strategy to prevent foot ulceration (Bus et al., 2008). If the role of weight-bearing activity on ulceration was better understood, then less costly and less invasive interventions could be more effectively implemented for DFU prevention.

Weight-Bearing Activity and Foot Ulceration

Excessive and repetitive plantar pressures contribute to 90% of DFUs and are the most important DFU predictor (Mueller, et al., 2008; Orsted et al., 2007). Armstrong and colleagues have suggested that over an extended period of time, repetitive pressures can lead to inflammation, focal tissue ischemia, necrosis, and ulceration (Armstrong, Peters, Athanasiou & Lavery, 1998). High and abnormally distributed plantar pressure has been linked to ulceration, delayed ulcer healing, and ulcer recurrence (Lavery, Armstrong, Wunderlich, Tredwell, & Boulton, 2003; Mueller, Smith, Commean, Robertson, & Johnson, 1999).

According to the Physical Stress Theory (Mueller et al., 2008), three components of plantar pressure contribute to foot ulceration: the magnitude of pressure, the amount of time pressure is applied, and the direction, or shear, of pressure. The magnitude of pressure refers to the amount of force applied on the plantar surface of the foot during weight-bearing activity (Mueller et al., 2008). Theoretically, the area with the highest magnitude of pressure, called peak plantar pressure, is the area at the highest risk of DFU. Therefore, peak plantar pressure has been the primary interest for magnitude of pressure in the literature. Duration of pressure refers to the amount of time pressure is applied to the plantar surface of the foot during weight-bearing activities. Duration of pressure is operationalized as duration of standing and walking and as number of steps taken (Mueller et al., 2008). The direction, or shear, of pressure refers to the lateral dispersion of pressure within the soft tissues of the plantar. Shear pressure has not been well-studied because measures of shear pressure have not been well-developed (Mueller et al., 2008). Therefore, because they are measurable, magnitude and duration of pressure are key components that could be useful in a clinical model to identify persons at risk for foot ulceration.

Although substantial evidence has established that plantar pressure is a major factor in foot ulceration (Mueller et al., 2008), it has rarely been incorporated into DFU prediction models or in clinical practice (Crawford, Inkster, Kleijnen, & Fahey, 2007; Orsted et al., 2007), possibly because the critical threshold for plantar pressure in predicting ulceration has not been well-established. The magnitude of pressure for ulceration varies from person to person (Mueller et al., 2008), suggesting that plantar pressure alone is insufficient to predict foot ulceration or recurrence.

Unlike magnitude of pressure, duration of pressure (i.e., duration of standing and walking and number of steps) has not been extensively examined for its role in foot ulceration and recurrence. Weight-bearing activity contributes to cumulative plantar pressure and, therefore, can increase the risk of ulceration and recurrence (Orsted et al., 2007). Findings of the studies that have examined weight-bearing activity on ulceration are mixed, because comprehensive and objective measures of weight-bearing activity have not been employed to examine the relationship between weight-bearing activity and ulceration. Of the four studies which examine the impact of weight-bearing activity on ulceration, three of the studies only measured number of steps taken per day using two-dimensional activity monitors (LeMaster et al., 2003; Lott et al., 2005; Maluf & Mueller, 2003).

The major problem with limiting the measurement of weight-bearing activity to number of steps taken per day is that cumulative duration of plantar pressure associated with standing is missing. Pressure associated with standing might be more important in this population as Najafi et al. (2010) reported that persons with diabetes spend more time standing than walking. Although LeMaster et al. (2003) measured duration of both standing and walking, this study was limited by self-report, lending itself to recall bias. The impact of weight-bearing activity on ulceration and recurrence needs to be examined using more objective and comprehensive measures (i.e., both standing and walking) for weight-bearing activity.

Conceptual Framework

A comprehensive conceptual framework of weight-bearing activity and its relationship with ulcer occurrence and recurrence is proposed in Figure 4.1. This model was developed based on the Physical Stress Theory (Mueller et al., 2008). In this model, cumulative plantar pressure is conceptualized as consisting of both dynamic and static components. The dynamic component refers to plantar pressures that are applied as a result of walking. The static component refers to plantar pressures that are applied as a result of standing. Magnitude of pressure contributes to both cumulative dynamic and static plantar pressure. Cumulative dynamic plantar pressure is the product of magnitude of dynamic plantar pressure, duration of walking (i.e. minutes spent walking/day), and number of steps taken (Maluf & Mueller, 2003). Similarly, cumulative static plantar pressure is the product of magnitude of static plantar pressure and duration of standing. According to the model, increased cumulative dynamic and/or static plantar pressure can lead to a foot ulceration or recurrence.

Measurement of Weight-Bearing Activity

To comprehensively examine the impact of weight-bearing activities on cumulative plantar pressure, measures of weight-bearing activities need to include: 1) duration of walking, 2) number of steps taken (two components of dynamic plantar pressure), and 3) duration of standing (one component of static plantar pressure). Traditional physical activity monitors, accelerometers, have been able to capture duration of walking and number of steps taken, but few have been able to measure standing time. Newer activity monitors include inclinometer functionality in addition to accelerometers which makes it possible to distinguish between different postures. In this way, duration of standing can be differentiated from duration of sitting and lying. Recent monitor models developed by ActiGraph and activPAL^{TM} include the inclinometer feature (Ridgers et al., 2012) and are potential instruments through which to examine weight-bearing activities in persons with diabetes.

ActiGraph (Model: GT3X+, ActiGraph, Pensacola, FL, USA) is a small lightweight device that adheres the hip with a clip or a belt in order to enable the inclinometer feature. ActiGraph needs to be worn on the hip. The ActiGraph has been tested for validity and accuracy in at least two studies (Carr & Mahar, 2012; John & Freedson, 2012). ActiGraph allows the measurement of number of steps taken and duration of time spent lying, sitting, and standing. It also records when the monitor is not being worn. It cannot, however, distinguish duration of standing from duration of walking. In 36 healthy, college-aged adults, ActiGraph demonstrated an accuracy of 66.7% for lying, 63.4-85.1% for sitting, and 60.6-71.8% for standing in the measurement of posture duration (Carr & Mahar, 2012).

ActivPAL^{TM} (PAL Technologies Ltd., Glasgow, UK) is a small lightweight device that attaches directly to the skin on the midline of the anterior thigh. The activPAL^{TM} determines posture on the basis of thigh acceleration, including the gravitational component and uses an algorithm to classify time as sitting/lying, standing or stepping. Information on cadence, number of steps taken, sit-to-stand and stand-to-sit transitions and estimates of energy expenditure are also provided. Similar to ActiGraph, activPAL™ can measure number of steps taken and duration of different postures, but it does not distinguish between sitting and lying time like ActiGraph can. However, activPAL™ can distinguish duration of standing and duration of walking. The activPAL™ has been shown to be a reliable and valid measure of steps and sitting time. In one validation study by Grant et al., a mean percentage difference of 0.19% was observed between the activPAL™ and direct observation for time spent sitting (Grant, Ryan, Tigbe, & Granat, 2006). Kozey-Keadle and colleagues also found activPAL™ to be highly correlated with directly observed sitting time (R^2=0.94) (Kozey-Keadle, Libertine, Lyden, Staudebmayer, & Freedson, 2011).

Although these two monitors have been tested in healthy populations (Carr & Mahar, 2012; Grant et al., 2006), they have not been tested in persons with diabetes. Persons with diabetes, especially those at risk of DFU, often have foot deformity, neuropathy, foot ulceration, and foot amputations, conditions which could possibly change the accuracy of activity monitors as compared to their accuracy for healthy adults. Therefore, both monitors need to be assessed for the accuracy in measuring weight-bearing activities in persons with diabetes. The purpose of this study was to evaluate the accuracy of ActiGraph and activPAL™ in persons with prior DFUs. Study aims were:

- Aim 1: Determine the agreement between each monitor and direct observation (criterion standard) for measuring time spent walking.

- Aim 2 Determine the agreement between each monitor and direct observation (criterion standard) in measuring number of steps taken.
- Aim 3: Determine the agreement between each monitor and direct observation (criterion standard) for measuring time spent standing.

Methods

Design, Setting and Samples

A cross-sectional descriptive design was used to evaluate the accuracy of ActiGraph and activPAL™ in measuring weight-bearing activity. All participants were recruited from an ongoing study that examined predictors of diabetic ulcer complications (DFU study: NIH/NINR R01NR009448, PI: Gardner). The DFU study sample was recruited from two medical centers in a Midwestern state of the United States. The participants were required to meet the following criteria: 1) aged 18 years or older, 2) had a non-ischemic diabetic foot ulcer on the hallux or the plantar and 3) had no osteomyelitis. Details of the DFU study have been described elsewhere (Gardner, Hillis, Heilmann, Segre, & Grice, 2013). Recruiting from the DFU study ensured that the participants for the present study had diabetes, neuropathy, and were at risk for foot ulceration.

A total of 98 participants who completed participation in the DFU study were recruited for this study using mailed letters. Those who agreed to a phone call from the research team were screened via structured phone interviews. The inclusion criterion was the ability to walk and to perform study activities (i.e. walking, standing, sitting, and lying) without assistance from others for at least five minutes. The exclusion criterion include: 1) amputation of the DFU study foot, and 2) being restricted from any of the study activities due to medical conditions. The recruitment process is summarized in Figure 4.2. Study procedures were approved by the Institutional Review Board (IRB) at the University of Iowa. All eligible participants signed informed consent before participating in the study.

Study Variables

The study included both primary and secondary study variables.

Primary Study Variables

Primary study variables were 1) two dynamic plantar pressure components: duration of walking time and number of steps taken and 2) one static pressure component: duration of standing time. Each variable was measured with direct observation (reference standard), ActiGraph, and activPAL™. Direct observation was conducted by two trained researchers for each activity test.

Dynamic Plantar Pressure Components

Dynamic plantar pressure components were tested in five walking activities: self-paced walking, walking at 60 steps/min, walking at 100 steps/min, self-paced stair climbing, and stair climbing at 60 steps/min. To assure accurate walking pace, participants were asked to wear and follow the pace of a metronome during the 60 and 100 steps/min activities (Meideal® Shenzhen Meideal Musical Instruments Co., Ltd, Guangdong, China). For stair climbing, each activity included walking upstairs and downstairs. Different walking activities and paces were examined because they could alter gait and accuracy of the monitors. For example, walking upstairs, downstairs, and on even floor usually require different heights of leg movement and affect the monitors' ability to detect posture and count steps. Additionally, this study tested two standardized walking speeds, 60 steps/min (slow walking) and 100 steps/min (moderate walking), because these are estimated ranges of walking speed for this population due to foot deformities. In this way, study findings can be better generalized to other persons with diabetes. Self-paced walking allowed for examination of individual typical walking speed. This study tested a variety of walking activities and walking speeds in order to capture the most common walking activities in the daily life of persons with diabetes.

Participants were asked to walk for 2.5 minutes for each assigned walking activity described above. The start and end time of each activity was recorded by the researchers. To eliminate any remaining small differences in time between the monitors and observation, data from the first and the last 15 seconds of each activity were eliminated. That is, of the 2.5 minutes of data for each activity, only the data of the middle 2 minutes (120 seconds) were used for analyses. The beginning and ending times of each activity were used to calculate the duration of walking for each walking activity. If, for example, participants walked from 3:00:00 to3:02:30 pm, then the duration of walking for direct observation (reference standard) was walking 120 seconds between 3:00:15 and 3:02:15 pm.

To assure the time of direct observation (actual activity performance) was consistent with ActiGraph and activPAL™, a La Crosse® atomic digital clock (La Crosse Technology, Pembroke Pines, FL) was used to record the time of activity for direct observation. Prior to each activity testing, the time on the clock was confirmed to be identical to the study computer that was used to download monitor data.

ActiGraph was programmed prior to each activity test, and data were downloaded using the software ActiLife 6®. The device was programmed at a 15-second epoch for data extraction, so the data were reported using 15 seconds as a unit. Data on posture and total duration of each posture during the 2 minutes were extracted for the corresponding timeframe of the direct observation.

ActivPAL™ was also programmed prior to each activity test, and data were downloaded using the activPAL3™. Similar to the process for ActiGraph, data on posture and total duration (seconds) spent on each posture during the 2 minutes were extracted for the corresponding timeframe of the direct observation.

Number of Steps Taken

To facilitate step counting, participants' gaits were video recorded for all activities. To assure the time of video recording was consistent with ActiGraph and activPAL™, the La Crosse® atomic digital clock was also recorded in the video. Two researchers separately reviewed participants' gaits on the videos and counted the steps taken using a tally counter for all five walking activities. One step is defined as each time a participant's foot came off the floor and back to the floor, no matter how small the step was. The steps from the two observers were averaged as the reference standard of number of steps taken. If the two researchers were five steps or more apart, a third researcher measured the steps and the closest two measures were used for analysis.

Similar to the methodology followed for duration of walking, data on total steps recorded on ActiGraph and activPAL™ during the 2 minutes were extracted using the same procedure for duration of walking.

Static Plantar Pressure Component

Duration of Standing

The static plantar pressure component was tested while the subject was standing still. Participants were asked to stand without leg movement for 2.5 minutes. The start and end time of each activity was recorded by researchers and only the middle 2 minutes were used for analysis. Data from ActiGraph and activPAL^{TM} were extracted using the same procedure for duration of walking.

Secondary Study Variables

Secondary study variables included: duration of non-weight-bearing activities and foot characteristics. Although measurements of non-weight-bearing activities were not of specific interest in this study, measures of non-weight-bearing activities were important to test. This is because inaccurate measurements of non-weight-bearing activity are possible sources for inaccurate measurements of weight-bearing activities. For example, if one monitor always erroneously codes sitting (non-weight-bearing activity) as standing (weight-bearing activity), measuring weight-bearing activity using that monitor is likely to be overestimated. Foot characteristics were collected in order to describe the gait of participants in this study and provide information to determine the appropriate population for generalization.

Data on foot characteristics included history of foot ulcer and amputation, current foot ulcer, foot pain, and use of offloading devices and walking assistance. For foot pain, participants were asked to rate their level of foot pain on the foot of the previous study ulcer. The pain level was rated on a 0-10 scale, with 0 indicating no pain and 10 indicating extreme pain. The assessment of foot characteristics was conducted via a semistructured interview guided by an interview guide (Appendix H). These foot characteristics will help describe the gait of participants in this study, help interpret findings regarding monitor accuracy, and provide information for generalizability to other populations.

Duration of Non-Weight Bearing Activities

Non-weight-bearing activities examined included eight different lying or sitting postures: 1) sitting 90º, 2) sitting 90º & pedaling, 3) sitting 60º, 4) sitting 45º, 5) lying 30º 6) lying flat, 7) lying on the left, and 8) lying on the right. A variety of sitting and lying postures were examined in order to capture a variety of possible sleeping postures and static activities that may alter trunk inclination and leg movement, and possibly alter accuracy of activity monitors. Additionally, sitting while pedaling was tested because it is a physical activity that could result in health benefits for DUF patients but is not weight bearing. This was done to examine whether or not the monitors can accurately identify this activity as sitting (non-weight-bearing activity) rather than walking (weight-bearing activity).

Similar to duration of walking and standing, participants were asked to sit on the standardized exam chair or table to perform each assigned activity for 2.5 minutes. The researchers monitored the accuracy of each activity throughout the test session. For lying 30º, and sitting 45º and 60º , the degree of the participant's head in relation to the exam table was measured by the Starrett® angle meter (L. S. Starrett Company, Athol, MA). The beginning and ending times of each activity were documented and used to calculate the duration of non-weight-bearing activities (i.e., sitting and lying). Data from ActiGraph and activPAL™ were extracted as the procedure for duration of walking.

Data Collection Procedure

Study procedures were conducted in a laboratory setting. Data collection involved: 1) assessment of demographic and foot characteristics, and 2) activity testing. Participants were asked to fill out a demographic questionnaire. Trained researchers interviewed the participants regarding foot pain, history of ulceration and amputation as well as assessed current foot ulcers and the use of devices and/or walking assistants.

Prior to the activity testing, participants were asked to wear two one ActiGraph and one activPAL™. Both monitors were programmed before use. ActiGraph was worn on the hip using an adjustable belt, while activPAL™ was worn on the anterior midline of the thigh attached by a hydrogel adhesive pad. Both monitors were worn on the side of participants' prior study ulcer.

Participants were asked to perform the 14 assigned weight-bearing or non-weight-bearing activities described in the previous sections. Based on the individual preference and tolerance of each participant, the order and length of each activity was slightly adjusted.

Data Analysis

Study data were stored in the Research Electronic Data Capture (REDCap) database, hosted at The University of Iowa (Harris et al., 2009) and analyzed using the Statistical Package for the Social Sciences software version 21 (SPSS 21; IBM Corporation, New York, NY). Descriptive statistics were analyzed to describe participants' demographics (age, gender, and race) and foot characteristics (foot pain, foot ulceration, amputation, and use of offloading devices and walking assistances).

Duration of Walking/Standing/Sitting and Lying

Measurement accuracy of ActiGraph and activPAL™ were analyzed separately using direct observation as the reference standard on measurements of weight-bearing and non-weight-bearing activity. Analyses of the accuracy of each monitor in measuring duration of different postures (walking, standing, sitting and lying) were done in a similar manner for all activities/postures. Data on the total duration (seconds) of accurate posture coding during the 2 minutes recorded in the corresponding timeframe were extracted from each monitor. For example, if the monitor recorded duration of standing as 90 seconds during the 2-minute timeframe when the participant was standing still, then 90 seconds was the duration of accurate posture coding for this activity.

Note that because ActiGraph and activPAL™ have different functions distinguishing postures, their reference standard for posture coding was not identical. Specifically, for activPAL™, the reference standard of posture coding for walking activities is walking. For ActiGraph, the correct coding was defined as standing for all walking activities because ActiGraph cannot differentiate walking from standing (i.e., there is no walking posture coded). Similarly, because ActiGraph is able to distinguish sitting and lying, the coding for these two postures was separate. ActivPAL™ cannot distinguish sitting and lying, so the correct coding for these two postures was defined as sitting/lying on the activPAL™.

Using the data of total duration of the postures from direct observation (typically 120 seconds for each activity) and total duration (seconds) of accurate posture coding from each monitor, the accuracy rate for measuring duration of postures for each activity was calculated using the following formula:

$$\text{Percentage Accuracy} = \frac{\text{Seconds in the posture per monitor}}{\text{Seconds in the posture per direct observation}} \times 100\%$$

Number of Steps Taken

For numbers of steps taken, the average of the steps counted by the two researchers and number of steps taken recorded by each monitor during the corresponding timeframe were used to calculate the accuracy of number of steps taken using the following formula:

$$\text{Percentage Accuracy} = 1 - \left(\frac{|\text{Steps recorded on the monitor} - \text{steps from direct observation}|}{\text{Averaged steps from direct observation}}\right) \times 100\%$$

This formula allowed quantification of the extent of inaccuracy but not the direction of inaccuracy. That is, whether the monitor underestimated or overestimated number of steps cannot be distinguished based on this formula. The accuracy rate for duration of different postures and for number of steps taken was calculated for every activity and every participant. After the accuracy rates were calculated for each participant, the investigator scrutinized accuracy rates by the device ID for both ActiGraph and activPAL™ to determine whether or not any particular devices was malfunctioning, which would have cause an overestimation of the inaccuracy of that monitor when all values were averaged across participants. No particular device appeared to produce prominently different results than other monitors. The investigator also scrutinized accuracy rates for each participant across all activities to determine whether any particular participant was overly contributing to inaccurate readings. No particular participant appeared to produce prominently different results than other participants. Following these evaluations, an average accuracy rate across participants was calculated to determine the accuracy rate of each monitor for each posture/activity and for counting steps.

Results

A total of 31 participants were enrolled in this study. Participants' demographic and foot characteristics are summarized in Table 4.1. Participants had a mean age of 56 years (SD±7.5, range= 37-76). Fourteen (45%) participants had some part of either foot amputated. Twenty-seven (87%) participants used at least one kind of offloading device during the study visit. A small proportion of participants also used walking devices during the study visit; 4 (13%) used canes and 2 (6%) wore a prosthetic. Seven (23%) participants had an ongoing diabetic foot ulcer during study participation. A total of 51% of participants reported some level of foot pain.

The majority of participants completed all of the activity tests in their entirety, including all weight-bearing and non-weight-bearing activities. One participant was unable to perform walking at 100step/min and another was unable to perform stair climbing at 60steps/min due to foot pain and walking disability. Other missing data occurred with 5 participants due to temporary equipment failure in ActiGraph, activPAL™, or the exam table.

The accuracy for ActiGraph and activPAL™ in measuring duration of walking is summarized in Table 4.2. ActiGraph had high accuracy (98-100%) in detecting posture for walking activities except for walking at 60 steps/min, which had an accuracy of 73%. Note that ActiGraph is unable to distinguish walking from standing, so the correct code for ActiGraph is standing for walking activities. In contrast, activPAL™ was able to distinguish walking from standing and had high accuracy (98-100%) across all five walking activities.

ActiGraph had a low to moderate accuracy in measuring number of steps taken, and its accuracy varied greatly across the five walking activities (Table 4.3). Its accuracy was highest during walking at 100steps/min (81%, SD±21%), followed by self-paced walking (79%, SD±22%). Accuracy of number of steps taken for self-paced stair climbing and stair climbing at 60 steps/min was 69% (SD±15%) and 70% (SD±15%), respectively. Number of steps taken during walking at a 60 steps/min was the least accurate with an accuracy of 43% (SD±26%). In contrast, activPAL™ had higher and more stable accuracy for number of steps taken with ranges from 91 to 98% (SD±2.5-10%).

For standing posture, ActiGraph had a low and widely varied accuracy in determining time spent standing still with percentage accuracy at 50% (SD±48%) and a range of 0-100%. In contrast, the accuracy of activPAL™ was stable and high at 100% (SD±0%), consistently for all participants with no errors.

For non-weight-bearing activity, percentage accuracy of ActiGraph was widely varied across activities, while that of activPAL™ is consistently and highly accurate (Table 4.4). For sitting postures, ActiGraph could accurately detect sitting posture for sitting at 45º for all cases with no errors (100%). Interestingly, the accuracy rates decreased and were more varied as the degrees of sitting increased to 60 or 90º (77-88%, SD±32-41%). The accuracy rate decreased further as the participants pedaled while sitting (45%, SD±50%). The accuracy of ActiGraph was 83% (SD±38%) for lying flat but only 25% (SD±43%) for lying on the left and on the right sides. The accuracy was even worse for lying at a 30º angle. ActiGraph failed to correctly identify lying at 30º as lying for all cases with no exception.

The activPAL^{TM} was consistently high in measuring duration of both sitting and lying postures. Its accuracy rates were 100% for all cases with no exception for five of the assigned activities and 97%for the other three activities. The high accuracy rate of activPAL^{TM} could be partially due to the fact that this monitor does not distinguish between sitting and lying.

Discussion

This is the very first study examining the accuracy of ActiGraph and activPAL^{TM} in measuring weight-bearing activity in persons with diabetes. Previous studies examining the association between weight-bearing activity and DFU either measured only walking with an accelerometer, or measured walking and standing with a self-report questionnaire because monitors previously available were unable to capture standing time.

ActiGraph had high accuracy in measuring duration of walking (98-100%), except for slow walking (73%). In contrast, activPAL^{TM} demonstrated consistently high accuracy (98-100%) for measuring walking across all five walking activities, including slow walking. ActiGraph had low to moderate accuracy for measuring number of steps taken across all paces of walking and had an especially low accuracy during slow walking (43%). On the other hand, activPAL^{TM} had high accuracy (91-98%) in measuring number of steps taken across all walking paces. These results suggest activPAL ^{TM} to be a superior monitor for measuring dynamic weight-bearing activity when compared to the ActiGraph. The inability of ActiGraph to distinguish walking from standing is a major limitation. In contrast, activPAL^{TM} can distinguish walking from standing and has a consistently high accuracy in measuring dynamic weight-bearing activities.

ActiGraph demonstrated widely varied accuracy in measuring static weight-bearing activity. Although the ability to measure standing is a major innovative feature of ActiGraph, as compared to other traditional monitors, its inaccuracy in measuring standing limits its usefulness for this purpose. In fact, ActiGraph is likely to underestimate weight-bearing time and to inaccurately code standing time as sitting or lying time (i.e., non-weight-bearing activity). The ability to accurately measure standing is especially important in persons with diabetes because most of their weight-bearing activity is spent standing vs. walking (Najafi et al., 2010). In contrast, activPAL™ was consistently accurate in measuring duration of standing. In addition, activPAL™ can distinguish standing from walking and, therefore, is the better monitor for measuring static weight-bearing activity in persons with diabetes.

Although the purpose of this study was to determine the accuracy of ActiGraph and activPAL™ in measuring weight-bearing activity, their accuracy in measuring non-weight-bearing activities was examined in order to estimate the contribution that error in non-weight-bearing activities may have on the error associated with weight-bearing activities. The accuracy of ActiGraph is highly inconsistent in measuring non-weight-bearing activities (i.e., duration of sitting and lying), while activPAL™ had consistently high accuracy in measuring duration of sitting and lying. This might stem from the fact that ActiGraph differentiates lying and sitting, while activPAL™ combines these two postures as sitting/lying. The differentiation between sitting and lying is unnecessary for the measurement of weight-bearing activity, because they are both non-weight-bearing activities. Therefore, if an inaccuracy was due to the differentiation between sitting and lying, the error would not affect the accuracy of measurements of weight-bearing activity and could be eliminated by combining lying and sitting postures in analysis.

Differences between ActiGraph and activPAL^{TM} have implications for studies examining weight-bearing activities. The inability of activPAL^{TM} to differentiate sitting from lying is not important if the goal is to measure weight-bearing activities, because these are non-weight-bearing activities. Moreover, activPAL^{TM} can distinguish duration of standing from walking, while ActiGraph is unable to do so, because it codes walking as a standing posture. Distinguishing walking from standing is important for measures of weight-bearing activity because they affect different components of plantar pressure (dynamic vs. static plantar pressure). To overcome this limitation of ActiGraph, it would be possible to examine posture data in conjunction with steps data in order to manually calculate duration of standing and duration of walking. That is, standing with no steps taken could be coded as standing, while standing with steps taken could be coded as walking. However, this function is not available in the ActiGraph monitor and would require extensive recoding by the user. In addition, ActiGraph is worn on the hip, which could potentially alter its accuracy in identifying correct postures in individuals with large abdominal circumference, due to interference with correct plane of the monitor. Conversely, activPAL^{TM} is worn on the thigh, and the plane of the monitor would not likely be influenced by abdominal circumference. In terms of functionality, activPAL^{TM} appears to be more ideal than ActiGraph in measuring weight-bearing activities but ActiGraph may be more compatible with patient preferences since it is worn on the hip.

In summary, activPAL^{TM} is an accurate and comprehensive measure of weight-bearing activity that can further advance our understanding of the impact of weight-bearing activity on diabetic foot ulcers. ActivPAL^{TM} allows the differentiation between static and dynamic weight-bearing activity so that these two types of weight-bearing activity can be examined separately for their impact on foot ulceration and recurrence. Future studies are needed to examine the feasibility of using activPAL^{TM} over an extended period in persons with diabetes in order to determine if this monitor will be useful in prospective studies of weight-bearing activity and ulcer occurrence and recurrence.

Limitations

The small convenience sample of this study limits the generalizability of the results to all persons with diabetes, due to the homogenous demographic characteristics of this sample as well as, other unknown variables. However, the sample enrolled in this study utilized a variety of off-loading devices, with some participants having partial amputations, current foot ulcers, and neuropathic pain typical in this population. . In addition, the small sample of this study limited the ability to examine monitor accuracy while controlling for characteristics, such as gait, foot deformity, body weight, and the use of offloading devices. Another limitation of this study was the decision to use a 15-second epoch when extracting data from ActiGraph. Data were extracted in units of 15 seconds rather than in units of 1 second, which is standard for activPAL^{TM} monitors. This approach possibly introduced errors to ActiGraph measures of weight-bearing activity that may have led to either overestimation or underestimation of the monitor. Finally, another limitation is that the direction of monitor inaccuracy, overestimation or underestimation, was not analyzed in this study.

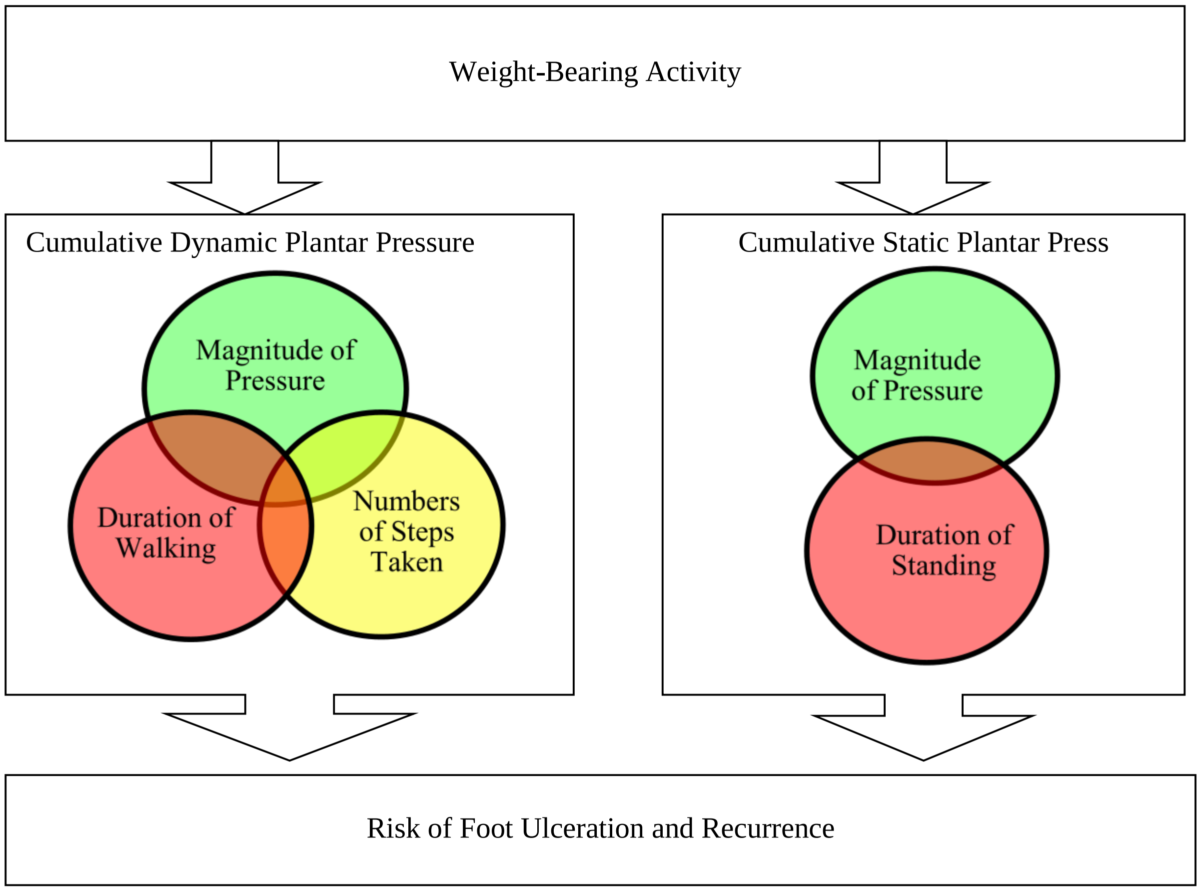


Figure 4.1. The Conceptual Framework of Weight-Bearing Activity and Diabetic Foot Ulceration

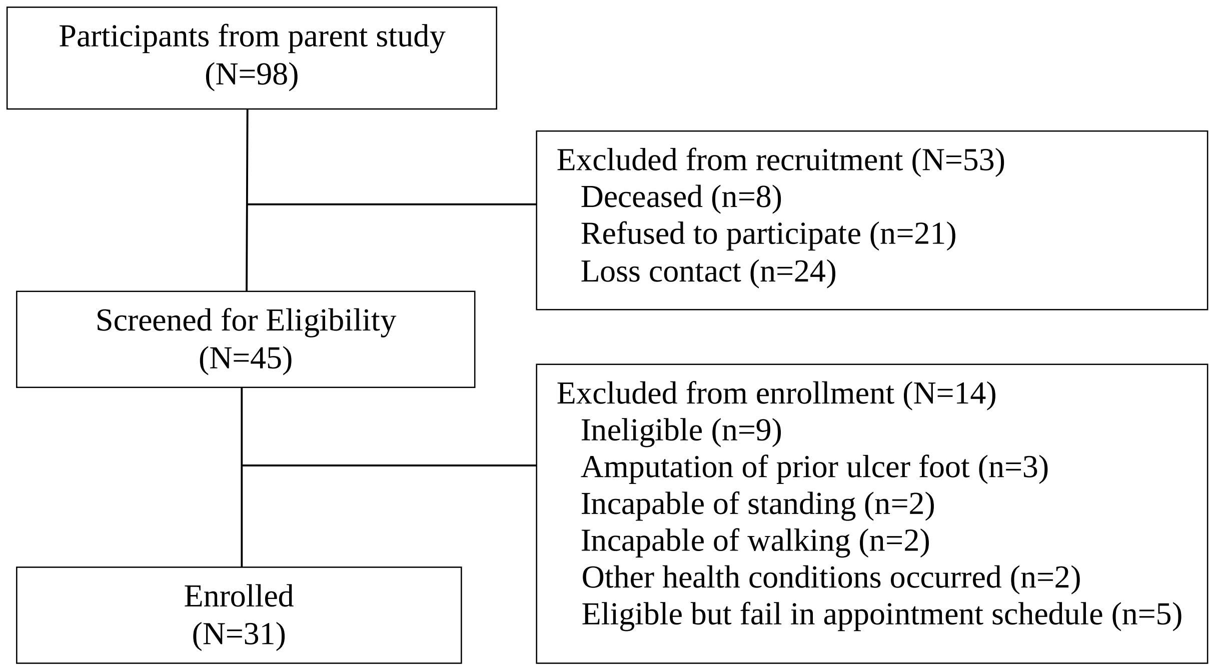


Figure 4.2. Recruitment Process

Table 4.1. Demographics and Baseline Cognitive Function

(N=31 Participants)

Characteristic	*Frequency (%)*
Age, years, mean ± SD	56.26±7.55 years (range: 37-76 years)
Gender, Male	20 (64.52%)
Race, Caucasian	26 (83.87%)
Foot amputation, Yes	14 (45.16%)
Foot of previous ulcer, left	19 (61.29%)
Using any kind offloading devices, Yes	27 (87.10%)
Diabetic shoes	24 (77.42%)
Removable boots or total contact casts	6 (19.35%)
Using cane	4 (12.90%)
Using prosthetics	2 (6.45%)
Current foot ulcer existed, Yes	7 (22.58%)
Foot pain, Yes	16 (51.61%)

Table 4.2. Percentage Accuracy of Duration of Walking and Standing

	ActiGraph			ActivPAL^{TM}		
Activity	N	Correct Code	Percent Accuracy (±SD, range)	N	Correct Code	Percent Accuracy (±SD, range)
1.Walking, self-paced	30	Standing	100% (±0, 100%)	30	Walking	100% (±0,100%)
2.Walking, 60 steps/min	30	Standing	73.33% (±39.63, 0-100%)	30	Walking	97.95% (±6.04, 73.3-100%)
3.Walking, 100 steps/min	29	Standing	98.28% (±9.28, 50-100%)	29	Walking	100% (±0,100%)
4.Stair climbing, self-paced	30	Standing	99.17% (±4.56, 75-100%)	30	Walking	97.64% (±4.67, 81.3-100%)
5.Stair climbing, 60 steps/min	29	Standing	98.28% (±5.51, 75-100%)	29	Walking	98.55% (±5.51, 71.3-100%)
6.Standing Still	30	Standing	50.42% (±47.96, 0-100%)	29	Standing	100% (±0,100%)

Table 4.3. Percentage Accuracy of Number of Steps Taken

Activity	Percent Accuracy (±SD, range)			
	N	ActiGraph	N	ActivPAL™
Walking self-paced	30	79.02% (±22.17, 47.4-100%)	30	98.34% (±2.45, 90.6-100%)
Walking 60 steps/min	30	43.02% (±26.23, 0-99.5%)	30	90.74% (±10.04, 58.3-99.7%)
Walking 100 steps/min	29	81.40% (±21.35, 46.9-100%)	29	98.47% (±2.08, 98.47-100%)
Stair climbing self-paced	30	68.96% (±15.09, 32.0-88.5%)	30	91.21% (±8.15, 66-100%)
Stair climbing 60 steps/min	29	70.35% (±15.44, 38.3-98.3%)	29	91.68% (±7.17, 72.4-100%)

Table 4.4 Percentage Accuracy of Duration of Sitting and Lying

Postures	ActiGraph			ActivPAL™		
Activity	N	Correct Code	Percent Accuracy (±SD, range)	N	Correct Code	Percent Accuracy (±SD, range)
1. Sitting 90º	30	Sitting	76.67% (±41.49, 0-100%)	29	Lying/sitting	100% (±0,100%)
2. Sitting 90º & pedaling	30	Sitting	45.42% (±49.84, 0-100%)	30	Lying/sitting	100% (±0,100%)
3. Sitting 60º	29	Sitting	87.79% (±31.73, 0-100%)	29	Lying/sitting	96.55% (±18.56, 0-100%)
4. Sitting 45º	30	Sitting	100% (±0, 100%)	30	Lying/sitting	96.67% (±18.26, 100%)
5. Lying 30º	30	Lying	0% (±0, 0%)	30	Lying/sitting	96.67% (±18.26, 0-100%)
6. Lying flat	30	Lying	83.33% (±37.90, 0-100%)	30	Lying/sitting	100% (±0,100%)
7. Lying on the left	29	Lying	24.57% (±43.36, 0-100%)	29	Lying/sitting	100% (±0,100%)
8. Lying on the right	29	Lying	25.43% (±43.36, 0-100%)	29	Lying/sitting	100% (±0,100%)

CHAPTER V

SUMMARY AND DISSCUSSION

Summary of Aims and Findings

This dissertation includes three studies, chapters II-IV, to address the following research aims:

- Aim 1: Develop and evaluate the psychometric properties of Person-Environment Apathy Rating (PEAR) that measures apathy and the care environment stimulation concurrently.
- Aim 2: Describe the association between care environments and apathy in institutionalized residents with dementia.
- Aim 3: Describe the accuracy of ActiGraph and activPAL^{TM} in measuring weight-bearing activity among persons with a previous diabetic foot ulcer.

The results of each study are summarized individually.

Aim 1: Development and Psychometrics of the PEAR

The PEAR scale has been developed in Chapter 2. The PEAR consists of environment and apathy subscales. Each subscale has six items developed via literature review. A panel of three experts in dementia research established the content validity of the PEAR. The construct validity and reliability of the environment and apathy subscales were evaluated using videos collected in a parent study on long-term care residents with dementia.

The construct validity of the environment subscale was evaluated using the Crowding Index and the Ambiance Scale. Findings revealed that the Crowding Index was slightly yet significantly correlated with the total environment score and the scores of three individual items (stimulation specificity, social involvement, and physical accessibility), but was not significantly correlated with the other three items (stimulation clarity, stimulation strength, and environmental feedback). This suggests that the Crowding Index only partially validated the PEAR-Environment. For the Ambiance Scale, neither the Ambiance Engaging score nor the Soothing score were correlated with any individual items or total score of the PEAR-Environment, suggesting that the Ambiance Scale did not support the validity of the PEAR-Environment. For reliability, the PEAR-Environment also showed excellent internal consistency and moderate to good inter-rater and intra-rater reliability.

The validity results of the PEAR–Environment are not completely unexpected because the two criterion measures, the Crowding Index and the Ambiance Scale, do not fully match the PEAR-Environment. The Crowding Index is only partially relevant to the environmental stimulation that the PEAR-Environment measures. The Crowding Index only measures the number of people while the PEAR-Environment broadly captures environmental stimulation generated by not only people but also ongoing events and surrounding objects (e.g., music and exercise programs). For the Ambiance Scale, the time of its measurement (which was taken once at the end of each video recording) did not match the segments selected for the PEAR-Environment (which could be any time during the 20 minutes of video recording). Validity of the PEAR-Environment might be more accurately and comprehensively evaluated after identifying other compatible scales.

The PEAR-Apathy was validated using the Passivity in Dementia Scale (PDS), the Neuropsychiatric Inventory-Apathy subscale (NPI-Apathy), and the NPI-Depression.

The results demonstrated that the PEAR-Apathy was highly correlated with the PDS (ρ=.814, p<.001) and the NPI-Apathy (ρ=.710, p<.001), two data sets that suggest good convergent validity. The PEAR-Apathy had a moderate correlation with the NPI-Depression (ρ=.462, p<.001), suggesting moderate discriminate validity. In fact, it was better than the NPI or PDS in discriminating apathy from depression. For reliability, the PEAR-Apathy subscale showed good internal consistency and intra-rater reliability. Its inter-rater reliability was moderate for facial expression and eye contact and good for the other four items (i.e., physical engagement, purposeful activity, verbal tone, and verbal expression). The relatively low inter-rater reliability of facial expression and eye contact may be explained by the fact that the video samples of dementia residents used for this study came from a previous study not focused on facial expression.

Aim 2: Associations between Care Environments and Apathy

The association between care environments and apathy was examined using samples from the same study as Aim 1. Details are reported in Chapter 3. The results revealed that the clarity and strength of environmental stimulation are two major factors significantly associated with a lower level of apathy. Specifically, an increase of 1 point in stimulation clarity is associated with a decrease of 1.3 points in apathy. Similarly, an increase of 1 point in stimulation strength is associated with a decrease of 1.9 points in apathy. In other words, the clearer the stimulation is and the stronger it is, the less apathy.

In the PEAR-Environment, the clearest environmental stimulation is described as an environment that contains at least one primary stimulus that is very straightforward, consistent, well-organized, and clearly guided without overwhelming background noise or competing stimuli. Whereas, the least clear environmental stimulation is described as an environment that contains multiple competing, disorganized, or overwhelming stimulations as a whole without a single discernible stimulus. This kind of stimulation is complicated and indiscernible. For stimulation strength, an environment that contains a primary stimulation that is clear and continuous is considered as sufficiently strong stimulation. The minimal strength of stimulation, in contrast, is described as an environment that has no detectable stimulation.

The effects of other environmental characteristics were minimal and not statistically significant but showed positive trends to reduce apathy. The characteristics corresponding to a lower apathy level were: a high level of social involvement and environmental feedback, engagement of environmental ambiance, sound, and how well the caregiver knew the residents. In contrast, environmental characteristics corresponding to a higher apathy level were: stimulation specificity and accessibility of environmental stimulation, a soothing level of ambiance, crowding (the closer the person, the stronger the effect), how often and how long caregivers had cared for the residents, a high or low level of light (versus a moderate level), and a low level of sound.

Aim 3: Accuracy of ActiGraph and ActivPAL™ in Measuring Weight-Bearing Activity

The accuracy of ActiGraph and activPAL™ was evaluated in 31 participants recruited from a diabetic foot ulcer study. This study revealed that ActiGraph had widely varied accuracy in measuring posture for static weight-bearing (50.4%), dynamic weight-bearing (73.3-100%), and non- weight-bearing postures (0-100%) as well as step counting for dynamic weight-bearing activities. In contrast, activPAL™ had greater than 90% accuracy rates in measuring posture for all 14 p activities (including walking, standing, and non-weight-bearing activities) and counting steps for dynamic weight-bearing activities. Additionally, activPAL^{TM} allows the measurements of all three indicators of weight-bearing activities (duration of walking, number of steps taken, and duration of standing), while ActiGraph does not allow differentiation of postures between walking and standing (i.e., static versus dynamic weight-bearing activity). Therefore, these findings suggest that activPAL^{TM} is a valid and comprehensive measure for weight-bearing activity to be used in persons with diabetes.

Implications for Research

Findings from this dissertation will have implications for research and clinical practice in several aspects including apathy measurement, care environment for apathy, and measurement of weight-bearing activity on persons with diabetes.

Measure of Apathy and Care Environment in Dementia

Findings of this dissertation suggest that two new approaches should be introduced to measure apathy. The first measure is the PEAR scale developed and validated in the study described in Chapter 2. Although there are several apathy scales available for the dementia population, the PEAR is a novel one in several ways. First, the PEAR-Apathy subscale is an observation scale. This feature allows apathy level in nursing home residents with moderate to advanced dementia to be measured by direct observation when information from self-report and family informants are challenging to obtain. Also, the observation feature of this scale allows the study of apathy through video observation. This has been evidenced by the reports of psychometrics in Chapter 2. The PEAR is also the first instrument that measures apathy while considering environmental stimulation. This approach is consistent with the diagnostic criteria for apathy (Robert et al., 2009) that lists patients' responses to environmental stimulation as one of the criteria for apathy diagnosis. This approach also enables the differentiation of people who appear to be apathetic because of lack of environmental stimulation from people who are truly apathetic.

Moreover, the PEAR-Environment subscale is the first scale specifically tailored to apathy. Additionally, findings in Chapter 3 revealed that the clarity and strength of environmental stimulation, two items in the PEAR-Environment, are the only variables among four other sets of environmental measures that showed significant effect on apathy. Although some measurement limitations existed in that study, the findings indicate that the items of the PEAR-Environment were more relevant factors. Using this scale, future studies can further examine the relationship between care environments and apathy in larger studies with different research designs. The environment subscale may also be useful for studying other neurobehavioral symptoms in dementia in the future.

The other measure for apathy introduced in this dissertation is the measure of activity. The two activity monitors are ActiGraph and activPAL™. The lack of an objective measure is one of the assessment challenges for apathy in dementia (Kuhlmei, et al., 2011). Levy and Dubois (2006) suggest that apathy should be conceptualized as a quantifiable symptom and therefore define apathy as a disorder of voluntary and goal-directed behavior. New technology for activity measure has been proposed to be a supplementary measure for apathy assessment. David and colleagues (2012) measured mean physical activity using ActiGraph (Motionlogger) in 107 patients with Alzheimer's disease and found that apathetic individuals had a significantly lower activity level than those who were not apathetic. Specifically, apathy is negatively correlated with daytime activity level (r = -.72, *p*=.01) and positively correlated with napping duration per day (r = .45, *p*=.01). Further examining the association of activity level with individual domains of apathy symptoms, this study revealed that emotional blunting, lack of initiative, and lack of interest all have similar and significant association with daytime activity level (r = .52-55, *p*=.01) and napping duration (r = .48-.55, *p*=.01). These findings suggest that activity levels measured by activity monitors are promising as a proxy measure for apathy (David et al., 2012; Kuhlmei et al., 2011).

The two monitors tested in this dissertation, ActiGraph and activPAL^{TM}, are newer models of activity monitors. In addition to measuring locomotive activity (e.g., steps taken, activity intensity, and sleep time) as other traditional monitors, the innovative feature of these two monitors is the measurement of postures (e.g., walking, standing, sitting, and lying), which therefore allow the capture of more comprehensive parameters of individuals' activity.

For posture measures, ActiGraph and activPAL^{TM} have different strengths and limitations. ActiGraph is able to differentiate lying, sitting, and standing, as well as determine when the monitor has been taken off, while activPAL^{TM} is able to differentiate lying/sitting, standing, and walking. For the measure of apathy, differentiating lying and sitting may be helpful. The unique feature of ActiGraph to distinguish between lying and sitting allows for more precise assessment of an individual's activity pattern. This is especially important for the population with a lower cognitive and functional level who mostly perform static activities. Therefore, theoretically, ActiGraph is a more ideal monitor to assess apathy.

However, the accuracy rate of ActiGraph is widely varied from 0% to 100% for measuring posture and 43%-81% for measuring steps. In contrast, activPAL^{TM} does not have the feature to differentiate between lying and sitting, but its accuracy rate is as high as 96%-100% for measuring posture and 91-98% for measuring steps. Therefore, given its overall high accuracy rate, activPAL^{TM} is recommended to be evaluated in further studies of apathy for its potential to serve as an objective indicator of apathy in persons with dementia. ActiGraph might be more favorable than activPAL^{TM} in the future if its accuracy rate can be improved.

Relationship between Care Environments and Apathy in Dementia

The study in Chapter 3 is one of very few studies examining the relationship between care environment and apathy. This study tested a variety of environmental factors, including physical and social environments, to explore their relationship with apathy. The two significant environmental factors identified (i.e., stimulation clarity and strength) can be further developed as new interventions to prevent or manage apathy in practice settings and future studies. The impact of environmental clarity and strength could also be further examined by controlling patients’ cognitive and sensory function. The information will help tailor individualized environmental stimulation based on patients’ functional levels.

The other variables tested in the Chapter 3 include items on environmental stimulation, ambiance, crowding, staff familiarity, and light and sound. Although they did not show significance on apathy in the study, it is premature to exclude them from significant variables, due to limitations of small samples and secondary measures of the study. It is worthwhile for future study to replicate this study using a different methodological approach and a larger sample. Results from this study have improved our understanding of the effect direction and effect size of each environmental variable. These data can be used as references for further studies and inform methodological considerations. For example, the relationship could be tested using primary data. It is also important to know if cognitive function and sensory function play a role on the relationship between environment and apathy. It will also be helpful to duplicate this study in home-dwelling individuals.

The understanding of the environmental effect on apathy can also shed light on the theoretical underpinning of nursing care for apathy in dementia. Currently, the theories that guide our understanding of neurobehavioral symptoms in dementia include the Need-Driven Dementia-Compromised Behavioral Model (NDB model, Algase et al., 1996) and the Progressively Lower Stress Threshold (PLST) Model (Hall & Buckwalter, 1987). However, these models have not been well tested on apathy in dementia. Therefore, it is unclear if these theories can also be applied to apathy. Notably, both environmental models involve environmental factors.

The NDB model, as described in Chapter 3, lists physical and social environments as proximal factors that have an impact on behavioral symptoms in dementia but this relationship is understudied in apathy. Further testing this relationship between care environment and apathy will help explore the usefulness of this model on the study of apathy. The PLST model suggests that patients with dementia have a reduced threshold of stress tolerance and intolerable stress is associated with the neuropsychiatric symptoms of dementia (Hall & Buckwalter, 1987). Because environmental stimulation can be a great source of stress, testing environmental stimulation on apathy will help examine if the PLST model works for apathy.

Activity Measurement

Relieving foot pressure by using offloading devices (e.g., diabetic shoes or total contact casts) and restricting weight-bearing activity is a widely disseminated principle in treating and preventing diabetic foot ulcers (ADA, 2012). But research has revealed inconsistent evidences on the impact of planar pressure and weight-bearing activity on diabetes. This is likely explained by the lack of a comprehensive and accurate measure of weight-bearing activities. The majority of literature either use self-report or only measure steps taken for dynamic weight-bearing activity. The study in the Chapter 4 has revealed that activPAL™ is a comprehensive and accurate device in measuring weight-bearing activities. Using this measure, as compared to accelerators measuring steps taken, adds two indicators: duration of static weight-bearing activity and duration of dynamic weight-bearing activity to study the impact of weight-bearing activity on plantar pressure and diabetic foot ulcer. This new approach may help resolve these unanswered questions.

Implications for Clinical Practice

Measurement of Apathy

Although it currently has only been used for research purposes, the PEAR scale can also be implemented in clinical practice. The feature of observational scale could especially facilitate assessment of nursing home residents with advanced dementia. The PEAR-Environment subscale can be used to assess environmental stimulation at individual levels, yet it also can apply to the facility level. At the individual level, data can inform clinicians to tailor environmental stimulation and guide individualized dementia and activity programs. At the facility level, the collective data of the PEAR-Apathy and Environments in the same facility will be an evaluation for the environmental design and care model. For example, if most residents in a nursing home have a very low score on environmental stimulation and high score on apathy level, it is suggested that the care environment may need to be improved. The score of individual items on the environment subscale also informs the characteristics that need to be enhanced. If the low score item is environmental feedback, then clinicians' education on clinical communication might be helpful. The emphasis of the PEAR on the environmental features will draw the attention of clinicians, especially those in administration, on the care environment for dementia.

Dementia Care

Findings in the Chapter 3 regarding the effect of environmental features on apathy are helpful for implementation in clinical care for persons with dementia. In particular, the results reveal that environmental clarity and strength are associated with a lower apathy level. Based on these findings, enhancing clarity and strength may play an important role in motivating patients with dementia. This notion will be helpful to apply to environmental design, activity program and communication in dementia care. For example, for activity programs in nursing homes, residents may engage better if the activities are novel and interesting, and have a certain level of sensory stimulation with little distraction or other stimulation existing in the same place, which could be overwhelming. It is also always helpful to have clear instructions about the activity.

The other environmental factors that are potentially beneficial for apathy in dementia include: social involvement and environmental feedback, an engaging level of ambiance, how well the direct caregiver knows the residents, and a high level of sound. Whereas, environmental characteristics that potentially corresponded to a higher apathy level include: stimulation specificity and accessibility, soothing level of the ambiance, crowding, the frequency and duration of care from direct caregivers for the residents, a high or low level of light, and a low level of sound. These findings suggest that a care environment that is engaging and promptly involves patients in social interactions will be potentially associated with lower apathy level. For staffing, it is helpful to improve the nature of caregiver-resident relationship, although simply having the same nursing staff care for the resident for a long period of time does not impact apathy level. Overall, in a social environment aspect, the nature and quality of social interaction are more important than its quantity. That is, an environment that is welcoming and that prompts high-quality interaction is more important than a group of people present with consistent caregivers but no established rapport. For the physical environment, a stimulating environment with straightforward stimulation, louder sound and moderate light benefit dementia care.

Care for Diabetic Foot Ulcers

Findings from the Chapter 4 have identified that activPAL™ is a valid and more comprehensive measure than accelerometers for weight-bearing activities. This new approach will enhance our understanding of the impact of plantar pressure and weight-bearing activity on diabetic foot ulcers. Consequently, the findings may change clinical care for diabetic foot ulcers.

Implications for Education

Results from this dissertation also offer some resources for nursing education. The PEAR scale can be used in education for clinical dementia care. Not only can this scale enhance the understanding of the concept and measurement of apathy, but it will also enhance the understanding of the importance of environmental stimulation for patients with dementia and apathy. Findings on the association between care environments and apathy further introduce a variety of measurements for environmental features and inform important features for apathy.

Limitations of This Dissertation

There were a few limitations in the three studies of this dissertation. First, there is no optimal criterion measure to fully evaluate the construct validity of the PEAR-Environment subscale. Its content validity, internal consistency, and inter-rater and intra-rater reliability have been well-established. Also, alternatively, the crowding index was used to partially evaluate the construct validity of the PEAR-Environment subscale. Second, while testing the psychometrics using video observation allowed repeated reviewing and observations by multiple raters, the videos samples from the parent study were not collected for this study and did not always offer the best angle to observe the participant’s apathy level and their immediate environment, especially on the facial expression and eye contact levels of the apathy subscale. This could underestimate the reliability and validity of the PEAR scale. The investigator has made efforts in screening procedures to assure the quality of video for study purposes. The results have shown good validity and reliability for the majority of the items. Future studies may duplicate the psychometric test on video samples designed for the study purpose and on direct observations.

Fourth, some independent variables tested in Chapter 3 were secondary data extracted from the parent study. This allowed testing additional environmental variables in a cost-effective approach. One consequence was that those data measured one or three times over the 20 minutes of video observation mostly did not match the timeframe of the selected video samples used for apathy measurement (the dependent variable), which introduced measurement errors. This may partially explain the lack of significance in the findings. However, these findings still provide information on effect size and direction to guide future studies. Finally, the sample sizes were relatively small for the three projects due to limited funding and resources. The small sample limited the power to detect significant factors and the generalizability of the findings. Despite the small sample size, the three studies still generate useful results and fulfill the intended aims. Future studies may expand these three projects using a larger sample size.

Conclusion

In summary, this dissertation has accomplished the three main research aims. The PEAR scale has been demonstrated to be a valid and reliable instrument to measure care environment and apathy in long-term care residents with dementia. Using the PEAR scale along with other measures, this dissertation has also described the relationship between care environments and apathy, and identified the environmental factors that have significant effect on apathy in persons with dementia. We have also tested the accuracy of ActiGraph and activPAL^{TM} in measuring weight-bearing activity in persons with a prior diabetic foot ulcer. Findings from these three studies will have significant impact on research and clinical care in dementia and apathy, as well as diabetic foot ulcers. Future studies can build on findings from this dissertation to expand research on the topic of care environments for apathy in patients with dementia and that of weight-bearing activities in diabetes patients.

APPENDIX A

PERSON-ENVIRONMENT APATHY RATING (PEAR)

Environment Subscale				
	1	**2**	**3**	**4**
Stimulus Clarity	Chaotic	Uncomplicated but indiscernible	Complicated but discernible	Straightforward
Stimulus Strength	Minimal	Weak	Moderate	Strong
Stimulus Specificity	Not toward the participant	Partially toward the participant	Toward the participant	Directed and related to the participant
Social Involvement	No social interaction	Does not include the participant	Passively includes participant	Actively includes the participant
Physical Accessibility	Very inaccessible	Somewhat inaccessible	Somewhat accessible	Very accessible
Environmental Feedback	Restrictive	Inattentive	Attentive	Prompting
Apathy Subscale				
	1	**2**	**3**	**4**
Facial Expression	Extreme expression	Moderate expression	Mild expression	Minimal expression
Eye contact	Sustained eye contact with specific target	Random eye contact with unspecific target	Eyes open but blank	Eyes closed
Physical Engagement	Enthusiastic engagement	Basic engagement	Slight engagement	Minimal engagement
Purposeful Activity	Self-initiated purposeful activity	Purposeful activity with prompt	Activity without observable purpose	Minimal activity
Verbal tone	Loud volume and/or extreme intonation	Moderate intonation and/or volume	Flat intonation and/or soft volume	Silent, no observable verbal communication
Verbal Expression	Self-initiated OR greatly expressive	Expanded but passive OR moderately expressive	Brief and passive OR not expressive	No verbal expression

APPENDIX B

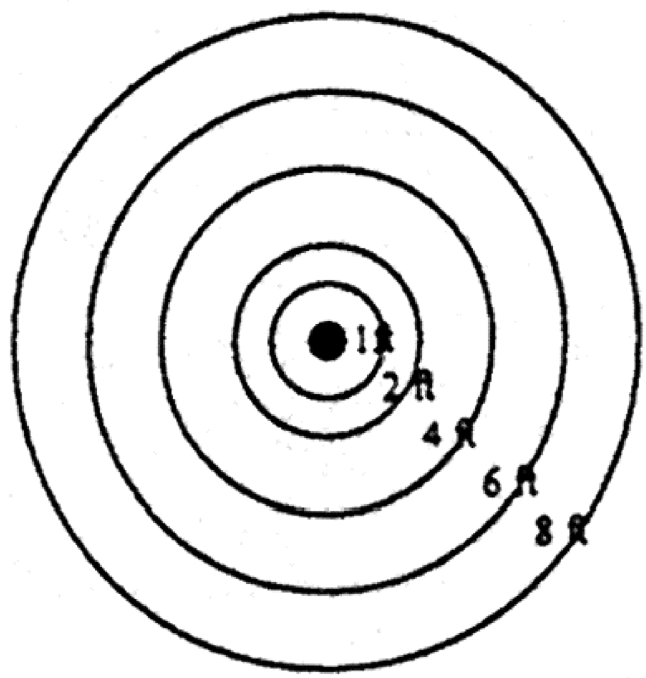
AMBIANCE SCALE

Engaging Subscale								
Definition	Homelike	Score					Institutional	Definition
Casual, unofficial	Informal	2	1	0	-1	-2	Formal	Official, strict
Humble, plain, open, easy	Unpretentious	2	1	0	-1	-2	Pretentious	Full of pretense or pretension
Harmony, tranquility	Peaceful	2	1	0	-1	-2	Chaotic	Wholly confused or disordered
Soothing Subscale								
Definition	Homelike	Score					Institutional	Definition
To act as a stimulus	Stimulating	2	1	0	-1	-2	Custodial	Protective, guarding, confusing
Friendly, kindly or affectionate	Warm	2	1	0	-1	-2	Cold	Feeling an uncomfortable, lack of warmth
Decorated, garnished	Embellished	2	1	0	-1	-2	Stark	Barren, desolate
Kindly greeting or reception	Welcoming	2	1	0	-1	-2	Impersonal	Have no personality, human traits
Abounding in color	Colorful	2	1	0	-1	-2	Drab	Drab, gray
Abounding in color	Colorful	2	1	0	-1	-2	Drab	Drab, gray
Of a new and different kind	Novel	2	1	0	-1	-2	Boring	Dull, tedious

(Algase et al., 2007)

APPENDIX C

CROWDING INDEX



(Algase et al., 2011)

APPENDIX D

PASSIVITY IN DEMENTIA SCALE

Thinking

1. Take initiative
2. Relies on self
3. Is conscientious
4. Expresses his/her thoughts through speech
5. Is intellectually curious

Emotions

1. Has an unchanging facial expression
2. Smiles if prompted or on his/her own
3. Shows feelings in his/her voice
4. Is enthusiastic
5. Is affectionate
6. Laughs
7. Has dull emotions
8. Endures unpleasant situations rather than protesting
9. Gets angry
10. Uses gestures to express feelings

<u>Interacting with environment</u>

1. Influenced by environment
2. Interacts with surroundings
3. Avoids stimulating surroundings
4. Tries different activities

<u>Interacting with people</u>

1. Spends time with friends, staff and others
2. Makes eye contact with others
3. Is generous
4. Is responsive to others
5. Is interested in others
6. Is involved with others
7. Withdraws from others
8. Prefers being others
9. Is submissive to others

<u>Activities</u>

1. Maintains positions quietly and does nothing
2. Participates in routine daily activities
3. Performs activities slowly
4. Looks for things to do

(Colling, 2000)

APPENDIX E

NEUROPSYCHIATRIC INVENTORY-APATHY

Nursing Home Version

	Not at all	**Mild**	**Moderate**	**Severe**
1. Has the resident **lost interest in the world** around him/her?	0	1	2	3
2. Does the resident fail to **start conversation**?	0	1	2	3
3. Does the resident fail to show **emotional reactions that would be expected**?	0	1	2	3
4. Has the resident **lost interest in other people** around him/her?	0	1	2	3
5. Is the resident **not enthusiastic** about any activity or things going around him/her?	0	1	2	3
6. Does the resident sit quietly **without paying attention** to things going around him/her?	0	1	2	3
7. Does the resident show any other signs that he/she doesn't care about doing new things?	0	1	2	3

(Cummings et al. 1994; Wood et al. 2000; Sajatovic, & Ramirez, 2003)

APPENDIX F

NEUROPSYCHIATRIC INVENTORY-DEPRESSION

Nursing Home Version

	Not at all	**Mild**	**Moderate**	**Severe**
1. Does the resident cry at times?	0	1	2	3
2. Does the resident say, or act like he/she is depressed?	0	1	2	3
3. Does the resident put him/herself down or say that he/she feels like a failure?	0	1	2	3
4. Does the resident say that he/she is a bad person or deserves to be punished?	0	1	2	3
5. Does the resident seem very discouraged or say that he/she has no future?	0	1	2	3
6. Does the resident say he/she is a burden to the family or that the family would be better off without him/her?	0	1	2	3
7. Does the resident talk about wanting to die or about killing him/herself?	0	1	2	3
8. Does the resident show any other signs of depression or sadness?	0	1	2	3

(Cummings et al. 1994; Wood et al. 2000; Sajatovic, & Ramirez, 2003)

APPENDIX G

STAFF FAMILARITY MEASURES

Q1.How well do you know the resident? 1. Not at all 2. Not so well 3. Well 4. Very well
Q2. How long have you know the resident? 1. One week or less 2. One month or less 3. Three months or less 4. 6 months or less 5. 12 months or less 6. More than 12 months
Q3. How often do you provide any type of care for the resident? 1. Less than once a week 2. Once or twice a week 3. More than twice a week 4. Once or twice a day 5. More than twice a day

(Kolanowski et al., 1994)

APPENDIX H

DEMOGRAPHIC AND FOOT ASSESSMENT

Demographic Assessment

1. **What is your gender?** Male ☐ Female
2. **How old are you?** ☐☐ **years old**
3. **What is your race?**

   ☐ Caucasian

   ☐ African American

   ☐ Hispanic

   ☐ Asian

   ☐ Pacific Islander

   ☐ Other:____

4. **What is the highest level you have completed in school?**

   ☐ Less than high school

   ☐ High school completed

   ☐ Some college

   ☐ College completed (4-year degree)

   ☐ Some graduate education

   ☐ Graduate degree completed

5. **What is your marital status?**

☐ Single (Never married)

☐ Married

☐ Separated

☐ Divorced

☐ Widowed

☐ Other

6. **What is your living situation (who do you live with?)**

☐ Alone

☐ With spouse/partner

☐ With spouse/partner and child (children)

☐ With child (children)

☐ Assisted living

☐ With friend/roommate

☐ Other

7. **What is your current employment status?**

☐ Work full-time

☐ Work part-time

☐ Retired

☐ Disability

☐ Unemployed

☐ Homemaker

☐ Other

Foot Assessment

1. Are you currently using any offloading devices on a regular basis:

☐ Yes (answer 1-1)

☐ No (skip 1-1)

1-1 **What offloading device do you use?**

☐ Therapeutic foot wears (including diabetic shoes and insoles)

☐ Removable boot (including DH boot, walking boot, and removable cast walker)

☐ Total Contact Cast (TCC)

☐ Others________

2. Are you currently having any foot ulcer:

☐ No

☐ Yes (answer 2-1)

2-1.**Where are the ulcer(s) located? (Check all that apply)**

Left

☐ #1 hallux

☐ #2 medial forefoot (under hallux)

☐ #3 central forefoot (under 2-3th toe)

☐ #4 lateral forefoot (under 4th-5th toe)

☐ #5 medial midfoot

☐ #6 lateral midfoot

☐ #7 hind foot

Right

☐ #1 hallux

☐ #2 medial forefoot (under hallux)

☐ #3 central forefoot (under 2-3th toe)

☐ #4 lateral forefoot (under 4th-5th toe)

☐ #5 medial midfoot

☐ #6 lateral midfoot

☐ #7 hind

3. Please rate your foot pain on a 0 to 10 scale for each activity? _____

(0 = no pain and 10 = extreme pain)

4. Do you have any amputation: (as observed by the researcher)

- **Left foot:** ☐None ☐Toe ☐Forefoot ☐Foot ☐Below Knee ☐Above Knee
- **Right foot:** ☐ None ☐Toe ☐Forefoot ☐Foot ☐Below Knee ☐Above Knee

5. Are you using any offloading device on the feet:

☐No

☐Yes

Left foot: ☐None ☐Therapeutic foot wear ☐ Removable boot

☐Total Contact Cast (TCC) ☐Other: ___________________________

Right foot: ☐None ☐Therapeutic foot wear ☐ Removable boot

☐Total Contact Cast (TCC) ☐Other: ___________________________

6. Walking assistance during activity test:

☐None ☐Crutch ☐Cane ☐Walker☐ Other: _________________________

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