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Cargivers' Pain Recognition in Older Adults with Chronic Pain and Dementia

Rebecca Anne Morgan

ACCEPTANCE

This dissertation, CAREGIVERS' PAIN RECOGNITION IN OLDER ADULTS WITH CHRONIC PAIN AND DEMENTIA by REBECCA ANNE MORGAN was prepared under the direction of the candidate's dissertation committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing and Health Professions, Georgia State University.

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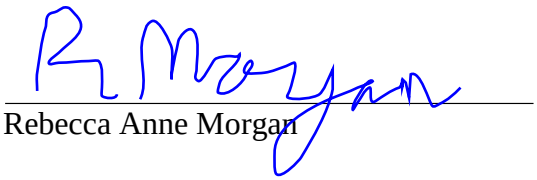

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ASBSTRACT

CAREGIVERS' PAIN RECOGNITION IN OLDER ADULTS
WITH CHRONIC PAIN AND DEMENTIA

by

REBECCA ANNE MORGAN

Problem: Older adults with pain and dementia often are cared for by informal caregivers. Persons with dementia may not always be able to verbally communicate when they experience pain and inaccurate pain identification can result in adverse outcomes. Informal caregivers, typically spouses/family members, are tasked with accurately identifying pain for care recipients that cannot verbally communicate their pain, making their assessment skills and use of pain relieving strategies important. The purpose of this study was to examine the feasibility of an informal caregiver pain management intervention (education about pain and pain management strategies and training of how to use a pain assessment a structured scale; PASS) when caring for older adults with dementia and arthritis.

Methods: The design was a single-group design with two intervention sessions and a two week follow-up. Informal caregivers of care recipients with arthritis and moderate/severe dementia were recruited from an existing memory assessment disorder clinic database. Measures included daily diary for recording structured pain scale scores, pain intensity scores, pain management strategies and care recipient negative behaviors. Additional standard instrument measured care recipient negative behaviors, and caregiver confidence and knowledge in pain assessment and management. An exit interview about using PASS was done.

Results: A total of four informal caregiver/patient dyads were enrolled and received the PASS intervention. All four caregivers completed the study and used the structured pain assessment daily except for 4 days. Pain intensity on average was mild 1.8± 1.9. Descriptively, care recipients had low pain scores and caregivers used few nonpharmacological pain management strategies. After the PASS intervention caregivers reported fewer care recipients' negative behaviors and these behaviors were less bothersome to caregivers. Caregivers' confidence and knowledge in assessing and managing pain was slightly higher after the PASS intervention.

Conclusions: Informal caregivers and care recipients may benefit from pain management interventions. The current study was a first step in examining the feasibility of informal caregivers learning more about pain management including using a structured assessment pain tool as part of pain management. A larger study is needed to further refine the PASS intervention and examine its effect on caregiver and care recipient outcomes.

CAREGIVERS' PAIN RECOGNITION IN OLDER ADULTS WITH CHRONIC PAIN AND DEMENTIA

by

REBECCA ANNE MORGAN

A DISSERTATION

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LIST OF ABBREVIATIONS

ADRC	Alzheimer's Disease Research Center
ANOVA	Analysis of Variance
CAS	Colored Analogue Scale
CES-D	Center for Epidemiologic Studies Depression Scale
FLACC	Faces-Legs-Activity-Crying-Consolability
HIPPA	Health Insurance Probability and Accountability
IRB	Institutional Review Board
M	Mean
MHLC	Multidimensional Health Locus of Control Questionnaire
MMSE	Mini-Mental State Exam
MoCA	Montreal Cognitive Assessment
NRS	Numeric Rating Scale
OR	Odds Ratio
PAINAD	Pain Assessment in Advanced Dementia Scale
PASS	Intervention (consisting of providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale)
PBQ	Pain Beliefs Questionnaire
PCS	Perceived Competence Scale
RMBPC	Revised Memory and Behavior Problem Checklist

SCMP	The Social Communication Model of Pain
SD	Standard Deviation
SPI	Student Principal Investigator
SPSS	Statistical Package for the Social Sciences
VDS	visual descriptive scale

CHAPTER I

INTRODUCTION

Pain and dementia are prevalent in the older adult population affecting millions ages 65 and older (Alzheimer's Association, 2013; American Academy of Pain, n.d.; American Pain Society, 2011b). Reports of pain prevalence within the older adult population have been reported as being as high as 60% to 85% (Brown, Kirkpatrick, & Lee, 2011; Thomas, Peat, Harris, & Wilkie, 2004). About 50% of older adults are living with arthritis (CDC, 2010). There are also approximately five million older adults in the United States living with Alzheimer's (Alzheimer's Association, 2013). Older adults with pain and dementia are being cared for by informal caregivers. The informal caregivers are tasked with accurately identifying pain for care recipients that cannot communicate their pain verbally. Care recipients may not have the ability to effectively verbally express the presence of pain to their caregiver due to communication deficits. This relates to older adults with dementia as they often have difficulty communicating needs. Thus, caregivers of persons with dementia may have to rely on other cues making their assessment skills important.

Informal caregivers often do not have a medical background and may not have received any training on pain management or recognizing other expressions of pain. Inaccurate pain identification can result in adverse outcomes such as overmedicating or under- medicating persons with dementia (Chen, Lin, & Watson, 2010; Jensen-Dahm, Vogel, Waldorff, & Waldemar, 2012; Shega, Boughman, Stocking, Cox-

Hayley, & Sachs, 2012). The caregiver may also misinterpret behaviors associated with pain because these behaviors (i.e. anger, restlessness, appetite changes, aggressive behaviors, and wandering) are also present in symptoms of dementia and other chronic conditions (Eritz & Hadjistavropoulos, 2011; Family Caregiver Alliance, 2012; Fruchs-Lacelle & Hadjistavropoulos, 2004). Cognition deficits are associated with incongruent caregiver and care recipient proxy ratings of pain and the inability of caregivers in identifying pain in their care recipient (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Chen et al., 2010; Horgas, Elliot, & Marisiske, 2009; Jensen-Dahm et al., 2012; Kauppila, Pesonen, Tarkkila, & Rosenberg, 2007; Monroe, Carter, Feldt, Tolley, & Cowan, 2012; Reynolds, Hanson, DeVillis, Henderson, & Steinhauser, 2008; Shega et al., 2012).

Unmanaged pain leads to a decreased quality of life and affects the person physically, physiologically, and psychologically. Pain affects a person's overall health and well-being (American Pain Society, 2011a; Brown et al., 2011; International Association for the Study of Pain, 2005; Jensen-Dahm et al., 2012; Thomas et al., 2004). Unmanaged pain also can result in a significant financial burden on the economy, healthcare system, and the person in pain (American Academy of Pain Medicine, n.d.; Gaskin & Richard, 2012; Stewart, Ricci, Chee, Monrganstein, & Lipton, 2003).

There is some evidence that pain management efforts can be improved. Formal caregivers using a systematic pain assessment tool to assess pain, along with receiving education to the caregiver about pain and pain management, has resulted in increased pain identification, decreased pain levels, more accurate pain assessments, decreased

care recipient negative behaviors, and an increased use of pain management strategies by the formal caregivers caring for patients with dementia (Cervo, Bruckenthal, Fields, Bright-Long, Chen, Zhang, & Strongwater, 2012; Jordon, Hughs, Pakresi, Hepburn, & O'Brien, 2011; Kamel, Phlavan, Malekgoudarzi, Gogel, & Morley, 2001; Manias, Gibson, & Finch, 2011; Young, Siffleet, Nikoletti, & Shaw, 2006). The formal caregivers have also demonstrated increased confidence after this intervention and caregiver confidence may be associated with a more accurate pain assessment of care recipients' pain (Chen et al., 2010). While improved outcomes have been found with formal caregivers, these interventions have not been tested in informal caregivers, typically family caregivers.

Education about pain and pain management strategies and teaching informal caregivers to use a structured pain assessment tool may aid the caregiver in assessing the care recipients' pain and improve pain management for care recipients. Using a systematic pain assessment tool has not been used in the informal caregiver population caring for older adults with dementia. There is a need to evaluate this intervention in this population. The purpose of this study is to pilot an informal caregiver pain management intervention (consisting of providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale) when caring for older adults with dementia and arthritis.

The Social Communication Model of Pain

The theoretical framework for this proposed study is The Social Communication Model of Pain (SCMP) (Craig, 2009), Appendix B. The SCMP is a comprehensive model of pain assessment that encompasses the biological,

psychological and social factors associated with pain. The SCMP consists of four main concepts which are personal experience, pain expression, pain assessment, and pain management. The SCMP focuses on the person that is in pain (the care recipient) as well as the caregiver who has the task of identifying the pain in the care recipient. The SCMP defines caregivers as a person "...in a position to influence the suffering person's pain" (p. 23). An assumption in this model is that caregivers want to recognize and alleviate the care recipients' pain.

In the SCMP, the care recipient has a painful stimulus. The painful stimulus can be caused by an injury, tissue damage, a disease process, or of an unknown origin. Pain may be communicated verbally, non-verbally, or physiologically. The caregiver assesses the care recipient and makes conclusions that affect pain management and alleviation of pain.

As stated earlier, persons with dementia may not have the ability to effectively verbally express the presence of pain to their caregiver due to communication deficits. Thus, caregivers of persons with dementia may have to rely on other cues making their assessment skills important in decoding care recipients' pain, as noted in the model (Craig, 2009). There are intrapersonal and interpersonal factors in the model that are factors that can influence the way in which pain presents in the care recipient and may also influence the ability of the caregiver to recognize pain in the care recipient (i.e. care recipient cognition status, caregiver confidence, care recipient age, and the amount of time the caregiver spends with the care recipient) (Boyer et al., 2004; Chen et al., 2010; Eritz & Hadjistavropoulos, 2011; Horgas et al., 2009; Jensen-Dahm et al., 2012; Kamel et al., 2001; Kauppila et al., 2007; Monroe et al., 2012; Shega et al., 2012).

Personal Experience of Pain

Craig (2009) explains that an antecedent to the major concept of personal experience of pain is potential or actual physical trauma. The actual or potential physical trauma can be caused by an injury, disease process, or have an unknown origin. This perceived or demonstrated physical trauma leads to the personal experience of pain. The major concept of personal experience of pain applies to the person in pain (care recipient). The personal pain experience is multidimensional and involves sensory, cognitive, and affective components. Pain is a subjective, emotional, sensory, and cognitive event involving thoughts, feelings, and sensations (Craig, 2009). For the purpose of this study, the pain stimulus of interest is chronic arthritis pain. The chronic arthritis pain leads to the personal pain experience where the care recipient experiences the painful stimulus. The pain experience is defined consistent with the SCMP in which the pain experience is multidimensional and involves sensory, cognitive, and affective components (Craig, 2009).

Pain Expression "Encoding"

The personal pain experience of pain has a bidirectional relationship with the major concept of pain expression. The concept of pain expression applies to the person in pain (care recipient). The pain expression involves verbal, non-verbal, and physiological reactions to a painful stimulus (Craig, 2009). For persons with dementia that cannot easily verbalize their pain, caregivers must rely on other forms of expressions such as non-verbal and physiological expressions to identify pain in care recipients. For example, body language and facial expressions of the care recipients can aid the caregivers in identifying pain. The pain expression is referred

to as “encoding” in the SCMP (Craig, 2009). After the care recipient encodes the pain experience and expresses the pain, the caregiver must decode the message.

Pain Assessment "Decoding" and Pain Management

During the pain assessment the caregiver recognizes and decodes the pain expressions the care recipient displays (Craig, 2009). The assessment process is complex and should include verbal, non-verbal, and physiological cues that are recognized by the caregiver. Once pain expression is decoded by the caregiver, pain management can be implemented. Pain management is contingent on the recognition of pain in the care recipient (Craig, 2009). This decoding may be influenced by the caregivers’ beliefs about pain.

Pain Management

Pain management has a bidirectional relationship with pain assessment (Craig, 2009). Once pain is identified, caregivers can implement interventions to reduce care recipients’ pain. Pain management can be influenced by level of training and the setting of the pain experience (i.e. clinical or home) (Craig, 2009). Pain management includes interventions that are pharmacological as well as non-pharmacological (Craig, 2009).

Intrapersonal influences and interpersonal influences. Intrapersonal and interpersonal influences can affect all the major concepts of the SCMP. Intrapersonal influences are factors that a caregiver or care recipient brings to the pain experience (Craig, 2009). Care recipient intrapersonal influences that may affect a care recipient’s personal experience or pain expression are personal history and biological endowment (Craig, 2009). Caregiver intrapersonal factors that influence the caregiver’s pain assessment are sensitivity, biases, and knowledge (Craig, 2009).

Intrapersonal factors that influence a caregiver's pain management of the care recipient are professional training and personal judgment (Craig, 2009). Interpersonal influences are factors associated with the social and environmental contexts in which the pain experience occurs (Craig, 2009). An interpersonal factor that affects the care recipient's personal experience of pain is the situational context (i.e. social and physical context) in which the symptom occurs (Craig, 2009). The social or physical context also can influence the care recipient's pain expression (Craig, 2009). Interpersonal factors than can influence the caregiver's pain assessment are the caregiver/care recipient relationship (i.e. friend, co-worker, parent, spouse, or enemy) and duties (Craig, 2009). The caregiver's roles, outside responsibilities, or sense of duty to assess the patient can affect pain assessment (Craig, 2009). A caregiver's interpersonal factor that can influence pain management is the setting in which the pain management occurs (i.e. clinical or home) (Craig, 2009). Based on the current literature of caregivers caring for those with dementia and arthritis, these intra-interpersonal influences are identified as being care recipient age, care recipient cognition status, caregiver confidence, and the amount of time the caregiver spends on caregiving activities (Boyer et al., 2004; Chen et al., 2010; Eritz & Hadjistavropoulos, 2011; Horgas et al., 2009; Jensen-Dahm et al. 2012; Kamel et al., 2001; Kauppila et al., 2007; Monroe et al., 2012; Shega et al., 2012).

Assumptions of the SCMP

An assumption of the SCMP is that the caregiver wants to recognize and alleviate the care recipient's pain (Craig, 2009). Another assumption is that humans have the capability to be empathetic, altruistic, and compassionate caregivers (Craig, 2009). Pain

is a subjective experience and a person that cannot communicate pain still can experience pain (Craig, 2009). Pain is a multidimensional experience involving affective and sensory input and should be assessed with this approach (Craig, 2009). Another assumption is that pain can be assessed and recognized by a caregiver using more than just self-report (Craig, 2009).

The SCMP as a Framework

The SCMP has not been extensively empirically evaluated. The model has been used as a framework evaluating pain in nonverbal pediatric children with caregivers (parents) tasked to recognize pain in their care recipients (Solodiuk, 2012). The purpose was to identify descriptors that parents used to recognize pain in their children with intellectual disabilities. The researchers also investigated factors that may influence the children's pain responses and compared parent pain descriptors to five pain assessment tools. The parent pain descriptors identified were categorized into seven categories (vocalizations, social behaviors, facial expressions, physiological, muscle tone, activity level, and self-injurious behaviors). Results indicated that the children's severity of pain, gender, and cause of intellectual disability were influential factors on the children's pain responses. The Non-communicating Children's Pain Checklist was identified has being the most comprehensive tool when compared to the parent descriptors of pain (Solodiuk, 2012).

The SCMP has also been used in a research study with young adult participants evaluating chronic pain (Bailey, McWilliams, & Dick, 2012). This study purpose was to evaluate potential influential factors of pain assessment when pain evaluators assessed pain in one of two different vignettes about a chronic pain patient. There was some

evidence that the coping style of the chronic pain patient (i.e. catastrophizing or distraction) may be an influential factor of the pain assessment as well as the pain evaluators' gender and attachment style (i.e. avoidance) (Bailey, McWilliams, & Dick, 2012). The SCMP has not been extensively tested in the dementia care recipient/caregiver population. However, this was one of the focus populations in which the model was created. The SCMP is a fairly new model that needs further testing to verify it's applicability in the elderly dementia population.

A Summary of the SCMP

The SCMP is a comprehensive model of pain assessment that encompasses the biological, psychological, and social factors associated with pain (Craig, 2009). The SCMP is a new model and needs further testing to support its applicability in research. The SCMP was created to guide research that evaluates and tests interventions that assist caregivers in assessing and managing pain in their care recipients who cannot communicate. Further testing is needed to strengthen the support for the use of the SCMP in the older adult population with dementia. There is some support that SCMP can be used as a framework for research studies that are specific to pain involving a caregiver and a care recipient that is unable to communicate.

In this study, the participants are elderly and diagnosed with dementia and arthritis. The physical trauma causing the pain is the result of chronic arthritis pain. The personal experience involves cognitive, sensory and affective factors and the pain expression (encoding) involves nonverbal, verbal, and physiological expressions. The caregiver then assesses the care recipients pain (decoding) and based on the finding pain management is implemented. Potential influential factors that were found in the literature

are care recipient age and cognitive status. There is also some support that caregiver confidence in pain assessment and pain management may an influential factor. There is also some support caregivers that spend less time involved in caregiving activities on a weekly basis may have a decreased ability to decode the care recipient's pain.

Hypotheses

The hypotheses for this proposed study are:

In a sample of informal caregivers caring for an older adult with dementia and arthritis:

1. Those caregivers receiving the PASS intervention will implement more pain management strategies when compared to those caregivers that do not receive the PASS intervention at the two week follow-up.
2. Those caregivers receiving the PASS intervention will report less negative behaviors in care recipients when compared to caregivers that do not receive the PASS intervention at the two week follow-up.
3. Care recipients of caregivers receiving the PASS intervention will have decreased overall pain intensity levels compared to care recipients being cared for by caregivers that do not receive the PASS intervention at the two-week follow-up.
4. Those caregivers receiving the PASS intervention will have an increased level of confidence in assessing pain and managing pain when compared to caregivers that do not receive the PASS intervention at the two week follow-up.

The research question for this proposed study is:

1. What pain management strategies are caregivers using to treat pain in their care recipients with dementia and arthritis?

CHAPTER II

REVIEW OF LITERATURE

Pain and Dementia Affect Millions

Pain affects millions of people annually and is the number one reason that people seek healthcare (American Academy of Pain, n.d.; American Pain Society, 2011a). Pain is a common symptom in older adults, those persons 65 years of age and older. Brown et al. (2011) found that 85% of their older adult participants (N=125) recruited from the community reported moderate or severe pain within past month preceding the study. Thomas et al. (2004) reported of their older adult participants (N=11,230), 60% reported pain within the past four weeks. In the older adult population, pain is often times undertreated and underreported (American Pain Society, 2011b; Iyer, 2011). While acute pain may indicate a new health problem, chronic pain such as arthritis requires management to reduce the negative effects chronic pain can have on daily activities.

Dementia also affects millions of people annually particularly older adults. In 2013, there was an estimated five million older adults living with Alzheimer's in the United States and this is projected to increase by 40%, more than seven million by the year 2025 (Alzheimer's Association, 2013; National Institute on Aging, 2012). In the oldest age group of older adults, 90 years and older, approximately 40% are diagnosed with Alzheimer's or other form of dementia (Family Caregiver Alliance, 2012). Older Adults with dementia often are being cared for by their family and friends. In

2012, there were approximately 15.4 million family and friend caregivers providing care for older adults with dementia and this was equated to equal approximately 17.5 billion hours of uncompensated care provided by the informal caregiver (Alzheimer's Association, 2013). Informal caregivers provide a wide range of care activities and these often include assessing symptoms, administering medications, managing symptoms and interacting with healthcare professionals regarding treatment. Pain is a symptom that these informal caregivers often are faced with managing even though they may have little experience or training in principals of pain management.

Older adults are living with and managing a variety of chronic conditions such as heart disease, cancer, stroke, chronic obstructive pulmonary disease, Alzheimer's, dementia, arthritis, and diabetes (Sahyoun, Lentzer, Hoyert, & Robinson, 2001). Many of these conditions result in the symptom of pain. The Center for Disease Control and Prevention (2010) reported that arthritis was present in 50% of adults ages 65 and older in that there are a significant number older adults living with dementia and arthritis.

Caring for Elderly with Pain and Dementia

Pain is a subjective experience making pain increasingly difficult to identify in people that are unable to communicate (American Pain Society, 2011b). Many factors (i.e. genetic, environmental, and psychological) may influence a person’s painful experience making self-report the gold standard for pain assessment (American Pain Society, 2011b; Coghill, 2010). Caregivers of older adults with dementia and arthritis have barriers that impede pain identification due to the fact that care recipients may not be able to verbally communicate their pain. Alzheimer’s typically affects a person’s

ability to communicate during the middle stage of Alzheimer's and communication continues to decline in the late stage of Alzheimer's (Alzheimer's Association, 2013). Pain symptoms that persons with dementia may exhibit can be unrecognized or misinterpreted. Behaviors common to Alzheimer's or dementia such as anger, restlessness, repetitive behaviors, being uncooperative, refusing care, changes in appetite, aggressive behaviors, and wandering can also be common pain related behaviors (Eritz & Hadjistavropoulos, 2011; Family Caregiver Alliance, 2012; Fruchs-Lacelle & Hadjistavropoulos, 2004). Pain related behaviors such as restlessness, decreased activity, repetitive behaviors, wandering, being uncooperative, physical aggression, verbal aggression, anger, agitation, and anxiety have been related (r=.39 to .47, p= <.01) to painful events in 40 older adult care recipients with dementia cared for by formal caregivers (Eritz & Hadjistavropoulos, 2011). Although these same pain related behaviors were not shown to predict formal caregiver proxy pain intensity ratings in 81 dyads (caregiver/elderly care recipient with dementia) indicating disconnect in interpreting the cause of behaviors in this population (Fruchs-Lacelle & Hadjistavropoulos, 2004). Caregivers need to recognize that failure to communicate pain verbally does not necessarily mean that pain is absent. Almost half of caregivers (42%, N=34) reported their care recipients had a painful condition such as arthritis prior to the dementia diagnosis (Buffum & Haberfelde, 2007). In a sample of older adults with dementia recruited from dementia special care units (N=308, Mini-Mental State Exam MMSE ≤ 10 = 60%) over 60% had experienced pain in the past and 30% reported present pain indicating that pain reports may not be consistent (Chen et al., 2010). Caregivers will need to be able to assess and manage pain in their care

recipients with dementia especially if they also have other conditions that are known to cause pain such as arthritis. In a systematic review of literature, barriers to pain assessment and management in older adults with dementia were identified as inability of the caregiver to identify pain in the care recipient, caregiver lack of education and training in pain assessments for older persons with dementia, misdiagnosing of pain symptoms as psychiatric or psychological symptoms, and not using a systematic assessment tool to identify pain (McAuliffe, Nay, O'Donnell, & Fetherstonhaugh, 2009).

To be able to manage care recipients' pain, caregivers need to be able to decode their care recipients' pain communication whether it is verbal, physiological, or behavioral. When assessing persons with dementia, experts have recommended to first use a self-report if the person is able (American Pain Society, 2011b). Others suggest that caregivers should also search for causes of pain such arthritis or other chronic or acute conditions and observe the persons behaviors that may be caused by pain such as facial grimacing, moaning, groaning, rubbing, agitation, irritability, combativeness (especially in movement or daily activities) and appetite changes (Herr, Coyne, Manwarren, McCaffery, Merkel, Pelosi-Kelly, &Wild, 2006). Experts in caring for those with dementia also suggest using a systematic nonverbal pain assessment tool to assist the caregiver in identifying the care recipient's pain (Buffmun, 2009; Herr et al., 2006; McAuliffe et al., 2008).

Unmanaged Chronic Pain Results in Poor Outcomes

The presence of chronic pain can affect a person's health status and quality of life (American Pain Society, 2011a; Thomas et al., 2004). Unmanaged pain and

inadequate identification of pain can result in physiological, social, and emotional alterations (International Association for the Study of Pain, 2005). When chronic pain is unmanaged it can lead to care recipient depression, insomnia, anxiety, and immobility (American Pain Society, 2011a; International Association for the Study of Pain, 2005). In a study of 125 older adult participants, 85% reported the presence of pain; they also reported that the pain affected their general activity, mood, sleeping, concentration, walking, relationships, and overall enjoyment of life (Brown et al., 2011).

When older adult care recipients with dementia and pain are compared to older adult care recipients with dementia and no pain, care recipients with pain have a significantly decreased quality of life, higher levels of depression, and more behavioral disturbances (Jensen-Dahm et al., 2012). Thus, there is some evidence that unrelieved pain is associated to care recipient depression and a decreased quality of life. There is also some evidence that negative behaviors are associated with pain. Unmanaged pain in general can also have a financial impact. A person with moderate or severe pain spends an estimated $7,726 more annually on health care than a person without pain (Gaskin & Richard, 2012). Unmanaged pain leads to longer stays in the hospital and an increased financial burden (American Academy of Pain Medicine, n.d.). Pain related conditions, such as arthritis, headache, back pain, and musculoskeletal pain lead to an estimated $61.2 billion loss of productivity annually (Stewart et al., 2003). More important than the cost is the unnecessary suffering associated with untreated pain.

Cognition Deficits Create Barriers to Identifying Pain

Caregivers of older adults with dementia are charged with the task of being able to recognize and assess pain levels and to advocate for their care recipient. When caregivers are caring for older adults with dementia, there are many barriers that can impede the ability of the caregivers to recognize pain. The gold standard for recognizing pain is a self-report (American Pain Society, 2011 b). An older adult patient with cognitive impairments may not have the ability to communicate about their pain, leaving caregivers to draw their own conclusions even though most do not have an education about pain.

Cognition deficits are associated with increased difficulty in identifying pain when compared to those without cognitive deficits (Chen et al., 2010; Horgas et al., 2009; Jensen-Dahm et al., 2012; Kauppila et al., 2007; Monroe et al., 2012; Reynolds et al., 2008; Shega et al., 2012). The more severe the cognitive deficit, the more difficult it is to identify pain. When older adult nursing home residents (N=551) were compared based on cognition, pain was not identified as often in those with severe cognitive deficit when compared to those with no cognitive deficit (Reynolds et al., 2008). When the groups were compared based on illnesses or conditions that may cause a painful symptom, the groups were not significantly different. Thirty-four percent of these older adults with no cognitive deficits reported pain compared to 9.65% with severe cognitive deficits ($p<0.001$). Eighty percent of the persons with no cognitive deficit received a pain medication and 42% had scheduled pain medication compared to 56% of those with severe cognitive deficit receiving a pain medication and 23% having a schedule pain medication ($p=<0.001$) (Reynolds et al., 2008). When persons

are caring for those with cognitive deficits, experts recommend that a non-verbal assessment tool be used to assist with pain identification (American Pain Society, 2011 a; Buffmun, 2009; Buffum & Haberfelde, 2007; Herr, Bjoro, & Decker, 2006; McAuliffe et al., 2009). Furthermore, there are a variety of instruments such as Pain Assessment Checklist for Seniors with Limited Ability to Communicate (Fusch-Lacelle & Hadjistavropoulos, 2004), Mobilization-Observation-Behavior- Intensity-Dementia Pain Scale (Huesbo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2007), Abbey Pain Scale (Abbey, Piller, De Bellis, 2004), Assessment of Discomfort in Dementia Protocol (Kovach, Noonan, Griffie, Weisman, 2002), Non-Communicative Patients Pain Assessment Instrument (Snow et al., 2004), The Certified Nursing Assistant Pain Assessment tool (Cervo et al., 2007), Checklist of Non-verbal Pain Indicators (Feldt, 2000), and Pain Assessment in Advanced Dementia (Warden et al., 2003) that have been tested in the clinical setting and there is some evidence that they are reliable and valid forms of pain assessments in those that cannot communicate (Cervo et al., 2012; Ersek, Herr, Neradilek, Buck, & Black, 2010; Herr, Bjoro, & Decker, 2005; Horgas, Nichols, Schapson, & Vietes, 2007; Huesbo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2010; Mosele et al., 2012; While & Jocelyn, 2009).

Caregiver and Care Recipient Pain Rating In-congruency

Identifying pain or decoding pain behaviors in older adults with dementia is difficult even for the skilled professional. As the care recipients' cognition worsens their ability to communicate about their pain ability suffers making it increasingly difficult to identify pain, which can affect congruency in proxy-care recipients' reports (Boyer et al., 2004; Chen et al., 2010; Horgas et al., 2009; Jensen-Dahm et al., 2012;

Kauppila et al., 2007; Monroe et al., 2012; Shega et al., 2012). As older adults' cognitive deficits become more severe, pain agreement between pain raters (registered nurses, nursing assistants and elderly dementia patients) decreases (N=308, MMSE < 10, 60%, age mean 79.86, SD 8.84) (Chen et al., 2010). In one study, cognition levels were not associated with pain identification, but the average Mimi Mental State Exam (MMSE) scores were higher (MMSE >24, SD 2.6) in this study indicating less severe deficits in the study population (N=321 dyads) (Jensen-Dahm et al., 2012).

Congruency of Pain Reports in Older Adult Care Recipients and Caregivers

Older age has been identified as a factor that may affect congruency of proxy-care recipient reports of pain by formal caregivers, especially in those care recipients that are 85 years of age and older (Boyer et al., 2004; Chen et al., 2010; Kamel et al., 2001). Inability to adequately assess pain in this age group is a concern in that that they may be at risk of having increased pain intensity levels. Krueger and Stone (2008) found that as a person's age increases, so does the risk of experiencing higher levels of pain intensity.

Spending Time with the Care Recipient and Pain Assessment

Informal caregiver time spent with care recipients may also have an effect on the ability of caregivers to recognize and identify pain in care recipients, although more evidence is needed. One study examined the amount of time caregivers time spent with care recipients and the effect it has on pain assessment. When informal caregivers rated their care recipients' pain using a colored analogue scale (CAS) and were then compared to their care recipient's pain ratings using a CAS, those caregivers spending more than ten hours per week in caregiving activities were significantly more

congruent with care recipient pain ratings. When care recipients were unable to rate their pain, the caregivers rating was compared to a trained observer's rating (Eritz & Hadjistavropoulos, 2011). While it is understandable that caregivers who spend more time with care recipients may be more familiar with their behaviors, there is only preliminary evidence that length of time spent with care recipients may be related to better pain assessment.

Incongruent Pain Assessment Outcomes

Overestimation or Underestimation of Pain

When informal caregivers are assessing pain, they may either over estimate or underestimate their care recipients' pain levels (Balfour, O'Rourke, 2003; Chen et al., 2010; Jensen-Dahm et al., 2012; Shega et al., 2012). Overestimation of pain may lead to interventions that are unnecessary and underestimation may lead to unmanaged pain. Pain reports (self-report verses proxy-rated pain) from informal caregivers of persons with mild Alzheimer's and dementia (MMSE >20, 321 dyads) were statistically significantly different and incongruent in that caregivers rated care recipients' pain higher than the care recipients. Thirty-three percent of the care recipients reported pain and 52% of the caregivers reported pain (Jensen-Dahm et al., 2012). Family caregivers and community dwelling persons with dementia (N=115 dyads), used a visual descriptive scale VDS to assess and compare pain levels. The care recipients' (MMSE 16.6±7.2) reported pain 32% of the time and caregivers reported pain 53% of the time (Shega et al., 2012). In older adults living in a dementia care unit (304), 30% reported experiencing present pain while 18% of the registered nurses reporting that their patients had present pain. The registered nurses were not provided with education or

training about pain or pain assessment scales (Chen et al., 2010). These findings collectively illustrate the in-congruency in formal caregiver and care recipients with dementia pain ratings.

Outcomes of Using Systematic Pain Assessment Tools

Increased Pain Identification

There is some evidence that systematic pain assessments used for pain assessments on persons with dementia have been effective in assisting formal caregivers to perform better pain assessments by enabling the assessor to decode the pain communication of the care recipient. In nursing home residents ages 60 to 102 with dementia (N=305) using systematic assessment tools such as the visual analog scale, faces pain scale and a pain descriptive scale resulted in a 15% increase in diagnosing pain when compared to those using a numeric verbal rating scale ($p = <0.01$) (Kamel et al., 2001) In the care recipients, ages 85 years and older, nursing experts using a multi-dimensional pain assessment tool to assess pain significantly increased the frequency of identifying pain by 26% when compared to those using a numeric verbal rating system (Kamel et al., 2001).

Behavioral systematic tools have also been used to assess pain in other non-communicative patients such as ventilated unconscious or sedated patients (N=44). Using a pain assessment behavioral tool resulted in increasing the odds of identifying pain during repositioning (which was considered a painful procedure) (OR 25.37, $p=<0.001$). Using the systematic tool assisted formal caregivers in distinguishing between painful and non-painful events. During repositioning movements, pain was identified 73% of the time as opposed to a 14% of the time during non-painful

procedures such as eye care ($p<0.05$) (Young et al., 2006). Although only two studies, both using formal caregivers, these studies provide preliminary evidence that using a behavioral systematic tool may be effective in distinguishing persons in pain and from those that are not in pain.

Caregiver Confidence in Pain Assessment and Pain Management

Providing formal caregivers with education about pain and pain management strategies and training in using a systematic pain assessment tool can assist caregivers in becoming more confident in their assessment skills. There is evidence that higher levels of caregiver confidence in their pain assessment skills increases the odds of identifying pain levels that agree with the patient (OR=2.19, $p=0.02$) (Chen et al., 2010). Registered nurses who received pain related training, pain education, and used the behavioral observation scale for pain assessment were (OR=2.86) more likely to identify pain intensity levels that agreed with the care recipients' reported level (Chen et al., 2010). Training, education, and a systematic pain assessment may lead to increased caregiver confidence and more accurate decoding of the care recipient's pain communication, but evidence is needed to determine if informal caregivers of dementia patients in the home setting will have similar results if taught to use a systematic pain assessment instrument.

Influence of Better Pain Management on Care Recipient Outcomes

Decreased Pain Intensity in Care Recipients

When formal caregivers or nurses use a systematic pain assessment tool, with a pre-determined cut-off point to indicate the need for intervention, when caring for nursing home residents with advanced dementia (N=79) to assess pain, use of the tool

resulted in significant decreased pain levels (Jordon et al., 2011). Although in one study, when nursing home caretakers were instructed to use a systematic pain assessment tool and to intervene at a specific cut-off point on a pain assessment scale, 17% of the patients that met criteria for intervention did not receive an intervention for pain management. In this study the authors noted the limitation that there was missing data (35%) about whether the older adult patients received treatment for their pain or not in 21 of the 60 patient participants (Zwakhalen, Hof, & Hamers, 2012). Therefore, the large amount of missing data makes it difficult to draw conclusions.

Increased Accuracy and Pain Management

Systematic pain assessments can assist caregivers in applying the correct intervention for care recipients with dementia who are experiencing pain (Cervo et al., 2012; Jordon et al., 2011; Manias et al., 2011). Balfour and O'Rourke (2003) found that when older adults with Alzheimer's were compared to older adults with Alzheimer's and osteoarthritis, those with the chronic pain condition received significantly more benzodiazepines than elderly persons without a painful chronic condition. When formal caregivers used a systematic pain assessment tool to assist in identifying pain in elderly persons with dementia, care recipients received significantly less antipsychotic medications (Cervo et al., 2012). Illustrating that the systematic pain assessment tool may assist in distinguishing pain related behaviors from behaviors caused by other conditions and illnesses.

Less Negative Behaviors of Care Recipients

Better assessment and management of care recipients' pain may lead to decreased negative behaviors. After initiating an intervention involving systematic

pain assessments and education about pain causes, pain assessments, pain assessment barriers, pain interventions, and unmanaged pain consequences to healthcare providers and formal caretakers in three long term care facilities, care recipients with dementia (*n*= 215, MMSE < 20, *M* age = 84.9, SD=7.2) demonstrated significantly less physical aggression, physical nonaggression, and verbal nonaggression episodes (Cervo et al., 2012). When formal caregivers used a systematic behavioral scale to assess pain in older adult patients with dementia in painful episodes that had identifiable causes, the care recipients displayed significantly more negative behavioral indicators, negative social behaviors, negative physical behaviors, and negative physiological indicators during a painful event when compared to calm episodes (Fuschs-Lacelle & Hadjistavropoulos, 2004). Therefore, there is some evidence that care recipient negative behaviors may be linked to the experience of pain.

Increased Pain Management Interventions

When formal caregivers (*n*=17) received an educational intervention (consisting of appropriate application of a variety of systematic pain assessment tools and education about pain, pain assessment, and pain management) and were compared to a control group of formal caregivers (*n*=17), there were statistically significant differences between the groups in decreasing their patients pain intensity levels. The patients (N=192, mean age 80.75, SD 8.67) were recruited from geriatric units. Using a visual analogue scale to measure rest and on movement, there were significant decreases in pain intensity post pain management intervention when compared to the control group (Manias et al., 2011). Nurses in the intervention group used significantly more non-pharmacological interventions than the control group (Manias et al., 2011).

When using a systematic pain assessment tool, formal caregivers implemented pharmacological and non-pharmacological interventions resulting in significantly lower pain scores (Cervo et al., 2012; Manias et al., 2011). In another study, assessment driven treatments for pain and follow-up evaluation of pain in nursing home residents with dementia (mean age 87.09, SD 7.28) was significantly associated with pain management (pharmacological and non-pharmacological) implementation and cessation. In this same study, implementation of pain interventions was predicted by systematic pain assessments and follow-up evaluations after pain management implementation (Simpson, Kovach, & Stetzer, 2012).

Summary and Gaps Identified in the Literature

Systematic pain assessment tools have been recommended and tested by a variety of researchers in formal caregivers and found that the formal caregivers were able to decrease the care recipient's pain intensity levels, decrease care recipient negative behaviors, had increased accuracy of identifying pain, increased the use of pain management strategies, increased caregiver confidence, and increased caregivers' ability to identify pain in their care recipients with dementia. In these studies there were different levels of cognitive impairment based on MMSE scores. MMSE scores range from zero to 30 (25 to 30 indicates normal cognition, 20 to 24 indicates mild dementia, 13 to 20 indicates moderate dementia, and 12 or less indicates sever dementia) (Alzheimer's Association, 2013). The MMSE scores in previous studies ranged anywhere from less than 10, less than 19, less than 27, and greater than 20. The study designs were mostly cross-sectional, quasi-experimental designs with pre-post interventional measures in the formal caregiver setting. There is a need for an

experimental design in the informal setting with caregivers to evaluate the effectiveness of using education about pain and pain management strategies, along with training in using a systematic pain assessment tool for better pain assessment and management. Participants in previous studies have primarily been recruited from facilities in which care is provided by formal caregivers. Implementation of a systematic pain assessment by informal caregivers of persons with dementia has not been studied extensively.

While testing the use of a systematic pain assessment tool in informal caregivers of persons with dementia, follow up is needed to determine if pain management strategies were implemented to reduce pain or were provided as needed, what pain strategies are being used in the informal setting, and to monitor for safety in implementation of pain treatments. Thus, the proposed study will evaluate the use of a systematic pain assessment tool in informal caregivers and pain management strategies used based on assessment. Overall, there is evidence that care recipient age and cognitive levels seem to create barriers for caregivers decoding pain communication and managing pain. Evaluation of the effects that the PASS intervention has on decoding pain communication and implementation of pain management strategies is needed in informal caregivers that care for older adults with dementia. Further exploration of caregiver confidence in managing care recipient's pain is needed. There is limited evidence to support caregiver confidence in pain assessment and its effect on assisting in decoding and implementation of pain management strategies. There is a need to further explore this relationship in this specific population.

CHAPTER III

METHODS

Initial Design

The initial study proposed was a pilot feasibility study with a two-group experimental, pretest-posttest design. The goal was to recruit a total of 30 informal caregivers and randomly assign them to either the PASS intervention group or the control group. As participants were recruited, the plan was to randomize them using a restricted random assignment technique to allow for equal numbers in the control and intervention group. This method was chosen because of the pilot study sample size and is recommended for samples sizes less than 200 to avoid statistical analysis complications (Shadish, Cook, & Campbell, 2002).

Revised Study Design

During the study, due to challenges in recruitment, the decision was made to change the design of the study to a one group design in an effort to maximize testing feasibility of the intervention. This change was submitted in an amendment to Georgia State University's Institutional Review Board and approved. This also required a change in the research hypotheses. The revised hypotheses are:

In a sample of informal caregivers caring for an older adult with dementia and arthritis who receive the PASS intervention:

1. Caregivers will implement more pain management strategies after the PASS intervention at the two week follow-up.

2. Caregivers will report less negative behaviors after the PASS intervention at the two week follow-up.
3. Care recipients will have decreased overall pain intensity levels after the PASS intervention at the two week follow-up.
4. Caregivers will have a higher level of confidence in assessing pain and managing pain after the PASS intervention at the two week follow-up.

The recruitment process is discussed in detail in chapter four.

Sample

The sample consisted of informal caregivers and the care recipients for which they provided care. An informal caregiver was defined as a person who self-identified as providing the majority of care for an older adult with cognitive impairment in the home setting. Care recipients were adult persons with dementia and arthritis that received care from informal caregivers in the home setting.

Recruitment Setting

Participants were recruited from Emory University's Alzheimer's Disease Research Center ADRC, located in Atlanta, GA. The ADRC in Atlanta is one of 32 clinics in the nation. They have two clinics in the Atlanta area that provide services to those with dementia in the state of Georgia. The ADRC also provides services to informal caregivers and families members of persons with dementia (i.e. educational opportunities). The participants were recruited from an existing database maintained by the ARDC. Prior to the release of the list of potential participants to the student principal investigator (SPI), a user data agreement was obtained between Georgia State University and Emory University. Those potential participants included on the list had consented to

be contacted for research purposes. The list included all patients that met the cognition criteria within the data base. A list of potential participants was provided to the SPI from the ADRC. The potential participants on the list met specified cognition criteria (score 19 or less on the MMSE or score 17 or less on the Montreal Cognitive Assessment, MoCA). A recruitment flyer was also created to recruit participants from Emory's Memory Clinic. The flyers were distributed to the nurse practitioners at the memory clinic to refer patients meeting eligibility criteria.

Sample Size

The initial goal for recruitment was fifteen caregiver/care recipient dyads for this pilot feasibility study. A sample size of 12 participants per group has been recommended for a pilot feasibility study (Juilios, 2005). The goal of thirty informal caregivers was selected in anticipation of a 20% attrition rate over a two week period.

Informal Caregivers

The informal caregivers' inclusion criteria were: 1) self-identify as providing the majority of care to the older adult with Alzheimer's in the home setting, 2) currently live with the care recipient, 3) able to write, read, and speak English, and 4) score less than 16 on the Center for Epidemiologic Studies Depression Scale (CES-D). The caregivers' exclusion criteria were: 1) if they received pay for providing care to the care recipient, and 2) that they did not self-identify as having a major illness or psychiatric illness that would affect their ability to participate in the intervention. The rationale for the CES-D score criterion was that scores of 16 or greater indicate that the caregiver was experiencing a significant level of depressive symptoms which could

impede them in participating in this study. If caregivers scored 16 or greater on the CES-D, they were to be notified and a list of community health care resources was to be given to them as well a recommendation that they should follow-up with their regular healthcare provider. All caregivers screened for enrollment in this study scored less than the 16 on the CES-D. The rationale for the reading, writing, and speaking English criterion was that caregiver participants were asked to complete a written daily diary. The PASS intervention was implemented in a verbal and written format in English. The informal caregiver participants were asked to confirm that they were able to write and read English. The caregiver participants also verbalized their understanding the study after reading the consent.

Care Recipients

The care recipients' inclusion criteria were: 1) they self-identified or caregivers reported a diagnosis of Alzheimer's and any form of arthritis, 2) score 19 or less on the Mini-Mental State Exam (MMSE) or score 17 or less on the Montreal Cognitive Assessment (MoCA). The exclusion criteria were: 1) a history of severe psychological disorders (i.e. Schizophrenia), and 2) self-identified and/or caregiver reported other life-limiting painful illnesses (i.e. bone cancer). The diagnosis of Alzheimer's was chosen because 60% to 80% of all dementia cases are caused by Alzheimer's. Arthritis, a chronic painful condition, affects more than 50 million individuals of all ages (Arthritis Foundation, 2015). The MMSE and MoCA score parameters were selected to include those with moderate or severe dementia where communication is often affected (Alzheimer's Association, 2013; Nasreddine, 2015). The MMSE scores and/or the MoCA scores were provided by the ARDC on the list created for the SPI for recruitment

of participants.

PASS Intervention

The PASS intervention has four components and was given in two sessions. The first session was scheduled for one hour and the second session was scheduled for 40 minutes. The PASS intervention involved providing the informal caregiver education about pain and pain management strategies and training in using a systematic pain assessment tool in assessing their care recipient's pain. The PASS intervention's four components are: 1) education about pain, 2) use of a structured pain scale tool to assess care recipient's pain, 3) strategies to use in managing arthritis pain, and 4) safeguards in pain management. The first two components were administered during the first one hour session and the second two components were administered during the second 40 minute session. The PASS intervention was delivered by a doctoral SPI, which is a master prepared registered nurse. The SPI used a checklist to guide the intervention content and the information was in written format to reinforce teaching points. This ensured that the SPI was giving the same intervention to all persons in the intervention group.

PASS-Component 1: Education about Pain

The intervention caregiver group received education about pain. Topics in this educational session included information about pain in general (i.e. pain is a subjective experience, causes of pain, and that pain is a sensory and emotional experience). The caregivers also received education about behaviors that may present in painful episodes (i.e. anxiety, aggression, moaning, and appetite changes). The caregivers learned about consequences of unmanaged pain (i.e. immobility, depression, alterations in sleeping,

concentration, and quality of life). This information was in written format and verbally presented to the caregiver participants. This component was completed in 15 minutes.

PASS-Component 2: Use of a Structured Pain Assessment Tool to Assess Care Recipients' Pain

The systematic pain assessment tool that was used in the PASS intervention was the Pain Assessment in Advanced Dementia Scale (PAINAD). The caregivers in the intervention group were trained in using this scale to assess pain in their care recipients. This component was completed in 45 minutes. The caregivers watched a 23 minute training video about using the PAINAD scale. The SPI brought necessary equipment for viewing the video. They were also given written reinforcements about how to use the scale. The caregivers participated in guided practice using the tool. The caregivers were also instructed to use the scale daily, whenever pain is suspected, or one to two hours after implementing a pain management strategy.

The PAINAD scale is a behavior pain assessment tool that was developed to measure pain in elderly patients with dementia (Warden, Hurley, & Volicer, 2003). Warden et al. (2003) developed the PAINAD scale and it was based upon two other scales, Faces-Legs-Activity-Crying-Consolability (FLACC) and the Dementia of Alzheimer's Type scale. It was developed in a population of elderly patients in long term dementia care units with severe to moderate dementia (MMSE $\leq$16). The PAINAD scale has five items that are scored from zero to two by the caregiver. The items are breathing, negative vocalization, facial expression, body language, and consolability. The caregiver rates each item by observing the care recipient behaviors. The total scores range from zero to ten, where higher numbers indicate higher pain

severity. Interpretation of the scores has been compared to the numerical pain scale, where zero is no pain, one to three is mild pain, four to six is moderate pain, and seven to ten is severe pain (Costardi et al., 2007; Mosele et al., 2012; Warden et al., 2003).

During the initial development of the PAINAD scale, the sample size was small (N=19), the researchers then added more participants for the instrument evaluation (N=44). The internal consistency reliability coefficient was initially inadequate or less than 0.70 for the scale (Warden et al., 2003). Others have reported adequate internal consistency and/or reliability with Cronbach alphas above 0.70 (Costardi et al., 2007; Ersek et al., 2010; Mosele et al., 2012). Stability of the instrument has been confirmed during test re-test evaluation (0.88 p=0.045) (Costardi et al., 2007). Criterion-related validity was established by evaluating the scales concurrent validity, comparing the PAINAD scale to the visual analogue scale, Discomfort Scale of Alzheimer's Type, and the verbal numeric scale (p=<0.001), which is the gold standard of pain measurement (Costardi et al., 2007; Mosele et al., 2012; Warden et al., 2003). Inter-rater reliability and intra-rater reliability has shown to be adequate when raters are compared with themselves and others (p=<0.001) (Costardi et al., 2007; Mosele et al., 2012; Warden et al., 2003). Content validity was confirmed from experts in the literature and experienced dementia care technicians (Herr et al., 2006; Leong, Chong, & Gibson, 2006; Warden et al., 2006). A factor analysis confirmed construct validity and a one factor solution (eigenvalue 3.05) explaining 61% variance (Warden et al., 2003). PAINAD has also been shown to discriminate between painful and unpainful events (Ersek et al., 2010; Herr et al., 2006; Warden et al., 2003).

PASS-Component 3: Strategies to Use in Managing Arthritis Pain

The caregivers learned when to implement a pain management strategy (i.e. when pain is present and first begins). The caregivers were educated about non-pharmacological pain management strategies (i.e. relaxation, positioning, distraction, and music). The caregivers also learned about pain medication. This education included information about common pain medications used for managing arthritis pain, common over the counter medications given for pain, and scheduled medications verses as needed medications. Information was tailored based on the care recipient's recommended medications for arthritis. This information was in written format and verbally presented to the caregiver participants. This component was completed in 20 minutes.

PASS-Component 4: Safeguards in Pain Management

The caregivers received information about pain management safety. This component was completed in 20 minutes. The caregivers were instructed about what to do when pain is persistent or severe (i.e. call their healthcare provider). They were also instructed to call their healthcare provider if the care recipient had fever and pain or pain that increased in severity. The caregivers were also instructed to consult their care recipient's healthcare provider before giving any new over the counter medications for pain to ensure that it was not contraindicated for the care recipient. Information was tailored for safety precautions based on the care recipient's recommended medications.

Control Group

As part of the initial proposed deign, the caregivers within the control group were going to complete a daily diary including proxy pain intensity scores of their care

recipients' pain using a numeric rating scale (NRS), a pain management strategies log, and a pain behavior log during a two week period. They were to receive instructions on how to complete these requirements. The caregivers in the control group were to receive verbal and written instructions. The caregivers within the control group were also to be instructed to continue providing usual care to their care recipient during the two week period. At the time when the study design was changed to a one group design, no caregivers had been randomly placed into the control group. Therefore, there was not a control group in this study.

Instruments

Care Recipient Negative Behaviors

Negative behaviors were measured using the Revised Memory and Behavior Problems Checklist (RMBPC) (Teri et al., 1992). The RMBPC was revised from the 64 item Memory Behavior Problem Checklist (American Psychological Association, 2014). There are 24 items on the RMBPC scale. The caregivers were to reflect upon the past week and check "yes" or "no" next to any of the behaviors in which their care recipient displayed. To obtain a frequency score, these items were summed. The caregiver then rated the behavior from zero to four indicating how much the behavior bothered the caregiver. The items for each subscale were summed and totaled. The possible total scores range from zero to 96 where higher numbers indicate more bothersome behaviors. Construct validity has been confirmed via factor analysis, where three factors (Memory, Depression, and Disruption) have been identified (Johnson, Wackerbarth, & Schmitt, 2000; Roth et al., 2003). Internal consistency has been reported to be adequate (Cronbach alpha >0.70) (American Psychological Association,

2014; Johnson et al., 2000). Criterion related validity has been established by comparing the RMBPC to other established scales, the MMSE, Center for Epidemiological Studies-Depression Scale, and Hamilton Rating Scale for Depression (American Psychological Association, 2014; Roth et al., 2003). Stability (test and re-test) and discriminate validity have also been reported as adequate (Johnson et al., 2000; Roth et al., 2003).

Daily Diary for Pain Management

All of the caregivers completed a daily diary. In this diary, the caregivers recorded an overall daily proxy pain intensity score using the NRS. The caregivers also recorded pain behaviors observed and any pain management strategies used during a day. The caregivers completed this diary on a daily basis for a two week period. The two week period began after the PASS intervention was delivered to the caregivers. Initially the plan was that the intervention group of caregivers was to complete an additional section to the daily diary. Due to the change in design, all caregivers completed the additional section of the diary. The additional information completed by the caregivers was the PAINAD scale and was to be completed in the morning, when pain was suspected, and one hour after a pain management strategy was implemented as discussed earlier.

Proxy Pain Intensity. Proxy pain intensity was measured using the numeric rating scale (NRS) (American Pain Society, 2011b). The NRS is a scale from one to ten where higher numbers indicate more severe pain. It is the gold standard for measuring pain and is the most widely used scale to measure pain intensity. The response options are categorized as zero is no pain, one to three represents mild pain, four to six is moderate pain, and seven to ten represents severe pain (American Pain Society,

2011b). The reliability for this scale has been reported to be adequate with a Cronbach alpha greater than 0.70 (Kahl & Cleland, 2005). The caregivers used the NRS to provide an overall daily proxy pain intensity score for their care recipients. The caregivers in the intervention group used the NRS and the PAINAD scale that was discussed earlier to obtain proxy pain intensity scores. All caregivers were instructed to document their proxy pain intensity scores obtained during a two week period. Proxy pain intensity scores were documented in the daily diary.

Care Recipient Pain Behaviors. Care recipients' pain behaviors were captured using a behavior log within the daily diary. The behavior log consisted of a list of common painful behavioral symptoms (i.e. restlessness, decreased activity, being uncooperative, physical aggression, verbal aggression, anger, agitation, and anxiety). All caregivers recorded behaviors that their care recipient displayed on a daily basis. The caregivers in the intervention group also recorded behaviors they observed at the time pain intensity was assessed using the PAINAD. All caregivers were able to indicate any other behaviors their care recipients' displayed that were not on the list. The pain behaviors were scored by summing the total number of behaviors observed in a two week period.

Pain Management Strategies. Pain management strategies implemented by the caregivers to alleviate their care recipient's pain were captured in a daily log completed by the caregivers within the daily diary. The caregivers were asked to log any medications and/or non-pharmacological strategies implemented for pain on a daily basis. There was a list of common pharmacological and non-pharmacological pain management strategies and the caregivers checked next to the ones in which they

implemented. There was a space for the caregivers to write any additional pain management strategies not listed on the checklist. Pain management strategies were scored by summing the total number of strategies implemented in a two week period. Logs are a frequently used method to record data in research studies. Logs have been used to collect data about pain management strategies, observed pain behaviors, information about sleeping patterns, diet, and diabetes self-care strategies in other research studies (Deierlein, Morland, Scanlin, Wong, & Spark, 2014; Horgas, Nichols, Schapson, 2007; Kendrick, Wilson, Elder, & Smith, 2005; McCall & McCall, 2011; Zwakhalen et al., 2012).

Caregiver Confidence in Assessing and Managing Pain in Care Recipients

Confidence in assessing and managing care recipient pain was measured by the Perceived Competence Scale (PCS) (Deci & Ryan, 2014). The PCS has been used to measure perceived competence and confidence in the ability to quit smoking, provide self-diabetic care, and in research using the self-determination theory as a framework (Deci & Ryan, 2014; Williams & Deci, 1996; Williams, Freedman, & Deci, 1998). The PCS is a four item scale that was adapted to measure perceived competence and confidence for pain assessment and pain management. The questions were adapted to address the content of interest (e.g. I feel confident in my ability to manage pain in my care recipient or I am capable in assessing pain in my care recipient). Questions addressed confidence, feeling capable at completing a task, feeling able to complete a task, and feeling able to meet challenges (Deci & Ryan, 2014). The four items have a Likert-type response from one to seven with anchors "not at all true" and "very true", where higher scores indicate higher competence and confidence. The responses on the

four items are averaged, giving a possible range of total scores from one to seven with higher scores representing more confidence in pain management. Internal consistency has been reported to be above 0.70 (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998). Stability (test- re- test) has been reported to be adequate (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998). Construct validity has been shown to be adequate in a factor analysis where perceived competence items loaded onto a single factor (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998).

Caregiver Knowledge in Assessing and Managing Pain in Care Recipients

Caregiver knowledge in assessing and managing pain in care recipients was measured using the Pain Beliefs Questionnaire (PBQ). The PBQ is a 12 item questionnaire that measures beliefs about the causes and consequences of pain (Edwards et al., 1992). The PBQ is a six point Likert-type scale with anchors "never = 1" and "always = 6" (Edwards et al., 1992). Total scores are an average of the item scores and total scores range from one to six. The PBQ has two subscales (organic pain beliefs and psychological pain beliefs). Scores range from one to six for the organic subscale and one to six for psychological pain beliefs subscale. Higher scores on the PBQ indicate that a person's beliefs about pain and emotions about pain have a greater interference with personal control in managing pain (Pons, Shipton, & Mulder, 2012). Construct validity was confirmed through a factor analysis where a two factor solution was identified accounting for 82.37% of the total variance (Edwards et al., 1992). The first factor (organic pain beliefs) loaded eight items and the second factor (psychological pain beliefs) loaded 4 items. The PBQ is a reliable instrument with Cronbach alpha scores reported to be greater than 0.70 for each subscale (Edwards et al., 1992). Criterion related

validity was confirmed by comparing the PBQ to the Multidimensional Health Locus of Control Questionnaire (MHLC) (Edwards et al., 1992). The PBQ has been used to measure beliefs about pain causes and pain consequences with study participants with chronic pain as well as participants without pain (Baird & Haslam, 2013; Edwards et al., 1992; Pons et al., 2012). An additional item was added (People with dementia do not feel pain). Caregivers indicated whether the statement was true. This question was scored with a six point Likert-type scale with anchors "never = 1" and "always = 6".

Exit Interview

Participant intervention satisfaction and burden were captured by completing an exit interview after the completion of the study. The exit interview used was adapted from a satisfaction survey used in a previous research study (Davis, 2015). The items were adapted to address the content of interest. The questions addressed the participants experiences about participating in the study and in the intervention (i.e. How difficult was it to complete requirements while in the study?). They also were able to express whether or not the intervention seemed beneficial or seemed to be a burden. There were ten items on the exit survey. Three items were open ended questions and one item had a response of "yes" or "no". The other six items had five possible responses "definitely yes", "maybe yeas", "not sure", "maybe no", and "definitely no" and two of these six items asked the caregivers to further explain their responses.

Demographics

Demographic data were collected on all participant dyads. Caregiver characteristics included: age, gender, relationship to care recipient, last grade completed in school, working status as well as hours worked per week, marital status,

hours spent in caregiving activities per week, and income. Care recipient characteristics included: age, gender, medical history, current medications, and functional status (i.e. walks independently, uses a walker or wheelchair).

Screening Care Recipient Cognition

Cognition levels of the care recipient were used to screen potential care recipient participants for eligibility criteria. MMSE and MoCA scores were used to screen care recipient cognition. The MMSE is a widely used scale to measure cognition levels for researchers and in clinical practice. It is an 11 item questionnaire. The possible range of scores is zero to 30, where lower scores indicate lower levels of cognition or cognitive deficits (Folstein, Folstein, & McHugh, 1975). A score between 25 to30 indicates normal cognition, 20 to 24 indicates mild dementia, 13 to 19 indicates moderate dementia, and 12 or less indicates severe dementia (Alzheimer's Association, 2013). Any potential care recipient participant scoring greater than 19 was excluded from the study. The MoCA is a screening tool for health professionals to use to screen patients cognition levels. It is a 12 item questionnaire. The possible range of scores is zero to 30, where lower scores indicate lower levels of cognition or cognitive deficits (Nasreddine, 2015). A score of 27 to 30 indicates normal cognition, 18 to 26 indicates mild cognitive impairment, 10 to 17 indicates moderate impairment, and less than 10 indicates severe cognitive impairment (Nasreddine, 2015). The MMSE scores and/or the MoCA scores were provided by the ARDC on the list created for the SPI for recruitment of participants.

Screening Caregiver Depression

Caregiver depression was screened by using the Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D has been widely used scale to measure

depressive symptoms within the general population (Hann, Winter, & Jacobsen, 1999; Longmire & Knight, 2010; Radloff, 1977). The CES-D is a 20 item questionnaire. Scores range from zero to 60 where higher numbers indicate more depressive symptoms. A cut-off score of 16 has been established to identify those at risk for clinical depression (American Psychological Association, 2015). The CES-D has evidence of reliability with alpha coefficients reported to be greater than 0.70 (Hann et al., 1999; Radloff, 1977). Stability has been reported to be adequate (test-retest) (Hann et al., 1999; Radloff, 1977). Criterion related validity was confirmed when the CES-D was compared to other established instruments measuring depressive symptoms (Hann et al., 1999). Discriminate validity was confirmed when the CES-D was able to discriminate between persons with and without depressive symptoms (Hann et al., 1999; Radloff et al., 1977). Construct validity was confirmed via factor analysis where four factors were identified (depressed affect, positive affect, somatic, and retarded activity, and interpersonal) (Longmire & Knight, 2010; Radloff, 1977).

Procedures

After potential participants were referred from the ADRC, the SPI contacted the potential caregiver participants by telephone. The SPI explained the study and asked initial screening questions. Then an appointment was set to meet with the caregiver and the care recipient in their home. At the first meeting, the study was explained again. Written informed consent was obtained from the caregiver and informed consent/assent was obtained from the care recipient. At that time, additional screening (CES-D) was administered. If all screening criteria were met, the caregiver and care recipient were enrolled. Baseline questionnaires were administered. Then the first PASS session was

scheduled and an appointment for the second session was scheduled within a two week period. After the PASS intervention was delivered, the daily diary (pain intensity scores, pain behaviors, and pain management strategies) was explained to the caregivers. Written instructions were given to all participants. The caregivers then began the two week data collection period. All participants received a telephone call on the second day of the two week period of data collection to answer questions about their responsibilities and to remind them about the daily diary. At one week post-intervention, the SPI contacted the participant caregivers via the telephone to administer the RBMPC. At the end of the two weeks (post-intervention), the SPI administered the RBMPC, PCS, and PBQ in person and collected data completed by the participants during the two week period. The SPI then administered the exit interview. All caregiver participants received a ten dollar gift card for participating in the study.

Fidelity of the PASS Intervention

To ensure fidelity of the PASS intervention, the PASS intervention was only administered by the SPI, a master prepared registered nurse. The intervention protocol was followed to ensure precision and consistency (Melany & Morrison-Beedy, 2012). A detailed PASS intervention implementation manual was created and was reviewed by a panel of expert researchers. The SPI followed an outline for each session and used a checklist. Information provided to participants was scripted to ensure consistent delivery. The SPI also practiced implementation of the PASS intervention, prior to implementation of the study, to ensure adequate pacing (Melany & Morrison-Beedy, 2012).

Data Collection

At baseline, prior to the PASS intervention, data were collected from all caregiver participants and included: 1) caregiver confidence in pain assessment and pain management (PCS), 2) care recipient negative behaviors (RBMPC), 3) demographic data (caregiver and care recipient), and 4) caregiver knowledge in pain assessment and pain management (PBQ). The baseline data were collected by the SPI at the participant's home or mutually agreed upon location (i.e. ADRC facility). After the PASS intervention was delivered, which was delivered by the SPI, caregiver confidence and knowledge in pain assessment and pain management questionnaires were administered again. All caregivers completed a diary for a two week period (proxy pain intensity, pain management strategies, and pain behaviors). The caregivers captured proxy pain intensity levels by administering the PAINAD and by using the NRS. All caregivers received a telephone call at day two of data collection to answer questions and to remind them to complete the daily diary. All caregivers received a telephone call at the end of the first week, where the SPI verbally administer the RMBPC for care recipient negative behaviors. At the end of the second week, data were collected by the SPI in the participants' homes or mutually agreed upon location. Post-intervention data collected included: 1) caregiver confidence in pain assessment and pain management (PCS), 2) care recipient negative behaviors (RBMPC), 3) caregiver knowledge in pain assessment and pain management (PBQ), and 4) exit interview. The daily diary completed by the caregivers also was collected.

Data Analysis

The hypotheses for the initial study were unable to be evaluated as planned due to the fact that there was not a control group to compare with the intervention group. Due to challenges in recruitment, the data collected were evaluated descriptively (means, frequencies). All data were reviewed for accuracy and missing data. The results are described in chapter four. A description of the original data analysis plan is discussed below.

Initial Data Analysis Plan

All data was to be reviewed for accuracy, missing data, and outliers. Data distributions were to be evaluated. All participant characteristics were to be evaluated for differences between the experimental and control group using t-tests and chi- square analysis. A t-test is used to compare and identify differences between two groups (Kellar & Kelvin, 2013). When using a t-test, the dependent variable must be dichotomous and be normally distributed (Kellar & Kelvin, 2013). A chi-square analysis compares the proportion of participants in each participant group. When using a chi-square analysis; the data must be collected from an independent random sample, two variables are compared, and the variable measures are nominal or ordinal (Kellar & Kelvin, 2013). Data was to be evaluated for potential confounding variables. If potential confounding variables were identified they were to be controlled for during data analysis. Analysis of Variance (ANOVA) repeated measures was planned to be used to evaluate all four hypotheses. A repeated measures ANOVA is used when data is collected from the same participant at multiple time points (Kellar & Kelvin, 2013). When using this statistical analysis, the dependent variable must be measured a minimum of three times, and the

dependent variable needs to be a ratio or interval measurement (Kellar & Kelvin, 2013). Because this was a pilot study and the sample was not sufficiently large to achieve adequate to power to detect statistical significance, estimate effect sizes was planned to be used to determine the magnitude of any effects observed (i.e. r =.10 /small effect, r = .30/medium effect, r =.50 large effect) (Cohen, Field, 2009; 1988).

Protection of Human Subjects

This study was approved by Georgia State University Institutional Review Board (IRB). Written consent was collected from the caregiver and the care recipient upon entering the study. The care recipient's legal representative (if different from the informal caregiver) also provided consent for the care recipient due to the cognitive status of the care recipients within this study. The participants had the right to decide to participate or not participate in the study without coercion or repercussion. Assent was confirmed from care recipients. A request for a partial Health Insurance Probability and Accountability (HIPPA) waiver was obtained from the care recipient's legal representative for permission to access the care recipient's medical record for MMSE and MoCA scores. Taking part in this study involved minimal risks, but there was the possibility that some participants may become tired or distressed while participating in the PASS intervention. If a participant became too tired or distressed, the SPI was to stop the intervention. The intervention could have been restarted at a later time, if the participant chose to continue. If the distress did not subside, the SPI was to assist in obtaining help. A list of community health centers would have been given to the participants and the SPI would have recommended that the participant contact their primary care physician. Georgia State University was not to be responsible for any

treatment costs incurred. The participants were able to withdrawal at any time during the study without repercussion. All benefits, risks, and study participation requirements, were addressed on the informed consent. In the original design, the control group was to have access to the PASS intervention at the end of the study.

Confidentiality and privacy was maintained by assigning each participant a code number. Data were kept in a password and firewall protected computer. The participant key was kept in a locked cabinet. All questionnaires were kept in a separate locked cabinet from participant information. Access to data was limited to the SPI and research committee. The participant identifying information was not used to present or analyze the data.

Informed consent

The informed consent process was designed to ensure the potential participants were given information about the purpose of the study, risk, benefits, confidentiality, and burdens of the study (ANA, 2010; Monroe et al., 2013). The understanding of these risks and benefits were ensured through discussion and/or assessment. The written informed consent was written at an 8th grade literacy level. Sensory limitations were considered such as auditory and visual limitations. For example, the print on the information provided to the participant and on the informed consent was made in a larger font or verbally read for those that had visual limitations (i.e. presbyopia). The SPI asked the potential participants to verbally explain the study, after reading the consent, to ensure comprehension of the information provided to the potential participants (ANA, 2010).

When obtaining informed consent from persons with dementia, assessing the decisional capacity and/or consent capacity was important to ensure that the potential

participants entered the study voluntarily (Beattie, 2009; NIH, 1999). Consent capacity was assessed using questions related to the study purpose, benefits, burdens, and risks to confirm understanding (Beattie, 2009; NIH, 1999; Oruche, 2009). The caregiver recipients in the study had moderate/severe cognitive impairment. It was expected that many care recipient participants lacked decisional making capacity. Informed consent was obtained from a proxy (caregiver and/or legal representative). At minimal, assent was obtained from the care recipient (Monroe et al., 2013; NIH, 1999; Oruche, 2009). Assent was obtained by assessing the care recipient's willingness to participate in the PASS intervention using verbal and non-verbal indicators (i.e. saying yes, cooperating, positive facial expressions or shaking, grimacing, shrieking, agitation, and saying no) (Black et al., 2010; Monroe et al., 2013; Selage, Conner, & Carnevale, 2009). Implementation of a waiting period between providing information about the study and participation risks, benefits and burdens was implemented prior to officially obtaining consent (NIH, 1999). A waiting period gives the participants time to discuss and review information prior to consenting to the research study.

According to the Alzheimer's Association (2014) obtaining consent via proxy is necessary for participants with dementia. Participants with dementia should be allowed to enroll in minimal risk research (i.e. surveys, interviews, and observations) with a proxy informed consent. The intervention was designed to result in a possible benefit for the care recipient with dementia (i.e. more accurate pain identification and management strategies).

Caregiver Burden

Caregivers already have a higher level of burden when caring for care recipients with dementia (Chappell & Reid, 2002; Keyserlingk et al., 1995; Sequeira, 2013). The CES-D was administered to potential caregiver participants to screen for depressive symptoms. A score of 16 or greater indicated that the caregiver is experiencing a significant level of depressive symptoms which could impede them in participating in this study. If a caregiver scored 16 or greater on the CES-D, they were to be notified and a list of community health care resources were to be given to them as well a recommendation that they should follow-up with their regular healthcare provider. No caregivers scored above 16 on the CES-D during screening.

The PASS intervention supplied the caregiver with information about pain and pain management strategies as well as training in using the PAINAD scale for pain assessment. The PASS intervention was given in two sessions. The first session was one hour and the second session was 40 minutes. To decrease the burden of the PASS intervention, educational information was in written format that was easily accessible. The PAINAD was implemented while assisting the care recipients in usual activities of daily living in an attempt to decrease inconveniences and interruptions in daily routines (Keyserlingk et al., 1995). The caregiver was responsible for data collection in daily diary format for quick and easy implementation. There was a two week data collection period. The expected time for data collection was five minutes a day. Other data were collected by the researcher in person or via telephone. The in person collection of data were at baseline and upon exiting the study. A telephone call occurred at the one week period to administer the RMBPC. Part of this feasibility study was to assess burden of

the PASS intervention. As discussed earlier, this information was collected during the exit interview. The caregivers were aware that they can withdrawal from the study at any time without repercussion (OHRP, 1993).

The PASS intervention may result in decreasing the caregiver burden. There is some evidence that training, education, and a systematic pain assessment may lead to increased caregiver confidence in the formal caregiver setting (Chen et al., 2010). There is some evidence that higher caregiver confidence is significantly related to lower caregiver burden (Campbell et al., 2008; Chappell & Reid, 2002). Better assessment and management of care recipients' pain may also lead to decreased negative behaviors (Cervo et al., 2012; Fuschs-Lacelle & Hadjistavropoulos, 2004). There is some evidence that increased care recipient negative behaviors are significantly related to increases in caregiver burden (Chappell & Reid, 2002).

In the initial plan, the PASS intervention was to be randomly assigned to participants in the study. Randomization of the PASS intervention was going to give each participant an equal and fair chance of being in the intervention group or the control group (Shadish et al., 2002). The control group was to have access to the PASS intervention at the end of the two week period in which the PASS intervention could have been implemented. This strategy ensured that everyone was to have access to the intervention (Shadish et al., 2002). During the two week period, the control group was to continue care as usual. Due to the challenges in recruitment and the change of the study design to a one group design, there was not a control group in this study.

CHAPTER IV

RESULTS

This chapter presents the results of this feasibility study implementing an informal caregiver pain management intervention (consisting of providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale) when caring for older adults with dementia and arthritis. Sample characteristics and descriptive data findings are reported. SPSS version 20.0 was used for statistical analysis.

Challenges in Recruitment

Participants were recruited from Emory University's Alzheimer's Disease Research Center ADRC, located in Atlanta, GA. The ADRC also provides services to informal caregivers and families members of persons with dementia (i.e. educational opportunities). The participants were recruited from an existing data set. A list of potential participants was provided to the SPI from the ADRC. The potential participants on the list met specified cognition criteria (score 19 or less on the MMSE or score 17 or less on the MoCA). The list included all patients that met the cognition criteria within the data base. There were 37 potential participants to be contacted. Three caregiver/care recipient dyads, from the list, met criteria and consented to be part of the study. All three of the caregiver/care recipient dyads were randomly assigned to the intervention group. A recruitment flyer was also created to recruit participants from Emory's Memory Clinic. The flyers were distributed to the nurse practitioners at the

memory clinic. Recruitment from the memory clinic did not add any additional participants to the study. The ADRC then agreed to provide an additional list of potential participants from a second data base. The IRB was then amended to change the study to a one group design in an effort to focus on the feasibility of the intervention. The second list contained 28 potential participants. One caregiver/care recipient dyad, from the list, consented to be part of the study. In total, there were 65 caregiver/care recipient dyads contacted for recruitment. Out of these 65 caregiver/care recipient dyads, four caregiver/care recipient dyads met criteria and consented to be part of the study. Figure one displays detailed information about the recruitment process.

Sample Characteristics

There were four informal caregiver/care recipient dyads that participated in the study. Demographic information is displayed in Table 1. All caregivers provided the majority of care in the home setting. The care recipients on the list provided from the ARDC all had a diagnosis of Alzheimer's or other form of dementia and met cognitive inclusion criteria. The SPI screened participants to ensure that all other criteria were met and that all care recipients had a diagnosis of a form of arthritis.

All four caregivers were the spouses to the care recipients. The ages of the caregivers ranged from 62 to 75. Three of the four caregiver participants were female and White. Three out of the four care recipients were male and White. The ages of the care recipients ranged from 66-76. The annual family income ranged from $75,000 to greater than $100,000. Most caregivers and care recipients were college educated. All caregivers reported that they were not working at the time of the study. Caregivers reported spending an average of ten (SD 9.83) hours of caregiving activities (tasks that caregivers

complete for their care recipients that they cannot do for themselves), but the range of hours was large. All care recipients were able to walk independently.

Figure 1

CONSORT Diagram

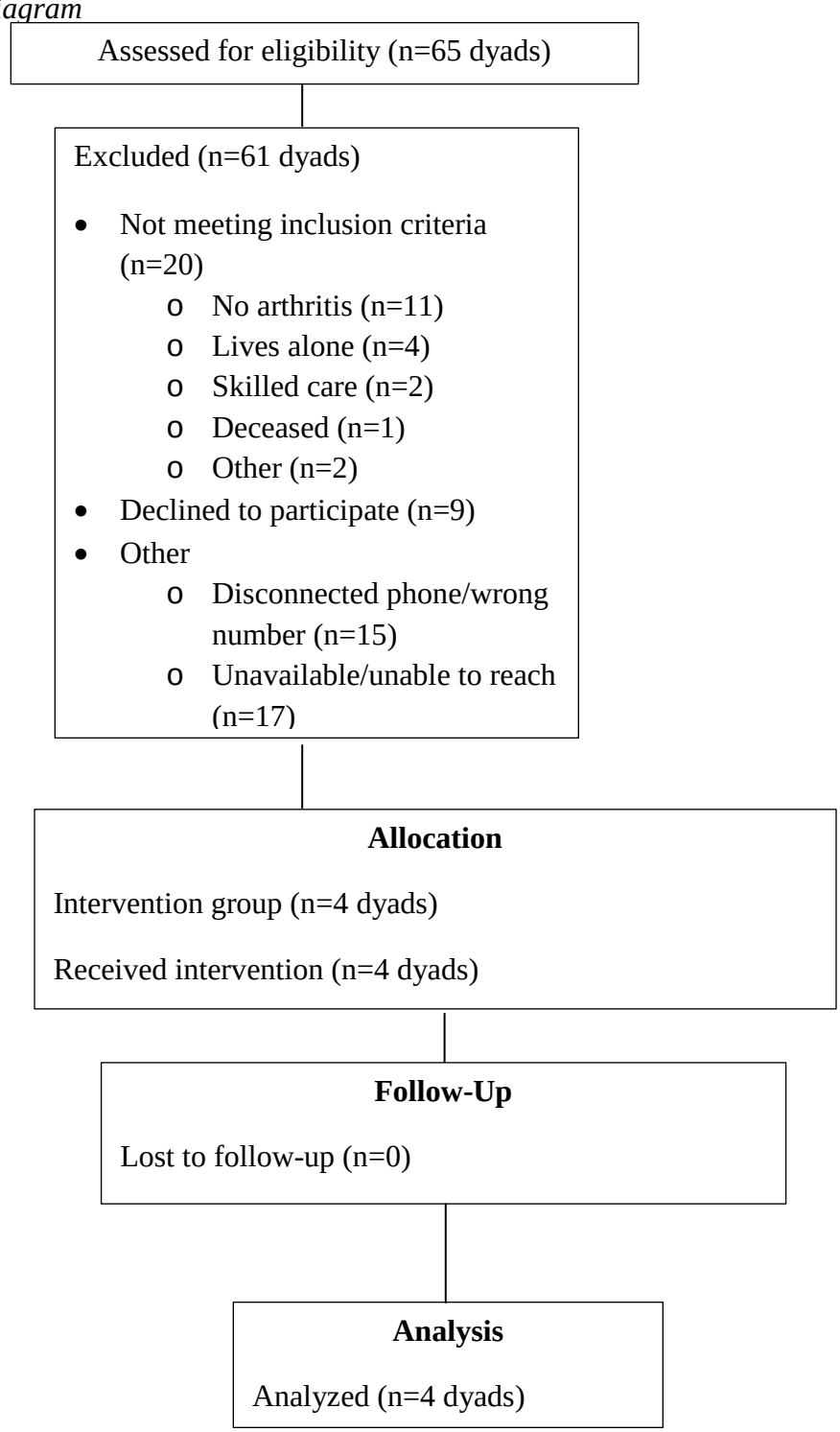

Table 1

Demographic Characteristics of the Sample

Characteristics	Caregivers (*n*=4)	Care Recipients (*n*=4)
Age (years)		
M (SD)	68.75 (6.24)	68.75 (6.24)
Min/Max*	62-75	66-76
Gender (*n*)		
Female	3	1
Male	1	3
Ethnicity (*n*)		
White	3	3
African American	1	1
Last grade completed in school (*n*)		
Some college	1	1
College graduate (undergraduate)	2	1
Graduate degree	1	2
CES-D score		
M (SD)	8.75 (2.87)	-
Min/Max	5-12	-
MoCA score		
M (SD)	-	11.75 (2.36)
Min/Max	-	10-15
Marital status		
Married	4	4
Annual family income (*n*)		
$75, 000-$99, 000	1	1
$100, 000 and over	3	3
Employment (*n*)		
Yes	0	-
No(Retired)	4	-
Hours spent of caregiving activities		
M (SD)	10 (9.83)	-
Min/Max	1-23	-
Functional status (*n*)		
Walks independently	-	4

Note. CES-D= Center for Epidemiologic Studies Depression Scale; MoCA=Montreal Cognitive Assessment; *Minimum/Maximum

Caregiver/Care recipient Dyad #1

The care recipient had a score of 15 on the MoCA evaluation. The caregiver had a score of five on the CES-D when screening for depression. The care recipient's additional health problems were a history of shortness of breath, fatigue, and asthma. The caregiver also reported that the care recipient typically took Tylenol and Percocet as needed for pain. The caregiver reported spending an average of 23 hours daily on caregiving activities.

Caregiver/Care recipient Dyad #2

The care recipient had a score of 12 on the MoCA evaluation. The caregiver had a score of nine on the CES-D when screening for depression. The caregiver reported that the care recipient did not have a history of any other medical issues. The caregiver reported that the care recipient typically took Tylenol as needed for pain. The caregiver reported spending an average of one hour daily on caregiving activities.

Caregiver/Care recipient Dyad #3

The care recipient had a MoCA score of 10. The caregiver had a score of 12 on the CES-D when screening for depression. The care recipient's additional health problems were hypertension, shortness of breath, and cancer that had been in remission for years. The caregiver reported that the care recipient typically took Ibuprofen as needed for pain. The caregiver reported spending an average of 12 hours daily on caregiving activities.

Caregiver/Care recipient Dyad #4

The care recipient had a MoCA score of 10. The caregiver had a score of nine on the CES-D when screening for depression. The care recipient's additional health

problems were hypertension, shortness of breath, neurological disorder, fatigue, heart problems, reflux, asthma, and sleep apnea. The caregiver reported that the care recipient currently took meloxicam and gabapentin daily for pain. The caregiver also reported that the care recipient typically took Ibuprofen and hydrocodone as needed for pain. The caregiver reported spending an average of four hours daily on caregiving activities.

Findings

Adherence to the PASS Intervention

Two of the four caregivers used the PAINAD and daily log the minimum of once a day for the two week period. One caregiver missed two days due to illness. One caregiver missed two days due to a trip. Three out of the four caregivers did not use the PAINAD to reassess pain after a pain management strategy was implemented. The other caregiver never implemented a pain management strategy during the two week period, so the PAINAD follow-up was not required. In the instructional video within the PASS intervention, caregivers were instructed that a pain score of two or greater would warrant delivery of a pain management intervention. Caregivers reported care recipients' pain intensity scores of two or greater 21 times over the two weeks. Caregivers delivered a pain management strategy to their care recipients 81% of the time when their care recipient had a pain intensity score of two or greater.

Pain Management Strategies

Three out of four caregivers implemented a few pain management strategies during both weeks of the study. During the first week, caregivers implemented an average of 6 pain management strategies (Table 2) and during the second week caregivers implemented fewer pain management strategies (Table 2).

Table 2

Number of Caregiver Pain management Strategies Implemented

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
1 week	6 (8.26)	2	0	18	4
2 week	4 (6.16)	0	0	13	3

The caregivers delivered a variety of pain management strategies to their care recipients during the two weeks of data collection (Table 3). Caregivers implemented three pharmacological pain management strategies. Two caregivers implemented non-pharmacological pain management strategies and two did not implement any. Caregiver three also implemented stretching, physical therapy exercises, and a salt bath for pain management.

Table 3

Caregiver Pain Management Strategies Implemented

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
Pharmacological	3.3 (3.4)	2	0	8	3
Ibuprofen	2.3 (3.9)	0	0	8	1
Hydrocodone	0.5 (1.0)	0	0	0	2
Tylenol	0.5 (1.0)	2	0	0	0
Non-Pharmacological	4.8 (8.2)	0	0	17	2
Distraction	1.0 (2.0)	0	0	4	0
Relaxation	0.5 (1.0)	0	0	0	2
Music	1.3 (2.5)	0	0	5	0
Massage	1.3 (2.5)	0	0	5	0
Other	0.8 (1.5)	0	0	3	0

Negative Care Recipient Behaviors

Care recipient negative behaviors were captured by using the RMBPC. This was administered at all three time points. Negative behaviors were also captured using the daily log where caregivers identified any negative behaviors the care recipient displayed at the time the PAINAD was used to assess pain intensity.

The RMBPC contains a list of 24 behaviors with a dichotomous response of yes or no. The caregivers are to identify behaviors that occurred over the previous week. The possible total scores range between zero and 24. At baseline, caregivers reported care recipients displayed an average of 13.3(SD = 3.5) negative behaviors, over the midpoint of the scale. Caregivers also rated how much the behaviors bothered the caregiver. The possible total scores range from zero to 96 where higher numbers indicate more bothersome behaviors. The caregivers had an average score of 26.3(SD=6.4) which reflected how much the care recipients' behaviors bothered them. Additional evaluation of caregivers' reaction scores were made by averaging the reaction scores by care recipients' negative behaviors reported by the caregivers on the RMBPC. The possible total scores range from zero to four where higher numbers indicate more bothersome behaviors. The caregivers had an average score of 2.1(SD=0.4) over the midpoint of the scale. On average care recipient negative behaviors were substantially less at both follow up weeks. The caregivers' reaction to care recipients' negative behaviors reaction score of how bothersome the care recipient behaviors were followed a similar pattern, decreasing at both follow-up time points. Table 4 displays the RMBPC results.

In the daily diary during the first week, caregivers identified that their care recipients displayed few negative behaviors with less negative behaviors in the second week. Table 4 displays caregiver reports of care recipient negative behaviors from the diary maintained while implementing the intervention. The most common negative behaviors reported in the daily diary over the two weeks were anxiety, decreased activity, agitation, and verbal aggression.

Table 4

Caregiver Reports of Care Recipient Negative Behaviors

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
RMBPC					
Negative behaviors					
Baseline	13.3 (3.5)	9	12	17	15
1 week	7.8 (1.0)	7	8	7	9
2 week	7.5 (3.9)	6	12	9	3
RMBPC					
Reaction score					
Baseline	26.3 (6.4)	21	27	35	22
1 week	11.8 (7.9)	16	20	2	9
2 week	12.8 (13.6)	15	31	4	1
Reaction average					
Baseline	2.1 (0.4)	2.3	2.3	2.1	1.5
1 week	1.5 (1.1)	2.3	2.5	0.3	1
2 week	1.5 (1.2)	2.5	2.6	0.4	0.3
Daily Diary					
Negative Behaviors					
1 week	6.8 (6.7)	0	2	12	13
2 week	2.3 (2.6)	0	1	6	2

Note. RMBPC=Revised Memory Behavior Checklist; Daily Log Negative Behaviors= care recipient behaviors displayed at the time the pain intensity was assessed; 1 week and 2 week= data collected after the intervention; Reaction average=caregivers' reaction scores averaged by care recipients' negative behaviors reported by the caregivers on the RMBPC.

Pain Intensity

Care recipient pain intensity was measured by the PAINAD scale and the NRS in the daily diary. Interpretation of the scores for both scales is; zero is no pain, one to three is mild pain, four to six is moderate pain, and seven to ten is severe pain. For both weeks, the caregivers reported care recipients' pain intensity as mild. For both weeks the average pain intensity score for the care recipients, although similar, was slightly lower when using the PAINAD scale. Table 5 displays caregivers' reports of care recipients' pain intensity.

Table 5

Caregiver Reports of Care Recipient Pain Intensity

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
PAINAD					
1 week	2.02 (2.26)	0	0.14	4.14	3.83
2 week	1.19 (1.14)	0	0.57	1.60	2.60
NRS					
1 week	2.49 (2.52)	0	0.67	4.29	5.00
2 week	2.34 (2.93)	0	0.80	2.00	6.57

Note. PAINAD= Pain Assessment in Advanced Dementia Scale; NRS= numeric rating scale with higher scores indicating higher pain severity for both scales.

Caregiver Confidence

Caregivers' confidence in assessing pain and managing pain in their care recipients were captured using the PCS and are reported in Table 6. At baseline (prior to the intervention) caregiver confidence was slightly lower than both times points after the intervention had been completed.

Table 6

Caregiver Confidence in Assessing Pain and Managing Pain in Their Care Recipient

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
PCS					
Baseline (Pre-PASS)	6.38 (1.90)	7.0	7.0	6.8	4.8
Post PASS	6.94 (0.13)	7.0	7.0	7.0	6.8
2 week	6.56 (0.88)	7.0	5.3	7.0	7.0

Note. PCS= Perceived Competence Scale; PASS= providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale

Caregiver Knowledge of Assessing and Managing Pain in Care Recipients

Caregiver knowledge of assessing pain and managing pain in their care recipient was captured using the PBQ and results are in Table 7. On the PBQ, total scores and the subscale scores range from one to six where lower numbers indicate that emotions and beliefs about pain would be less likely to interfere with the caregivers' ability to manage pain. The PBQ has two subscales (organic pain beliefs and psychological pain beliefs). On the PBQ, caregivers scored slightly lower after the intervention than at baseline. However, at the end of two weeks, the caregivers scored higher on the PBQ than at baseline. On the additional item (People with dementia do not feel pain) caregivers responded on a Likert-type scale with anchors "never = 1" and "always = 6". On average, caregivers scored higher prior to the intervention than at both time points after the intervention indicating that caregivers agreed their care recipients' could feel pain after the intervention.

Table 7

Caregiver Knowledge of Assessing Pain and Managing Pain in Their Care Recipient

	Overall (*n*=4) *M (SD)*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
PBQ					
Baseline (Pre-PASS)	4.15 (.60)	4.08	3.58	5.00	3.92
Post PASS	4.10 (.26)	4.08	3.75	4.33	4.25
2 week	4.25 (.9)	3.5	3.42	5.00	5.08
PBQ organic pain beliefs					
Baseline (Pre-PASS)	3.84 (4.36)	3.69	3.50	4.63	3.63
Post PASS	3.69 (3.89)	3.13	3.75	4.00	3.88
2 week	3.97 (1.24)	2.38	3.63	4.75	5.33
PBQ psychological pain beliefs					
Baseline (Pre-PASS)	4.75 (.84)	5.00	3.75	5.75	4.50
Post PASS	4.94 (.92)	6.00	3.75	5.00	5.00
2 week	4.81 (1.25)	5.75	3.00	5.50	5.00
Additional question					
Baseline (Pre-PASS)	2.75 (2.36)	3.00	6.00	1.00	1.00
Post PASS	2.50 (2.38)	2.00	6.00	1.00	1.00
2 week	1.00 (0)	1.00	1.00	1.00	1.00

Note. PBQ= Pain Beliefs Questionnaire; PASS= providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale; additional question= people with dementia do not feel pain

Exit Interview

The caregivers completed an exit interview at the end of the study and results are in Table 8. Responses were mixed about being more comfortable in identifying pain with two being favorable. Three caregivers responded favorably about being more comfortable in managing pain. Three caregivers did not see a difference in their care recipients' pain symptoms. When asked to explain two caregivers gave explanations such as the care recipient did not have any pain during the study and the care recipient was irritable because of the restrictions that chronic pain have on everyday tasks.

The caregivers were asked if they were using more pain management strategies since the beginning of the study. Three were favorable. Three caregivers provided examples such as patting the shoulder of the care recipient, rubbing the care recipient's shoulders, distraction, music, using more medications, and relaxation.

All of the caregivers indicated that using the scale in the study was somewhat easy or very easy. All of the caregivers responded that they would participate in the study again. When the caregivers were asked if they would recommend the intervention to others, caregiver responses were mixed.

The caregivers were asked about the most challenging part of the intervention, two caregivers responded that there was nothing challenging. One caregiver also stated that "It was easy and only took a few minutes". Other caregivers stated that the challenging part of the intervention was "…trying to keep track of how many different ways I can use to pick up on pain levels" and that the challenging part of the intervention was "…trying to remember to do it with all of the other daily activities".

The caregivers were asked about the best part of the intervention. Caregivers' responses included "it made me more aware of looking for pain", the intervention led to an increase in monitoring for pain and an increased awareness of pain, learning about different ways to identify care recipient pain because the care recipient is unable to communicate if pain is present, and the intervention led to an increased patience with pain related behaviors.

Table 8

Caregiver Exit Interview Responses

	Overall (*n*=4) *n*	Dyad 1	Dyad 2	Dyad 3	Dyad 4
Comfortable identifying pain					
Definitely no	1	1	0	0	0
Not sure	1	0	1	0	0
Maybe yes	1	0	0	0	1
Definitely yes	1	0	0	1	0
Comfortable managing pain					
Not sure	1	1	0	0	0
Maybe yes	2	0	1	0	1
Definitely yes	1	0	0	1	0
Difference in pain symptoms					
Definitely no	3	1	1	0	1
Definitely yes	1	0	0	1	0
Using more pain management strategies					
Definitely no	1	0	1	0	0
Maybe yes	1	1	0	0	0
Definitely yes	2	0	0	1	1
Difficulty using the scale					
Somewhat easy	2	0	1	1	0
Very easy	2	1	0	0	1
Participate again					
Yes	4	1	1	1	1
Recommend the intervention to others					
Definitely no	1	0	1	0	0
Not sure	1	1	0	0	0
Definitely yes	2	0	0	1	1

The caregivers were asked to provide suggestions to improve the intervention. There responses included "…might be better for someone with more severe memory problems", Tylenol should be listed as an option on the daily diary, and that a few of the survey questions be more straight forward with yes and no responses and that the

intervention might be better for a care recipient that is nonverbal. One caregiver stated the intervention was "…very comprehensive and wonderful. People should know about this that has issues with loved ones. It is so important to be able to know the pain level. I have struggled with this at home and in the hospitals."

Summary of the Results

The results indicate that the caregivers could perform the intervention and some found it helpful. The caregivers indicated they were performing more nonpharmacological pain interventions, but the daily dairy results indicated most used few nonpharmacological pain management strategies. After the PASS intervention caregivers reported that care recipients' negative behaviors decreased after the PASS intervention and that the negative behaviors that the care recipients' did display were not as bothersome. There was minimal change in pain intensity scores during the two weeks after the intervention and caregivers' reported care recipients' pain to be mild. Caregivers' confidence and knowledge in assessing pain and managing pain increased slightly after the PASS intervention.

CHAPTER V

DISCUSSION AND CONCLUSIONS

The purpose of this study was to examine the feasibility of an informal caregiver pain management intervention (consisting of providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale) when caring for older adults with dementia and arthritis. In this chapter, the feasibility of the PASS intervention is discussed as well as additional conclusions, limitations, and suggestions for future research.

Discussion of Findings

Feasibility of the PASS Intervention

Overall, the PASS intervention was successfully delivered to informal caregivers and informal caregivers were able to use the PAINAD assessment tool in the home setting and found it relatively easy to use. The caregivers were able to use the PAINAD scale daily to assess their care recipients' pain and most caregivers did use a pain management strategy as instructed when care recipient pain intensity scores were two or greater. However, the caregivers were instructed to use the PAINAD and to document care recipient negative behaviors when pain was suspected and/or one hour after a pain management strategy was delivered to their care recipient. Caregivers may not have understood the need to reassess pain because three of the four caregivers did not follow-up and reassess pain after a pain management strategy was implemented. It is unclear as to why the PAINAD scale and documentation of care recipient negative behaviors were

not done after a pain management strategy was implemented. This part of the PASS intervention needs to be strengthened in the next test of the PASS intervention. Some ways to strengthen this portion of the intervention may be in explaining the need for reassessment of pain, providing written instructions for caregivers, and using follow-up telephone calls to remind and clarify how caregivers are to use the PAINAD scale.

All of the caregivers stated that they would participate in this study again, if they had the chance. However, not all of the caregivers would recommend the intervention to others or were unsure if they would recommend the intervention to others. When the caregivers provided an explanation, some stated that the intervention would be better for those with more severe cognitive deficits and some felt they knew the care recipient so well, because it was their spouse, they could identify pain better on their own. Caregivers explained that the tool would be useful, if they were unable to identify pain in their care recipient on their own. This response was unexpected because all the care recipients met criteria of having moderate/severe cognition impairment and two of the four caregivers thought their care recipient could not express pain intensity levels. The caregivers that explained that they could identify pain without an assessment tool also reported care recipients to have very little to no pain over the two week follow-up period. One possible explanation is that some caregivers may feel they should know if their care recipients are in pain because the care recipients are their spouses. The caregivers may feel they know the care recipient so well that they do not need a tool to assist them in recognizing signs when their loved one is in pain.

Care Recipient Negative Behaviors

In this study, caregivers reported fewer care recipient negative behaviors on average. This report is consistent with earlier studies where care recipient negative behaviors may be linked to the experience of pain (Eritz & Hadjistavropoulos; Fuschs-Lacelle & Hadjistavropoulos, 2004). Care recipients with dementia, during painful episodes that had identifiable causes, displayed significantly more negative behavioral indicators, negative social behaviors, negative physical behaviors, and negative physiological indicators during a painful event when compared to calm episodes (Fuschs-Lacelle & Hadjistavropoulos, 2004). There is also evidence that after initiating an intervention involving systematic pain assessments and education, there was a decrease in care recipient negative behaviors (Cervo et al., 2012; Fuschs-Lacelle & Hadjistavropoulos, 2004). After initiating an intervention involving systematic pain assessments and education about pain causes, pain assessments, pain assessment barriers, pain interventions, and unmanaged pain consequences to professional and skilled caregivers in three long term care facilities, care recipients with dementia (*n*= 215, MMSE < 20, *M* age = 84.9, SD=7.2) demonstrated significantly less physical aggression, physical nonaggression, and verbal nonaggression episodes (Cervo et al., 2012).

Care recipient behaviors associated with pain (i.e. anger, restlessness, appetite changes, aggressive behaviors, and wandering) are also present in symptoms of dementia and other chronic conditions (Eritz & Hadjistavropoulos, 2011; Family Caregiver Alliance, 2012; Fruchs-Lacelle & Hadjistavropoulos, 2004). The caregivers in this study reported that care recipient negative behaviors displayed during the two

week period of this study did not bother them as much when compared to the time period before the PASS intervention was implemented. Some caregivers reported that the PASS intervention made them more aware that certain negative behaviors may appear because of pain and that they found they had more patience for care recipient behaviors. One explanation may be that the PASS intervention assisted caregivers in distinguishing possible pain related behaviors from behaviors caused by other conditions or may be more empathetic. Use of a systematic pain assessment tool by professional caregivers assisted in distinguishing pain related behaviors from behaviors caused by other conditions and illnesses in a study of 215 nursing home residents (Cervo et al., 2012).

Pain Management Strategies

In previous work when professional and skilled caregivers received an educational intervention about pain management (consisting of appropriate application of a variety of systematic pain assessment tools and education about pain, pain assessment, and pain management) there was an increase in the number of pain management strategies used to significantly decrease care recipients' pain intensity levels (Cervo et al., 2012; Manias et al., 2011). Consistent with these findings, three of the four caregivers responded that they were using more pain management strategies after the PASS intervention than before the intervention. However, this was inconsistent from the daily diary data where most of the caregivers reported using few pain management strategies over the two week period. One possible explanation is that two caregivers reported that their care recipient had little pain. The caregivers that reported using more pain management strategies reported higher care recipient pain intensity levels over the two week period.

Caregivers used slightly more non-pharmacological interventions than pharmacological interventions during the two week period after the PASS intervention. These findings are consistent with a report that nurses, who received an intervention similar to the PASS intervention, used significantly more non-pharmacological interventions than the control group (Manias et al., 2011).

Caregiver Confidence and Knowledge of Pain

The expectation was that caregivers would have increased confidence in managing and assessing care recipients' pain after the PASS intervention was implemented. The caregivers did have a slight increase in confidence on the PCS after the PASS intervention was delivered. This is consistent with the report that providing formal caregivers with education about pain and pain management strategies and training in using a systematic pain assessment tool can assist caregivers in becoming more confident in their assessment skills (Chen et al., 2010). Results also revealed that caregiver knowledge (measured using the PBQ) about pain and pain assessments slightly increased after the PASS intervention. Prior to the intervention, some caregivers believed that their care recipient may not be able to feel pain and after the intervention all caregivers agreed that their care recipient is capable of feeling pain.

The exit interview had mixed results when caregivers were asked about their level of comfort in identifying and managing pain in their care recipients. One possible explanation is that two of the caregivers explained that their care recipient had little to no pain during the two week period. Training, education, and a systematic pain assessment may lead to increased caregiver confidence, but more evidence is needed to determine if informal caregivers of dementia patients in the home setting have increased

confidence after the PASS intervention resulting in an increased accuracy of identifying pain levels in their care recipients.

Care Recipient Pain Intensity

The caregivers reported care recipients' pain intensity levels in this study using both the NRS and the PAINAD and overall care recipients' pain levels were slightly lower across the two week period and fell within the mild range. Using the PAINAD, care recipients' pain scores were slightly lower than when using the NRS to assess care recipient pain intensity levels. There is some evidence that when professional caregivers use a systematic pain assessment tool to assess pain, use of the tool resulted in significantly lower pain levels (Jordon et al., 2011). There is some evidence that systematic pain assessment instruments used for pain assessments on persons with dementia have been effective in assisting formal caregivers to perform better pain assessments by enabling the assessor to decode the pain communication of the care recipient (Kamel et al., 2001; Young et al., 2006). The PAINAD may assist caregivers in decoding care recipient pain. However, it is difficult to evaluate whether the PASS intervention actually decreased care recipient pain intensity levels because the caregiver did not use the PAINAD after a pain management strategy was implemented and recipients had relatively mild pain intensity scores during the two week period.

Cognitive Deficits and Barriers to Pain Assessment

The MMSE and MoCA score parameters were set as eligibility for care recipients to include those with moderate/severe dementia, a stage where communication is often affected (Alzheimer's Association, 2013; Nasreddine, 2015). All of the care recipients had moderate cognitive deficits. Two of the four caregivers

explained that they knew the care recipients so well that they could identify pain intensity without the use of an aide. The other two caregivers explained they did need additional assistance to screen their care recipients for pain intensity levels and that they believed their care recipient could not communicate pain intensity levels. The caregivers explained that it is difficult for them to know whether their care recipients are in pain or not in pain. These findings are consistent with reports that cognitive deficits are associated with incongruent caregiver and care recipient proxy ratings of pain and the difficulty that caregivers have when identifing pain in their care recipient (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Chen et al., 2010; Horgas, Elliot, & Marisiske, 2009; Jensen-Dahm et al., 2012; Kauppila, Pesonen, Tarkkila, & Rosenberg, 2007; Monroe, Carter, Feldt, Tolley, & Cowan, 2012; Reynolds, Hanson, DeVillis, Henderson, & Steinhauser, 2008; Shega et al., 2012). It is unclear as to why some of the caregivers believed that their care recipient could communicate pain and why some caregivers did not believe their care recipients could communicate pain to their caregivers. A possible explanation is that informal caregivers often have known the care recipient many years even prior to caregiving and may have felt they know behavioral responses of the care recipient well. This knowledge about the care recipient may be a point of pride for caregivers in providing excellent care for their loved one and they may feel challenged if someone points out that they may need a formal tool to help them know their care recipients' needs. The current sample included all spouse caregivers. Findings may differ for adult

children or other caregivers. Studies with caregivers with different relationships with care recipients are needed. This idea needs to be explored in future research. Another explanation may be that these caregivers, because their care recipient had little to no pain daily, felt that they can assess pain and manage pain because it is not a daily challenge.

Time Spent with Care Recipients and Pain Assessment

There was a wide range of hours that the caregivers reported for spending time on caregiving activities. There has been one study that found when informal caregivers spend more than ten hours per week in caregiving activities; caregivers' ratings are significantly more congruent with care recipient pain ratings (Eritz & Hadjistavropoulos, 2011). In the current study, the caregiver that spent the most time with the care recipient in caregiving activities reported that the care recipient could communicate pain because the caregiver knew the care recipient so well. The caregiver could tell when the care recipient was in pain. However, the other caregiver that reported that the care recipient could communicate pain intensity spent the least amount of time in caregiving activities. While it is understandable that caregivers who spend more time with care recipients may be more familiar with their behaviors, there is not enough evidence to determine if length of time spent with care recipients may be related to better pain assessment.

The Social Communication Model of Pain

The SCMP is a comprehensive model of pain assessment that encompasses the biological, psychological, and social factors associated with pain (Craig, 2009). The SCMP was created to guide research that evaluates and tests interventions that assist caregivers in assessing and managing pain in their care recipients who cannot

communicate. The SCMP was useful in this study as a theoretical framework. The care recipients were older adults and diagnosed with dementia and arthritis. The physical trauma causing the pain was the result of chronic arthritis pain. The personal experience of the care recipient involved cognitive, sensory and affective factors and the pain expression (encoding) involved nonverbal, verbal, and physiological expressions. The PASS intervention addressed the decoding as described in the theory by having caregivers use a structured scale (PAINAD scale) and were to use the results to implement pain management. Further testing is needed with an adequate sample size to strengthen the support for the use of the SCMP in the older adult dementia population and to investigate expected outcomes (i.e. increased pain management strategies, less care recipient negative behaviors, decreased pain intensity levels, increased caregiver confidence).

Limitations

A limitation to this feasibility study was the challenges in recruitment of participants. These challenges resulted in changing the initial design to a single group design. The lack of a control group and the small sample size are major limitations to the study.

Another limitation is that the majority of the participants were well educated with a moderate annual family income. Therefore, we are unable to determine if those with lower education levels would be able to successfully participate in the in the PASS intervention. The caregivers also did not use the PAINAD for reassessment of pain or report to negative behaviors in the daily diary as planned (one hour after a pain management strategy was delivered to the care recipient) making it difficult to evaluate

differences in care recipient pain intensity levels and care recipient negative behaviors soon after post-pain management strategy. Unexpectedly, caregivers also reported care recipients as having mild to no pain intensity scores making it challenging to evaluate descriptively changes in pain intensity levels after attempts to manage pain.

Implications

The PASS intervention can be successfully implemented and caregivers found the PAINAD was generally easy to use. There is preliminary evidence from this study that the PASS intervention may have an impact on care recipient negative behaviors and/or the caregivers' perceptions of these behaviors. The PASS intervention may also lead to more pain management strategies used to treat care recipient pain. Unmanaged pain has been associated with a decreased quality of life and affects the person physically, physiologically, and psychologically. Pain affects a person's overall health and well-being (American Pain Society, 2011a; Brown et al., 2011; International Association for the Study of Pain, 2005; Jensen-Dahm et al., 2012; Thomas et al., 2004). There is some evidence that informal caregivers can use a systematic pain assessment tool and there is some evidence the PASS intervention may lead to improved pain management efforts.

Future Research

The PASS intervention needs to be further evaluated with informal caregivers. When the PASS intervention is delivered in the future, better explanations as when to use the PAINAD scale and record negative behaviors in the daily diary need to be clearer for the caregivers. Further research is needed to evaluate care recipient negative behaviors and how education and the PASS intervention affects negative behaviors and caregiver perceptions of care recipient negative behaviors. It is also unclear whether caregivers

spending more time participating in caregiving activities has an effect on congruency and accuracy of care recipient pain assessments.

Future studies need to use a two group design and an adequate sample size to examine the efficacy of the PASS intervention on expected outcomes (i.e. increased pain management strategies, less care recipient negative behaviors, decreased pain intensity levels, increased caregiver confidence). Formal caregivers using a systematic pain assessment tool to assess pain, along with receiving education to the caregiver about pain and pain management, have resulted in increased pain identification, decreased pain levels, more accurate pain assessments, decreased care recipient negative behaviors, and an increased use of pain management strategies by the formal caregivers caring for patients with dementia (Cervo, Bruckenthal, Fields, Bright-Long, Chen, Zhang, & Strongwater, 2012; Jordon, Hughs, Pakresi, Hepburn, & O'Brien, 2011; Kamel, Phlavan, Malekgoudarzi, Gogel, & Morley, 2001; Manias, Gibson, & Finch, 2011; Young, Siffleet, Nikoletti, & Shaw, 2006). Thus, it seems likely that informal caregivers and care recipients may benefit from the intervention. The current study was a first step in examining the feasibility of informal caregivers learning more about pain management including using a structured assessment pain tool as part of pain management. A larger study is needed to further refine the PASS intervention and examine its effect on caregiver and care recipient outcomes.

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APPENDIX A

Institutional Review Board Approval

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999
Phone: 404/413-3500
Fax: 404/413-3504

In Person: Dahlberg Hall
30 Courtland St, Suite 2

Georgia State University

February 17, 2016

Principal Investigator: Patricia Clark

Key Personnel: Cellar, Janet; Clark, Patricia; Cranford, Joan; Morgan,

Rebecca Study Department: B.F. Lewis School of Nursing, Dean of

Students

Study Title: Caregivers' Pain Recognition in Older Adults with Chronic Pain and Dementia

Funding Agency:

Review Type:

Expedited 7 IRB

Number: H16337

Reference Number:

336664

Approval Date:

02/17/2016

Expiration Date:

02/16/2017

The Georgia State University Institutional Review Board (IRB) reviewed and approved the above referenced study in accordance with 45 CFR 46.111. The IRB has reviewed and approved the study and any informed consent forms, recruitment materials, and other research materials that are marked as approved in the application. The approval period is listed above. Research that has been approved by the IRB may be subject to further appropriate review and approval or disapproval by officials of the Institution.

Federal regulations require researchers to follow specific procedures in a timely manner. For the protection of all concerned, the IRB calls your attention to the following obligations that you have as Principal Investigator of this study.

1. For any changes to the study (except to protect the safety of participants), an Amendment Application must be submitted to the IRB. The Amendment Application must be reviewed and approved before any changes can take place.

2. Any unanticipated/adverse events or problems occurring as a result of participation in this study must be reported immediately to the IRB using the Unanticipated/Adverse Event Form.

3. Principal investigators are responsible for ensuring that informed consent is properly documented in accordance with 45 CFR 46.116.

    - The Informed Consent Form (ICF) used must be the one reviewed and approved by the IRB with the approval dates stamped on each page.
    - A Waiver of Documentation of Consent has been approved for this study in accordance with the requirements set forth in 45 CFR 46.117 c.

4. For any research that is conducted beyond the approval period, a Renewal Application must be submitted at least 30 days prior to the expiration date. The Renewal Application must be approved by the IRB before the expiration date else automatic termination of this study will occur. If the study expires, all research activities associated with the study must cease and a new application must be approved before any work can continue.

5. When the study is completed, a Study Closure Report must be submitted to the IRB.

All of the above referenced forms are available online at http://protocol.gsu.edu. Please do not hesitate to contact the Office of Research Integrity (404-413-3500) if you have any questions or concerns.

Sincerely,

Cynthia A. Hoffner, IRB Vice-Chair

Federal Wide Assurance Number: 00000129

APPENDIX B

Amended Institutional Review Board Approval

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999
Phone: 404/413-3500
Fax: 404/413-3504

In Person: Dahlberg Hall
30 Courtland St, Suite 217

August 25, 2016

Principal Investigator: Patricia Clark

Key Personnel: Cellar, Janet; Clark, Patricia; Cranford, Joan; Morgan,

Rebecca Study Department: B.F. Lewis School of Nursing, Dean of

Students

Study Title: Caregivers' Pain Recognition in Older Adults with Chronic Pain and

Dementia Funding Agency: Internal GSU Department

Review Type: Expedited Amendment

IRB Number: H16337, Reference Number: 340820

Approval Date: 02/17/2016

Expiration Date: 02/16/2017

Amendment Effective Date: 08/25/2016

The Georgia State University Institutional Review Board reviewed and **approved** the amendment to your above referenced Study.
This amendment is approved for the following modifications:

- Due to challenges in recruitment, I would like to request to change the design of the study from a two group design (control and intervention) to a one group design. I would like all participants to receive the intervention.

The amendment does not alter the approval period which is listed above and the study must be renewed at least 30 days before the expiration date if research is to continue beyond that time frame. Any unanticipated/adverse events or problems resulting from this investigation must be reported immediately to the University Institutional Review Board.

For more information visit our website at www.gsu.edu/irb.

Sincerely,

Cynthia A. Hoffner, IRB Vice-Chair

Federal Wide Assurance Number: 00000129

APPENDIX C

Informed Consents

Georgia State University
Byrdine F. Lewis School of Nursing and Health Sciences
Informed Consent

Title: Caregiver's Pain Recognition in Older Adults with Chronic Pain and Dementia Principal Investigator: Dr. Patricia Clark

Student Principal Investigator: Rebecca Morgan MSN, doctoral student Committee Member/

Adviser: Dr. Janet Cellar

Funding Source: Kaiser Doctoral Student Award Fund

I. Purpose:

You are invited to participate in a research study. The purpose of the study is to investigate a way to help caregivers' manage pain in their loved one that has dementia and arthritis. You are invited to participate because you are an informal caregiver in the home setting. You provide the majority of care for a person with arthritis and moderate to severe dementia. A total of 40 participants will be recruited for this study. Participation will require 3 hours and 55 minutes of your time over 4 weeks. You will be asked to complete four study visits.

II. Procedures:

If you decide to take part in the study, you will be asked to complete a study visit. The visit will take place in your home. The study visit will last up to 30 minutes. You will fill out three questionnaires. The questionnaires are about pain and your loved one's behaviors.

You will then receive education about pain and pain management and will be trained to use a scale to assess pain. This training will be given in two sessions over two weeks. The first session lasts about one hour. The second session will last about 40 minutes.

You will then be asked to keep a daily log for two weeks. The log is a place to write about your loved one's pain status. You can also list anything you do to relieve your loved one's pain. This will require about five minutes of your time each day for two weeks. After the first week, you will receive a telephone call to complete one questionnaire about your loved one's behaviors.
This will take about five minutes of your time.

At the end of the two weeks, you will be asked to complete another study visit. You will fill out three questionnaires. The questionnaires are about pain and your loved one's behaviors. You will also complete a questionnaire about the pain education you received. This will require about 30 minutes of your time.

III. Risks:

There is the possibility that participation in this study may cause you to become tired or distressed. If you or your loved one with dementia becomes too tired or distressed, participation will be stopped. You can restart at a later time, if you choose to continue. If the distress does not subside, you can contact your primary care physician. If you do not have a primary care physician, you can contact a community health center.An example list can be provided. Georgia State University, Emory University,and Emory Healthcare will not be responsible for any treatment costs incurred.

IV. Benefits:

Participation in this study may not benefit you personally. Overall, we hope to gain information about the educational sessions about managing pain and if caregivers can use the pain questions to help manage their loved ones pain.

V. Compensation:

You will receive a $10.00 Target gift card for participating in the study. You will be collecting data for 2 weeks in a daily log. If you drop out, you will receive a $5.00 Target gift card for completing the first week. You will receive another $5.00 Target gift card for completing the second week.

VI. Voluntary Participation and Withdrawal:

Participation in research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. Whatever you decide, you and your loved one will not lose any benefits to which you are otherwise entitled.

VII. Confidentiality:

We will keep your records private to the extent allowed by law. Dr. Patricia Clark and Rebecca Morgan will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP)). We will use number rather than your name on study records. The information you provide will be stored in a locked cabinet in the office of the student principal investigator. Data will be kept in a password and firewall protected computer. The participant key will be kept in a locked cabinet and will be shredded at the end of the study. All questionnaires will be kept in a separate locked cabinet from

participant information. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VIII. Contact Persons:

Contact Dr. Clark at pclark@gsu.edu (404-550-9851) or Rebecca Morgan at rmorgan18@student.gsu.edu (678-873-0499) if you have questions, concerns, or complaints about this study. You can also call if you think you have been harmed by the study. Call Susan Vogtner in the Georgia State University Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu if you want to talk to someone who is not part of the study team. You can talk about questions, concerns, offer input, obtain information, or suggestions about the study. You can also call Susan Vogtner if you have questions or concerns about your rights in this study.

IX. Copy of Consent Form to Participant:

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, please sign below.

Printed Name of Participant/Caregiver	Date
Signature of Participant/Caregiver	Date
Principal Investigator or Researcher Obtaining Consent	Date

Informed Consent

Title: Caregiver's Pain Recognition in Older Adults with Chronic Pain and Dementia Principal

Investigator: Dr. Patricia Clark

Student Principal Investigator: Rebecca Morgan MSN, doctoral student

Committee Member/Adviser: Dr. Janet Cellar

Funding Source: Kaiser Doctoral Student Award Fund

I. Purpose:

You are invited to participate in a research study. The purpose of the study is to investigate a way to help caregivers' manage pain in their loved one that has dementia and arthritis. You are being asked to be in this study because you have dementia and arthritis. You are also being asked because you have someone helping take care of you at home. A total of 40 participants will be recruited for this study.

II. Procedures:

If you decide that you want to be in the study, you will continue to do your regular activities during the day. You will not be asked to do anything for this study. The way your pain is managed by the person that takes care of you may change over two weeks.

Your caregiver will be asked to complete a study visit. The visit will take place in your home. The study visit will last up to 30 minutes. Your caregiver will fill out three questionnaires. The questionnaires are about pain and your behaviors.

Your caregiver will receive the PASS intervention. Your caregiver will receive education about pain and pain management and will be trained to use a scale to assess pain. This training will be given in two sessions over two weeks. The first session lasts about one hour. The second session will last about 40 minutes.

Your caregiver will then be asked to keep a daily log for two weeks. The log is a place for your caregiver to write your pain status. Your caregiver can also list anything that is done to relieve your pain. This will require about five minutes of your caregiver's time each day for two weeks. After the first week, your caregiver will receive a telephone call to complete one questionnaire about your behaviors. This will take about five minutes of your caregiver's time.

At the end of the two weeks, your caregiver groups will be asked to complete another study visit. Your caregiver will fill out three questionnaires. The questionnaires are about pain and your behaviors. Your caregivers will also complete a questionnaire about the pain education they received. This will require about 30 minutes of your caregiver's time.

III. Risks:

There is the possibility that participation in this study may cause you to become tired or distressed. If you or your loved one becomes too tired or distressed, participation will be stopped. You can restart at a later time, if you choose to continue. If the distress does not subside, your caregiver can contact your primary care physician. If you do not have a primary care physician, you can contact a community health center. An example list can be provided. Georgia State University, Emory University, and Emory Healthcare will not be responsible for any treatment costs incurred.

IV. Benefits:

Participation in this study may not benefit you personally. Overall, we hope to gain information about the educational sessions about managing pain and if caregivers can use the pain questions to help manage their loved ones pain.

V. Compensation:

You will not receive any compensation for participating in this study.

VI. Voluntary Participation and Withdrawal:

Participation in research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. Whatever you decide, you and your loved one will not lose any benefits to which you are otherwise entitled.

VII. Confidentiality:

We will keep your records private to the extent allowed by law. Dr. Patricia Clark and Rebecca Morgan will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP)). We will use number rather than your name on study records. The information you provide will be stored in a locked cabinet in the office of the student principal investigator. Data will be kept in a password and firewall protected computer. The participant key will be kept in a locked cabinet and will be shredded at the end of the study. All questionnaires will be kept in a separate locked cabinet from participant information. Your name and other facts that might point to you will not

appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VIII. Contact Persons:

Contact Dr. Clark at pclark@gsu.edu (404-550-9851) or Rebecca Morgan at rmorgan18@student.gsu.edu (678-873-0499) if you have questions, concerns, or complaints about this study. You can also call if you think you have been harmed by the study. Call Susan Vogtner in the Georgia State University Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu if you want to talk to someone who is not part of the study team. You can talk about questions, concerns, offer input, obtain information, or suggestions about the study. You can also call Susan Vogtner if you have questions or concerns about your rights in this study.

IX. Copy of Consent Form to Participant:

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, please sign below.

Printed Name of Care Recipient	Date
Printed Name of Care Recipient Legal Representative	Date
Signature of Care Recipient Legal Representative	Date
Principal Investigator or Researcher Obtaining Consent	

Georgia State University
Byrdine F. Lewis School of Nursing and Health Sciences
Assent Script
Title: Caregiver's Pain Recognition in Older Adults with Chronic Pain and Dementia

Principal Investigator: Dr. Patricia Clark

Student Principal Investigator: Rebecca Morgan MSN, doctoral student

Committee Member/ Adviser: Dr. Janet Cellar

Hi. I am Rebecca Morgan and I want to tell you about a research study I am doing. The reason I am doing this study is to see if I can help the person that helps care for you manage your pain.

You are being asked to be in this study because you have dementia and arthritis. You are also being asked because you have someone helping take care of you at home.

If you decide that you want to be in the study, you will continue to do your regular activities during the day. You will not be asked to do anything for this study. The way your pain is managed by the person that takes care of you may change over two weeks.

During the study if you become tired or distressed, you can stop being in the study. You can restart at a later time, if you want to. Taking part in this study may not benefit you personally. Overall, I hope to gain information about the educational sessions about managing pain that I present to the person that helps care for you. I also want to see if the person that helps care for you can use pain questions to help manage your pain.

You do not have to be in this study if you do not want to. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may stop at any time. Whatever you decide, you and your loved one will not lose any benefits to which you are entitled.
All information that I receive from you and the person that helps care for you is confidential.
Name of Care Recipient_____
Care Recipient's Voluntary Response to Participate Yes_____ No_____

_____ _____
Principal Investigator or Researcher Obtaining Assent Date

GSU APPROVED
IRB NUMBER: H16337
IRB APPROVAL DATE: 02/17/2016
IRB EXPIRATION DATE: 02/16/2017

APPENDIX D

Recruitment Materials

The purpose of this study is to pilot an informal caregiver pain management intervention (consisting of providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale) when caring for older adults with dementia and arthritis.

Looking for a total of 20 caregivers and their care recipients:

Informal Caregivers :

- **Read, write, speak English**
- **Live with care recipient**
- **Do not receive pay for caregiving**
- **No memory concerns**
- **No major illness or psychiatric illness**

Care Recipients:

- **Moderate/severe Alzheimer's or other form of dementia**
- **Arthritis (any form) with no other life-limiting illness (i.e. cancer)**
- **No history of severe psychological disorders (i.e. Schizophrenia)**
- **Score 19 or less MMSE or 17 or less on MoCA**

Caregivers will have 4 study visits over 4 weeks. This takes place in your home. The study will require 3 hours and 55 minutes of your time. You will receive education about pain and pain management and will be trained to use a scale to assess pain. You will complete a daily log for two weeks and complete questionnaires.

Care recipients will not be asked to do anything for this study. The way their pain is managed by the person that takes care of you may change over two weeks.

If you are interested and want to be contacted:
Name: _____
Phone number: _____
If you have questions contact:
Rebecca Morgan RN MSN, 678-873-0499, rmorgan18@student.gsu.edu
For those interested in participating:

- Please let them know I will be contacting them.
- Give them their own copy of the flyer to take home with them.
- Write the potential participants most recent MMSE or MoCA score on the back of their personal copy of the flyer **only.** They will need this information for eligibility screening if interested in participating in the study.

Script for Cold Calls

Hi, I am Rebecca Morgan and I am a Registered Nurse. I am also a doctoral student at Georgia State University and I am conducting a research study. The purpose of the study is to investigate a way to help caregivers' manage pain in their loved one that has dementia and arthritis. I received your contact information from (state one of the following) **Emory's Alzheimer's Disease Research Center** or **Emory's Memory Clinic Flyer**.

A total of 20 participant caregivers and 20 participant care recipients will be recruited for this study.

I am seeking caregivers that:

- Self-identify as providing the majority of care to the older adult with dementia in the home setting
- Currently live with the care recipient
- Are able to write, read, and speak English
- Do not receive pay for providing care to the care recipient
- Do not self-identify as having a major illness or psychiatric illness that would affect their ability to participate in the intervention
- Does not have any concern about their memory

I am seeking care recipients that:

- Self-identify or caregivers report a diagnosis of Alzheimer's or other form of dementia
- Self-identify or caregivers report a diagnosis of any form of arthritis
- Do not have a history of severe psychological disorders (i.e. Schizophrenia)
- Does not self-identify and/or caregiver reports other life-limiting painful illnesses (i.e. bone cancer).
- Score 19 or less MMSE or 17 or less on MoCA

If you decide you would like to participate, Caregivers will have 4 study visits over 4 weeks. This takes place in your home. The study will require 3 hours and 55 minutes of your time. You will receive education about pain and pain management and will be trained to use a scale to assess pain. You will complete a daily log for two weeks and complete questionnaires.

Care recipients will not be asked to do anything for this study. The way their pain is managed by the person that takes care of you may change over two weeks.

If you are interested, I would love to schedule a visit with you.

Screening Form

Date_____

Informal Caregiver

- O Self-identify as providing the majority of care to the older adult with dementia in the home setting
- O Currently live with the care recipient
- O Are able to write, read, and speak English
- O Score less than 16 on the Center for Epidemiologic Studies Depression Scale (CES-D)
- O Do not receive pay for providing care to the care recipient
- O Do not self-identify as having a major illness or psychiatric illness that would affect their ability to participate in the intervention
- O Does not have any concern about their memory

Care Recipient

- O Self-identify or caregivers report a diagnosis of Alzheimer's or other form of dementia
- O Self-identify or caregivers report a diagnosis of any form of arthritis
- O Score 19 or less on the Mini-Mental State Exam (MMSE) or score 17 or less on the Montreal Cognitive Assessment (MoCA)
- O Do not have a history of severe psychological disorders (i.e. Schizophrenia)
- O Does not self-identify and/or caregiver reports other life-limiting painful illnesses (i.e. bone cancer).

** If criterion is not met, circle the reason for exclusion and place in the exclusion file.

APPENDIX E

PASS Intervention

PASS Intervention Outline

The PASS intervention has four components and will be given in two sessions. The first session will be one hour and the second session will be 40 minutes. The PASS intervention involves providing the informal caregiver education about pain and pain management strategies and training in using a systematic pain assessment tool in assessing their care recipient's pain. The PASS intervention's four components are: 1) education about pain, 2) use of a structured pain scale tool to assess care recipient's pain, 3) strategies to use in managing arthritis pain, 4) safeguards in pain management. The first two components will be administered during the first one hour session and the second two components will be administered during the second 40 minute session. The PASS intervention will be delivered by a doctoral SPI, which is a master prepared registered nurse.

I. General Pain Education
   a. What is pain
   b. What is Arthritis pain
   c. Causes of pain
   d. Common pain behaviors
   e. Consequences of unmanaged pain
   f. Pain and dementia

II. PAINDAD Scale
   a. Overview of PAINAD Scale
   b. Video implementing PAINAD scale
      i. How to Try This: Pain Assessment in Older Adults (Hartford Institute for Geriatric Nursing, 2012)
      ii. http://consultgerirn.org/resources/media/?vid_id=4669429#player_container
         1. Watch video from 15:43 to 36:41
   c. Guided practice using the PAINAD scale

III. Pain Management Strategies
   a. When pain management strategies should be implemented
   b. Common non-pharmacological interventions
      i. Description and instructions
   c. Pain medications for Arthritis (tailored for care recipients medications)
      i. Prescription versus over the counter
      ii. Review of current medications and over the counter medication specific to care recipient

IV. Safeguards
    a. When to call your primary physician
        i. Persistent pain and/or fever with pain
        ii. Before taking any over the counter medication
        iii. Review of pain medications and recommendations per their PCP on prescribed medications for care recipient pain.

PASS

Providing education about pain and Pain management strategies as well as training in pain Assessment using a Structured Scale

The PASS intervention has four components and will be given in two sessions. The first session will be one hour and the second session will be 40 minutes. The PASS intervention involves providing the informal caregiver education about pain and pain management strategies and training in using a systematic pain assessment tool in assessing their care recipient's pain. The PASS intervention's four components are: 1) education about pain, 2) use of a structured pain scale tool to assess care recipient's pain, 3) strategies to use in managing arthritis pain, 4) safeguards in pain management. The first two components will be administered during the first one hour session and the second two components will be administered during the second 40 minute session. The PASS intervention will be delivered by a doctoral Student Principle Investigator (SPI), which is a master prepared registered nurse. The SPI will follow an outline for each session and use it as checklist.

Interventionist: I am Rebecca Morgan a Registered Nurse and doctoral student at Georgia State University. I have the pleasure of delivering the PASS intervention to you today. The purpose of the study is to investigate a way to help caregivers' manage pain in their loved one that has dementia and arthritis. You will receive education about pain and ways to manage pain. You will also be shown how to use a pain scale. You are invited to take part because you are a family member or caregiver caring for your loved one in the home. As a caregiver, you provide the majority of care for a person with arthritis and moderate to severe dementia.

Interventionist: The PASS intervention has four parts and will be given in two sessions. The first two parts will be covered during the first one hour session and the second two parts will be administered during the second 40 minute session. The following is an outline of the information that will be covered with you. (Read outline to informal caregiver)

Pass Intervention Outline

V. General Pain Education
   a. What is pain
   b. What is Arthritis pain
   c. Causes of pain
   d. Common pain behaviors
   e. Consequences of unmanaged pain
   f. Pain and dementia

VI. PAINDAD Scale
   a. Overview of PAINAD Scale
   b. Video implementing PAINAD scale
      i. How to Try This: Pain Assessment in Older Adults (Hartford Institute for Geriatric Nursing, 2012)
      ii. http://consultgerirn.org/resources/media/?vid_id=4669429#player_container
         1. Watch video from 15:43 to 36:41
   c. Guided practice using the PAINAD scale

VII. Pain Management Strategies
   a. When pain management strategies should be implemented
   b. Common non-pharmacological interventions
      i. Description and instructions
   c. Pain medications for Arthritis (tailored for care recipients medications)
      i. Prescription versus over the counter
      ii. Review of current medications and over the counter medication specific to care recipient

VIII. Safeguards
    a. When to call your primary physician
        i. Persistent pain and/or fever with pain
        ii. Before taking any over the counter medication
        iii. Review of pain medications and recommendations per their PCP on prescribed medications for care recipient pain.

Component I: General Pain Education

(20 Minutes)

Interventionist: This is the first part of the PASS intervention. (Go over definition of pain and clinical definition with informal caregiver)

A. What is pain?

- Pain is "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (IASP, 2015). That is, it is symptom that lets us know something is going on in our bodies.
- Pain is subjective. Pain is what the person in pain states or expresses (APS, 2011).
- Pain is a subjective, emotional, sensory, and cognitive event involving thoughts, feelings, and sensations (Craig, 2009).
- Many factors (i.e. genetic, environmental, and psychological) may influence a person's painful experience making self-report the gold standard for pain assessment (Craig, 2009).
- Caregivers of adults with dementia and arthritis have barriers that impede pain identification due to the fact that their loved one may not be able to verbally communicate their pain.
- Pain is difficult to identify in people that are unable to communicate.
- In the older adult population, pain is often times undertreated and underreported (APS, 2011).

Interventionist: Pain can be difficult to identify in those that cannot communicate. Your loved one may not be able to tell you that they are hurting. When someone is unable to tell you they are hurting, you may have to observe other behaviors or emotions that can appear when someone is hurting.

Interventionist: Your care loved one has a form of Arthritis. (Read information below)

B. What is Arthritis Pain?

a. About 50% of older adults are living with arthritis (CDC, 2010).
b. There are 100 different forms of Arthritis. (Arthritis Foundation, n.d.).
c. Arthritis is a disease that causes joint pain (Arthritis Foundation, n.d).
d. Arthritis pain can be very painful (Arthritis Foundation, n.d.).
e. The pain is often times chronic. Chronic pain is pain that lasts longer than 6 months (Arthritis Foundation, n.d.).
f. Arthritis pain can affect a person's ability to get ready for the day and walk (Arthritis Foundation, n.d.).
g. Common Arthritis Symptoms (Arthritis Foundation, n.d.)
    i. Swelling of the joint, pain, stiffness, and decreased range of motion

Interventionist: Because your loved one has some form of Arthritis, they may be more likely to have pain. There can also be other causes of pain. (Read causes of pain)

C. Causes of Pain

- Pain can be caused by an injury, disease process (arthritis), or have an unknown origin (Craig, 2009).

Interventionist: Because your care recipient may not be able to tell you that he or she is having pain, you may have look for other signs of pain. I am going to review some common signs or behaviors that may appear if pain is present. (Read Common Pain Behaviors)

D. Common Pain Behaviors

a. There are common ways that pain may affect a person.

- Some behaviors that may indicate pain are:
  - Depression
  - Insomnia (difficulty sleeping)
  - Anxiety (worry)
  - Immobility (not able to move)
  - Decreased general activity
  - Mood disturbances (mood changes from normal such as more angry or sad)
  - Inability to concentrate
  - Alterations in social function (not interacting with you, friends, and other family members)
  - Decreased overall enjoyment of life
  - Anger
  - Restlessness (unable to be get comfortable)
  - Repetitive behaviors (doing something over and over)
  - Being uncooperative
  - Refusing care
  - Changes in appetite (not eating as much)

- Aggressive behaviors (hitting or yelling)
- Wandering
- Rapid breathing (breathing faster than normal)
- Crying
- Moaning
- Rigidity (being stiff)
- Repeating words
- Grimacing

(APS, 2011, Family Caregiver Alliance, 2012; Eritz & Hadjistavropoulos, 2011; Fruchs-Lacelle & Hadjistavropoulos, 2004; Brown et al., 2011, Warden et al., 2003).

Interventionist: When pain goes unmanaged it can affect your loved one. (Read consequences of unmanaged pain)

E. Consequences of Unmanaged Pain

- The presence of chronic pain can affect a person's health status and quality of life (APS, 2011).
- When chronic pain is unmanaged it can lead to depression, insomnia (trouble sleeping), anxiety (worry), immobility (not able to move), decreased general activity (not able to perform usual activities or not able to move around as much as usual), mood disturbances (mood changes from normal such as more angry or sad), inability to concentrate, alterations in social function (not interacting with you, friends, and other family members), a decreased overall enjoyment of life (not happy), and being unnecessarily uncomfortable (APS, 2011; Brown et al., 2011)
- Decreased activity (not moving) can lead to pneumonia, skin issues, or blood clots (APS, 2011).

Interventionist: Pain that goes untreated can cause your loved one to have changes from their normal behavior. When a person is in severe pain and is unable to move the person in severe pain can develop pneumonia. There may be fluid that develops in the lungs that is not removed by deep breathing. This can cause pneumonia. When a person does not move or change positions, it also puts pressure on the skin and that can cause sores on the skin. When a person does not move the blood does not move through the body as well. This can cause it to settle in one place and can cause a clot.

Interventionist: People with dementia are able to feel pain even when they can't tell you about it. (Read Pain and Dementia)

F. Pain and Dementia

- Pain can still be present even if a person cannot verbally communicate (talk about) their pain (APS, 2011).
- Pain symptoms that persons with dementia may exhibit can be unrecognized or misinterpreted.
- Behaviors common to Alzheimer's or dementia such as anger, restlessness (not able to be still), repetitive behaviors (doing something over and over again), being uncooperative, refusing care, changes in appetite (not eating as much as usual), aggressive behaviors (hitting or yelling), and wandering can also be common pain related behaviors (Family Caregiver Alliance, 2012; Eritz & Hadjistavropoulos, 2011; Fruchs-Lacelle & Hadjistavropoulos, 2004).

Interventionist: Do you have any questions about what we have just talked about? (Ask the caregiver if they need a short break)

Interventionist: At this point I am going to teach you about a scale you can use to help you in identifying pain in your loved one. The scale is called PAINAD. (Read Overview of PAINAD scale)

Component II: PAINDAD Scale

(40 Minutes)

A. Overview of PAINAD Scale

- The systematic (step by step) pain assessment tool. PAINAD stands for Pain Assessment in Advanced Dementia Scale.
- The PAINAD should be used in morning during regular caregiving activities (when you are getting your loved one ready for the day), whenever pain is suspected (when you see some behaviors that may appear with pain), or one hour after doing something to decrease your loves one's pain.
- The items or sections of the scale are titled breathing (watch your loved one breath), negative vocalization (listen to what your loved one says or noises that he or she is making such as moaning), facial expression (watch your loved one's facial expressions and see if he or she is smiling or grimacing), body language (watch your loved one to see if he or she is relaxed or stiff), and consolability (you see if your loved one is able to be comforted by touch or your voice). These are the names of each section. (So there are 5 sections to give a score)
- The caregiver rates each item or section by observing their loved ones behaviors.
- The total scores range from zero to ten, where higher numbers indicate higher pain severity. (the higher the number the more pain the care recipient is in)

- Interpretation of the scores has been compared to the numerical pain scale, where zero is no pain, one to three is mild pain, four to six is moderate pain, and seven to ten is severe pain (Mosele et al., 2012; Warden et al., 2003; Costardi et al., 2007).

Interventionist: If you rate each of the five sections from zero to ten and then add all the sections together, you will get a score. If the score is zero there is no pain suspected. If the score is one to three, mild pain is suspected. If the score is four to six, moderate pain is suspected. If the score is seven to ten, severe pain is suspected. Let's look at the scale together. You can see the five sections and a description about what to look for while getting your loved one ready for the day. (Read the PAINAD Scale)

Pain Assessment in Advanced Dementia (PAINAD) Scale	**Score**
Breathing independent of Vocalization 0=Normal (effortless, quiet breathing) 1=Occasional labored breathing (harsh or difficult breathing) short periods of hyperventilation (breathing fast) 2=Noisy labored breathing (loud, wheezing, strenuous breathing) long period of hyperventilation (breathing fast) cheyne-Stokes respirations (deep to shallow breathing with periods of apnea: breathing stops briefly)	
Negative vocalization 0=None (pleasant) 1=Occasional moan or groan low level speech with a negative or disapproving quality (muttering, mumbling, whining, grumbling, swearing, sarcastic tone) 2=Repeated troubled calling out (words or phrases used over and over in a tone suggesting anxiety, uneasiness, or distress) loud moaning or groaning (mournful or murmuring sounds, wails) crying	
Facial expression 0=Smiling or inexpressive 1=Sad, frightened, frown 2= Facial grimacing	
Body language 0=Relaxed 1=Tense, distressed pacing, fidgeting. 2=Rigid (stiff), fists clenched, knees pulled up, pulling or pushing away, striking out	
Consolability 0=No need to console 1=Distracted or reassured by voice or touch 2=Unable to console, distract or reassure	
TOTAL SCORE (add all scores together to a total score)	

Interventionist: If the score is zero there is no pain suspected. If the score is one to three, mild pain is suspected. If the score is four to six, moderate pain is suspected. If the score is seven to ten, severe pain is suspected.

Interventionist: We are now going to watch a video. This video describes the PAINAD and then shows you how to use the scale. I am going to give you two copies of the PAINAD Scale to refer to as we watch a video. In the video there are two different people being assisted in getting ready for the day. I will pause the video after each person is finished being assisted in getting ready for the day. You can then complete the PAINAD scale after watching the people on the video. This will give you some practice in using the scale. After you complete the scale we will resume the video where the results are discussed on the video. (Play video on lap top. Give two copies of PAINAD to caregiver on a clipboard along with a pencil)

B. Video implementing PAINAD scale
    i. How to Try This: Pain Assessment in Older Adults (Hartford Institute for Geriatric Nursing, 2012)
    ii. http://consultgerirn.org/resources/media/?vid_id=4669429#player_container
        1. Watch video from 15:43 to 36:41

C. Guided practice using the PAINAD scale (Have the caregiver complete the PAINAD twice during the video using the patients displayed on the video)

Interventionist: Do you have any questions about what we have talked about? This is the end of first session. (Confirm second session appointment)

Interventionist: This is the second and last session of the PASS intervention. Last time you learned about pain and how to identify pain in your loved one. Today we are going to discuss what to do if your loved one has pain. (Read Pain management Strategies)

Component III: Pain Management Strategies

(20 Minutes)

A. When pain management strategies should be implemented
    - When pain is present and first begins.

B. Common non-pharmacological interventions
    a. There are some things you can try to help pain in addition to medicines
    - Description and instructions
        - Relaxation: Relaxation is an activity that assists in managing pain, reduces stress, and reduces tension.
            - If your loved one can follow simple commands: have he or she close his or her eyes and concentrate on slow deep breathing.
            - Make a relaxing environment by decreasing the noise level, reducing harsh lighting, and minimizing strong odors.
        - Positioning: Change your loved one's position to reduce pressure. Another thing you can try is to use pillows to reduce pressure or elevate painful extremities.

- Distraction: Distraction can assist with managing pain.
  - Give your loved one a simple and enjoyable task to complete or turn on a favorite movie or television show.
- Music: listening to music can soothe, relax and assist in managing pain.
  - Play your loved one's favorite music.
  - Play soothing sounds such as white noise, rain, or sounds of the ocean.

Interventionist: (Give the caregiver a copy of the descriptions of non-pharmacological methods discussed.) Your loved one may have medications for pain. (Read Pain medications for pain)

C. Pain medications for Arthritis (tailored for care recipients medications)

- Prescription versus over the counter
  - Prescription medications are medications that must be ordered by your health care provider to obtain.
  - Over the counter medications are medications that do not require an order from a healthcare provider and can be obtained at a local store such as Ibuprophen (Advil or Motrin) or Naproxen sodium (Aleve).

Interventionist: I have taken the list of medications you gave to me and placed the pain medications your loved one is taking on a chart. (Read over pain medications)

- Review of current medications and over the counter medication specific to care recipient
    - List of all current pain medications that the care recipient is taking for pain:

Medication	Dose/Route/Time

Interventionist: You should treat your loved ones pain when pain is present. You can use any non-medication pain control activity (as we discussed earlier) to treat your loved ones pain. These activities can be used alone or with a medication. You can also use more than one activity such as playing music and repositioning. You can also use an over the counter medication such as Tylenol or Aleve. You should only give an over the counter medication to your loved one after your loved one's primary care physician has approved it. (Review other medications taken for pain specific to care recipient. Discuss any that are PRN and any given for moderate to severe pain such as an opioid. Also review and discuss any regular scheduled medication that the care recipient is taking that is an NSAID or has Tylenol in it. The care recipient may need to avoid other over the counter medications.)

Once anything (non-medication or medication) is given for pain to your loved one, you will need to repeat using the scale to see if it worked. This should be done an hour after you did anything to help your loved one's pain. Do you have any questions about what we have just discussed?

Component IV: Safeguards

(20 Minutes)

Interventionist: Let's discuss safety. (Read below)

A. When to call your primary physician

- Persistent pain and/or fever with pain
- Before taking any new over the counter medication that your primary physician is unaware.
- Your loved one should never take more medication than what is prescribed or recommended by your loved one's physician.

Interventionist: I have placed your care recipient's pain medications on a chart. Here you will find common side effects (drowsiness) and recommendations (take it with food or for severe pain) about your care recipients pain medications. (Read and review medications)

B. Review of pain medications and recommendations.

- List of Pain Medications for Care Recipients:

Medication	Dose/Route	Recommendations/common side effects

Interventionist: This concludes the PASS intervention. Do you have any questions about anything we have discussed? I appreciate your time and willingness to participate.

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APPENDIX F

Instruments

Revised Memory Behavior Checklist (RMBPC)

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened. Use the following scale for your reaction. Please read he description of the ratings carefully.

Has it occurred in the past week:

0=No
1 = Yes

Reaction Ratings:

0= not at all
1= a little
2= moderately
3= very much
4= extremely

Please answer all the questions for frequency and reaction.

Problem	**Has it occurred?** (in the past week)		**Reaction** (how much did it bother you)
1. Asking the same question over and over	NO	YES	
2. Trouble remembering recent events (i.E. items in newspaper or TV)	NO	YES	
3. Trouble remembering significant past events	NO	YES	
4. Losing or misplacing things	NO	YES	
5. Forgetting what day it is	NO	YES	
6. Starting, but not finishing, things	NO	YES	
7. Difficulty concentrating on tasks	NO	YES	
8. Destroying property	NO	YES	
9. Doing things that embarrass you	NO	YES	
10. Waking you or other family members up at night	NO	YES	
11. Talking loudly and rapidly	NO	YES	
12. Appears anxious and worried	NO	YES	
13. Engaging in behavior that is potentially dangerous to self or others	NO	YES	
14. Threats to hurt oneself	NO	YES	
15. Threats to hurt others	NO	YES	
16. Aggressive to others verbally	NO	YES	
17. Aggressive sad or depressed	NO	YES	
18. Expressing feelings of hopelessness or sadness about the future	NO	YES	
19. Crying and tearfulness	NO	YES	
20. Commenting about death of self and others	NO	YES	
21. Talking about feeling worthless or being a burden to others	NO	YES	
22. Comments about feeling worthless or being a burden to others	NO	YES	
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	NO	YES	
24. Arguing, irritability, and/or complaining	NO	YES	
Total			

Perceived Competence Scale (PCS)

1	2	3	4	5	6	7
Not at all true			Somewhat true			Very true

	Item	**Score**
1.	I feel confident in my ability to my care recipient's pain.	
2.	I am capable of handling my care recipient's pain now.	
3.	I am able to do my care recipient's pain management care now.	
4.	I feel able to meet the challenge of controlling my care recipient's pain.	
	Total	

Pain Beliefs Questionnaire (PBQ)

1 2 3 4 5 6
Never Always

Item (score each item using the scale above)	Score
1. Pain is a result of damage to the tissues of the body	
2. Physical exercise makes pain worse	
3. It is impossible to do much for oneself to relieve pain	
4. Being anxious makes pain worse	
5. Experiencing pain is a sign that something is wrong with the body	
6. When relaxed, pain is easier to cope with	
7. Being in pain prevents you from enjoying hobbies and social activities	
8. The amount of pain is related to the amount of damage	
9. Thinking about pain makes it worse	
10. It is impossible to control pain on your own	
11. Pain is a sign of illness	
12. Feeling depressed makes pain worse	
Total	

Additional questions	Score
1. People with dementia do not feel pain	

Center for Epidemiological Studies Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you've felt this way during the **past week**. Respond to all items.

Place a check mark (√) in the appropriate column. **During the past week….**	**Rarely or none of the time (less than 1 day)**	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of the day (3-4 days)**	**All the time (5-7 days)**
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family.				
4. I felt that I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				

Participant Exit Interview

Instructions to Caregivers: I am going to ask you some questions about your experience during this study. The answers to these questions will help me in understanding your satisfaction with this intervention for learning about how to manage your loved one's pain. Please be as honest as possible. There is no right or wrong answers.

1. Do you feel more comfortable identifying pain in your loved one?
   - O Definitely yes
   - O Maybe yes
   - O Not sure
   - O Maybe not
   - O Definitely no

2. Do you feel more comfortable managing your loved one's pain?
   - O Definitely yes
   - O Maybe yes
   - O Not sure
   - O Maybe not
   - O Definitely no

3. Did you see a difference in your loved one's pain symptoms since the beginning of the study?
   - O Definitely yes
   - O Maybe yes
   - O Not sure
   - O Maybe not
   - O Definitely no

   Please explain

   _____
   _____
   _____
   _____
   _____

4. Since the beginning of the study are you using more ways to manage your loved one's pain?
   - O Definitely yes
   - O Maybe yes
   - O Not sure
   - O Maybe not
   - O Definitely no

   Please give examples of new ways you try to manage your loved ones pain.

   _____
   _____
   _____
   _____
   _____
   _____

5. How easy or difficult was it to use the scale to identify pain in your loved one?
   - O Very difficult
   - O Somewhat difficult
   - O Somewhat easy
   - O Very easy

6. If you could go back, would you participate in this study again?
   - O Yes
   - O No

7. Would you recommend this intervention to others?
   - O Definitely yes
   - O Maybe yes
   - O Not sure
   - O Maybe not
   - O Definitely no

8. What was the most challenging part of the intervention and why?

_____
_____
_____
_____
_____
_____

9. What was the best part of the intervention and why?

_____
_____
_____
_____
_____
_____

10. Do you have any suggestions for how to improve this intervention?

_____
_____
_____
_____
_____
_____

1. Age_____
2. Gender:
    - O Male
    - O Female
3. Ethnic group:
    - O White (Caucasian)
    - O Black/African American
    - O Hispanic/Latino
    - O Asian
    - O Other. Please specify_____
4. Marital Status:
    - O Married
    - O Single
    - O Widowed
    - O Divorced
5. Relationship to care recipient:
    - O Child of care recipient
    - O Sibling of care recipient
    - O Spouse of care recipient
    - O Friend of care recipient
    - O Other. Please specify_____
6. Last grade completed in school:
    - O 8^{th} grade or less
    - O Some high school
    - O Graduated high school
    - O Some college
    - O College graduate (undergraduate)
    - O Graduate degree

7. Annual family income:
    - O Under $15,000
    - O $15,000 - $24,999
    - O $25,000 - $49,999
    - O $50,000 - $74,999
    - O $75,000 - $99,999
    - O $100,000 and over
8. Are you currently employed?
    - O Yes
    - O No

    If yes,
    - O Full-time
    - O Part-time
9. On average, how many hours do you spend in caregiving activities (things you do for your loved one that they can't do by themselves) per day?_____

1. Age_____
2. Gender:
    - O Male
    - O Female
3. Ethnic group:
    - O White (Caucasian)
    - O Black/African American
    - O Hispanic/Latino
    - O Asian
    - O Other. Please specify_____
4. Marital Status:
    - O Married
    - O Single
    - O Widowed
    - O Divorced
5. Last grade completed in school:
    - O 8^{th} grade or less
    - O Some high school
    - O Graduated high school
    - O Some college
    - O College graduate (undergraduate)
    - O Graduate degree
6. Functional Status:
    - O Walks independently
    - O Uses a walker/cane
    - O Uses a wheelchair
    - O Other. Please specify_____

7. Medical History:
    - O Diabetes
    - O High blood pressure
    - O Liver disease
    - O Shortness of breath
    - O Heart problems
    - O Asthma
    - O Neurological disorder
    - O Other. Please specify_____
      _____
      _____
      _____
      _____
      _____
      _____
      _____
      _____
      _____
      _____
      _____
8. Please list current medications:
   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____
9. What medications are you currently taking for pain (include all over the counter medications)?
   _____
   _____
   _____
   _____

Please complete BOTH pages at least once a day, one hour after a pain management strategy is given, or if pain is suspected for 14 days.

Pain Assessment in Advanced Dementia (PAINAD) Scale	**Score**
Breathing independent of Vocalization 0=Normal (effortless, quiet breathing) 1=Occasional labored breathing (harsh or difficult breathing) short periods of hyperventilation (breathing fast) 2=Noisy labored breathing (loud, wheezing, strenuous breathing) long period of hyperventilation (breathing fast) cheyne-Stokes respirations (deep to shallow breathing with periods of apnea: breathing stops briefly)	
Negative vocalization 0=None (pleasant) 1=Occasional moan or groan low level speech with a negative or disapproving quality (muttering, mumbling, whining, grumbling, swearing, sarcastic tone) 2=Repeated troubled calling out (words or phrases used over and over in a tone suggesting anxiety, uneasiness, or distress) loud moaning or groaning (mournful or murmuring sounds, wails) crying	
Facial expression 0=Smiling or inexpressive 1=Sad, frightened, frown 2= Facial grimacing	
Body language 0=Relaxed 1=Tense, distressed pacing, fidgeting. 2=Rigid (stiff), fists clenched, knees pulled up, pulling or pushing away, striking out	
Consolability 0=No need to console 1=Distracted or reassured by voice or touch 2=Unable to console, distract or reassure	
TOTAL SCORE (add all scores together to a total score)	

Pain assessment Information

Please color the circle next to any of the following problem behaviors that your care recipient displayed at the time pain was assessed.

- O No problem behaviors
- O Decreased activity
- O Being uncooperative
- O Physical aggression (hitting)
- O Verbal aggression (yelling)
- O Anger
- O Agitation (restless, rocking, shaking, wringing hands)
- O Anxiety
- O Other

If other, please list the behaviors:

_____
_____
_____
_____

Please color the circle next to any of the following problem behaviors that your care recipient displayed at the time pain was assessed.

- O Nothing provided for pain
- O Ibuprophen (Advil or Motrin)
- O Naproxen sodium (Aleve)
- O Distraction
- O Relaxation
- O Repositioning
- O Music
- O Massage
- O Other

If other, please list the pain management strategy:

_____
_____
_____

	Day 1
Please X on an overall pain score for today for your care recipient. **0=no pain 10=severe pain**	0 1 2 3 4 5 6 7 8 9 10
Please color in the circle next to any of the following problem behaviors that your care recipient may have displayed today.	O No problem behaviors O Decreased activity O Being uncooperative O Physical aggression (hitting) O Verbal aggression (yelling) O Anger O Agitation (restless, rocking, shaking, wringing hands) O Anxiety O Other If other, please list the behaviors: _____ _____ _____ _____ _____
Please color in the circle next to any pain management strategies you gave your care recipient today.	O Nothing provided for pain O Ibuprophen (Advil or Motrin) O Naproxen sodium (Aleve) O Distraction O Relaxation O Repositioning O Music O Massage O Other If other, please list the pain management strategy: _____ _____ _____ _____ _____

APPENDIX G

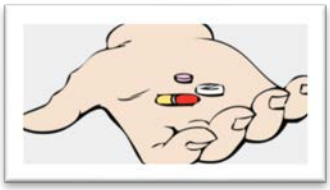
Handouts

Safety Reminders

Call your loved one's doctor

- Persistent pain and/or fever with pain

- Before giving your loved one any medication that their primary physician is unaware.



- Your loved one should never take more medication than what is prescribed or recommended by your loved one's physician.

- Read labels on all medicine because some contain several ingredients such as Tylenol (acetaminophen).

Relief from Pain

- Relaxation: Make a relaxing environment by decreasing the noise level, reducing harsh lighting, and minimizing strong odors.


- Positioning: Change your loved one's position to reduce pressure. Another thing you can try is to use pillows to reduce pressure or elevate painful extremities.



- Distraction: Give your loved one a simple and enjoyable task to complete or turn on a favorite movie or television show.

- Music: Play your loved one's favorite music. Play soothing sounds such as white noise, rain, or sounds of the ocean.

Pain Assessment in Advanced Dementia (PAINAD) Scale	**Score**
Breathing independent of Vocalization 0=Normal (effortless, quiet breathing) 1=Occasional labored breathing (harsh or difficult breathing) short periods of hyperventilation (breathing fast) 2=Noisy labored breathing (loud, wheezing, strenuous breathing) long period of hyperventilation (breathing fast) cheyne-Stokes respirations (deep to shallow breathing with periods of apnea: breathing stops briefly)	
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Body language 0=Relaxed 1=Tense, distressed pacing, fidgeting. 2=Rigid (stiff), fists clenched, knees pulled up, pulling or pushing away, striking out	
Consolability 0=No need to console 1=Distracted or reassured by voice or touch 2=Unable to console, distract or reassure	
TOTAL SCORE (add all scores together to a total score)	

1. Daily Log

2. Pain Scale

No pain  Pain

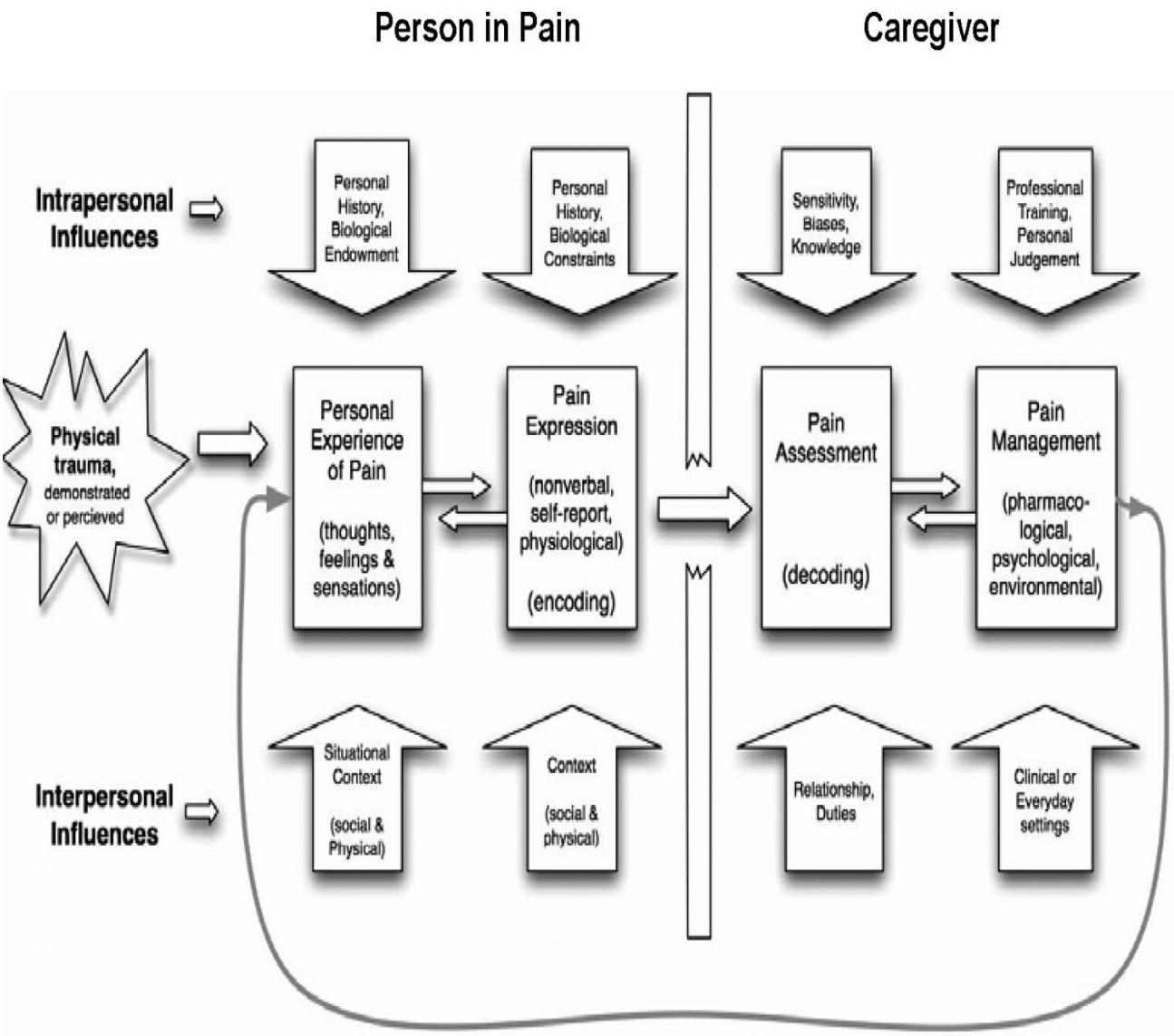
- Use the pain scale in morning when you are getting your loved one ready for the day.
- One hour after you do anything for your loved one's pain.
- When you think your loved one may be hurting.

APPENDIX H

The Social Communication Model of Pain

The Social Communication Model of Pain

(Craig, 2009)



APPENDIX I

PASS Intervention in the Social Communication Model of Pain

PASS Intervention in the Social Communication Model of Pain

(Craig, 2009)