

A QUALITATIVE ANALYSIS OF PAIN MENTAL MODELS
IN SPOUSAL CAREGIVERS OF VETERANS
WITH DEMENTIA AND PAIN

by

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ABSTRACT

Background: Although pain is prevalent among persons with dementia (PWDs), it goes underrecognized and undertreated due to impairments in the cognitive abilities needed to self-report it. Exploring spousal caregivers' pain mental models may provide valuable insight into how these informal caregivers conceptualize pain, and how such conceptualizations affect their identification of and response to PWDs' pain.

Study Objective: The purpose of this study was to identify and describe the pain mental model(s) of spousal caregivers of community-dwelling veterans with dementia and pain.

Research design: Qualitative

Participants and research context: Thirty female spousal caregivers (11 Black, 10 non-Hispanic White, and 9 Hispanic) participating in a psychosocial intervention aimed at preventing aggression in veterans with pain and dementia comprised the present sample. The PWDs all received their primary care from the Veterans Health Administration (VHA).

Methods: Secondary data analysis of intervention recordings. Data was analyzed using thematic analysis.

Results: Two themes were identified: Pain Assessment Beliefs and Knowledge (PA) and Pain Management Beliefs and Knowledge (PM). The PA theme included four subthemes, and the PM theme included seven subthemes. A pain mental model is proposed in which PA and PM affect the ways they answer two PA-related questions (*Is there a problem?*, *Is this problem pain?*) and three PM-related questions (*Is the pain treatable?*, *Is it worth treating?*, *How do I prefer to treat it?*). These caregivers are moved to action when they "connect the dots" by identifying a

problem in PWDs' behavior, labeling the problem as pain, and identifying a response (i.e., a treatment approach) they consider worth trying.

Conclusion: Caregiver disconnects in understanding of PWDs' behavior are common in this study sample, and predictably lead to inaction. The proposed mental model provides further explanation about how caregivers do or do not synthesize and apply pain knowledge and experience, allowing for the identification of potential areas of intervention (e.g., pain psychoeducation) to improve pain treatment for the PWDs under their care.

DEDICATION

This dissertation is in honor of Marty, my indescribably brilliant, hilarious, and dramatic brother. While he passed away after a brave battle with leukemia before I started graduate school, his unconditional love and support allowed me to believe what he always did: That I could achieve anything, even a Ph.D.

LIST OF ABBREVIATIONS AND SYMBOLS

AD	Alzheimer's disease
ADI	Alzheimer's Disease International
ADLs	Activities of Daily Living
BPSD	Behavioral and psychological symptoms of dementia
CAM	Complementary and alternative medicine
CG	Caregiver
CNA	Certified nursing assistant
IADLs	Instrumental Activities of Daily Living
<i>M</i>	Mean
MEDVAMC	Michael E. DeBakey Veterans Affairs Medical Center
OTC	Over-the-counter
PA	Pain Assessment Beliefs and Knowledge
PAVeD	Preventing Aggression in Veterans with Dementia
PM	Pain Management Beliefs and Knowledge
PT	Physical therapy
PWD	Person with dementia
PRN	Pro re nata or "as needed"
RC	Research clinician
<i>SD</i>	Standard deviation
TVAMC	Tuscaloosa Veterans Affairs Medical Center

VHA	Veterans Health Administration
\geq	Greater than or equal to
$<$	Less than
\leq	Less than or equal to

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CONTENTS

ABSTRACT	ii
DEDICATION	iv
LIST OF ABBREVIATIONS AND SYMBOLS	v
ACKNOWLEDGMENTS	vii
LIST OF TABLES	xi
LIST OF FIGURES	xii
INTRODUCTION	1
Background	1
Mental Models	3
Theoretical Models of Dementia Behavior	4
Informal Caregivers' Understanding of Dementia	6
Theoretical Models of Pain	8
Informal Caregivers of PWDs and Pain Management	9
Goals and Research Questions	13
METHODS	15
Participants and Procedures	15
Materials	19
Data Analysis	20
RESULTS	32
Characteristics of Study Participants	32

Main Results	32
A Proposed Mental Model: Results Related to Research Questions	104
DISCUSSION	136
Discussion of Findings	136
Situating Results within Existing Literature	138
Limitations	156
Implications	158
Future Directions for Research	162
Conclusion	163
REFERENCES	164
APPENDICES	179
APPENDIX A: PAVeD Clinician Manual Excerpts	179
APPENDIX B: PAVeD Workbook Excerpts	189
APPENDIX C: IRB Approval Letter	196

LIST OF TABLES

Table 1. Phases of thematic analysis	172
Table 2. Individualized demographic and pain details of participants	173
Table 3. Descriptive characteristics and demographics of participants	176

LIST OF FIGURES

Figure 1. Themes and subthemes	177
Figure 2. Proposed pain mental model of spousal caregivers of PWDs	178

INTRODUCTION

Background

Over 50 million individuals worldwide have dementia (Alzheimer's Disease International (ADI), 2019), and 9.9 million individuals are newly diagnosed annually (ADI, 2015). In 2020, healthcare costs for persons with dementia (hereafter referred to as PWDs) in the United States were estimated to be \$305 billion with \$206 billion of this cost paid by Medicare and Medicaid (Alzheimer's Association, 2020). Global costs of dementia care were around \$1 trillion in 2019 (ADI, 2019). Incidence rates of dementia increase with age (Katz et al., 2012), and, by age 85, 50% of individuals have dementia or other cognitive impairment (Reitz et al., 2011). In 2019, 9% of the world's population or 703 million individuals were aged 65 and over, which included 143 million individuals aged 80 years or older, and the world's population comprised of older adults is expected to double to 1.5 billion in 2050 (United Nations, Department of Economic and Social Affairs, Population Division, 2019). Alzheimer's Disease International (2019) projected that there will be 152 million individuals living with dementia by 2050. As such, effective care and treatment of individuals with dementia is imperative.

Pain is a prevalent problem for PWDs. A systematic review found the prevalence of pain in PWD to be 45.6% to 53.9% with comparable pain rates across different types of dementia (van Kooten et al., 2016). Despite the high prevalence of pain in PWDs, it is well established that pain is underidentified and undertreated in older adults (American Geriatric Society, 2002), especially those with dementia (Li et al., 2015; Malara et al., 2016). The inadequate treatment of pain in older adults is not due to lack of effective pain treatment options for older adults,

insufficient treatment guidelines for pain management professionals (Gibson, 2007), or decreased pain sensitivity in PWDs (Stubbs et al., 2016). Rather, older adults with dementia tend to be less likely to receive adequate pain treatment than older adults without dementia (Monroe et al., 2012), which may be due to the PWDs' compromised abilities to self-report pain, a complex higher-level cognitive skill (Snow & Jacobs, 2014). Ultimately, pain is a common problem for PWDs and effective ways to assure the PWDs' access to adequate pain treatment is a pressing need.

Since the inadequate treatment of pain in older adults is not due to ineffective treatment options, inadequate clinician skills regarding pain management (Gibson, 2007), or decreases in PWDs' pain sensitivity (Stubbs et al., 2016), barriers to adequate pain identification and treatment in PWDs need to be identified. PWDs receive the majority of their care, including pain management, from informal caregivers (e.g. family members) or semiskilled staff (e.g. certified nursing assistants). Ninety-two percent of PWDs in the United States receive care from informal caregivers, providing approximately 18.6 billion hours of unpaid assistance to PWDs in 2019 (Alzheimer's Association, 2020). As such, understanding how informal caregivers understand pain could be an impactful component in identifying barriers to effective pain management for PWDs. One way to improve knowledge of caregivers' understanding of pain is through the examination of the mental models of pain held by these individuals. Once this is accomplished, interventions targeted to dispel caregivers' misunderstandings of the causal process of pain and behavior in PWDs can be developed. The overall purpose of this study was to identify and describe the mental models of pain in a group of caregivers of veterans with dementia who participated in a larger study of pain and aggression.

Mental Models

Mental models are “personally constructed, internal conception[s], of external phenomena [...] that affect how a person acts” (Rook, 2013). Unlike conceptual models, which are scientifically accurate (Greca & Moreira, 2000), mental models are constructed and constrained by individual life experiences (Jones et al., 2011; Rizzo, 2015; Rook, 2013). Thus, mental models may be inaccurate or incomplete as well as dynamic, changing with new life experiences (Greca & Moreira, 2000; Jones et al., 2011). Mental models are invaluable schemas enabling individuals to understand, explain, and make predictions about the external world and various phenomena (Anderson et al., 2005; Greca & Moreira, 2000). As such, mental models influence our actions and decisions (Rizzo, 2015; Rook, 2013). Mental models guide decision-making in all aspects of life (Jones et al., 2011) and are an important component of creative problem solving (Hester et al., 2012).

Previous research has examined the impact of mental models on behavior and decision-making in a range of settings and situations, both health-related and non-health-related. Outside of healthcare, mental models have been used to examine gamblers’ risk perceptions (Spurrier et al., 2015), flash flood risk perceptions and responses (Lazrus et al., 2016), attachment in kindergarten student teachers (Horppu & Ikonen-Varila, 2004), and ethical decision-making (Bagdasarov et al., 2016). Within healthcare, mental models have been studied to understand patient adherence to outpatient physical therapy (PT) home exercise programs (Rizzo, 2015), the actions and care provided by nurse assistants in a residential nursing home (Anderson et al., 2005), and nurses’ administration of opioid medications when treating pain in hospitals (Guest et al., 2017). No research has yet examined the pain mental models of informal caregivers of PWDs.

Theoretical Models of Dementia Behavior

The present study is informed by a number of well-regarded theoretical models of dementia behavior. A conceptual framework for understanding the etiology of distress behavior in PWDs is foundational to this project because behaviors related to pain in PWDs are remarkably similar to behaviors related to a range of other causes and conditions, ranging from overstimulation to depression to constipation (particularly for PWDs with more language difficulty and/or advanced dementia). Specifically, (1) the Direct Impact of Dementia or Biological Model, (2) the Unmet Needs Model, (3) the Behavioral Model, and (4) the Environmental Vulnerability Model are helpful to understanding how to approach pain assessment and treatment in PWDs. These models are complementary and can be interactive (Cohen-Mansfield, 2015).

Direct Impact of Dementia - Biological Model

According to this model, behavioral symptoms are directly caused by neurological changes in the brain. In other words, severe deterioration of brain matter leads to behavioral disinhibition (e.g., being vocally disruptive) (Cohen-Mansfield, 2015). Another example would be if neurological changes in the brain made PWDs unable to communicate their pain and distress in words, causing them to display agitation and irritation as a means of communicating their discomfort (Kar, 2009).

Unmet Needs Model

This model is based on the premise that behavioral symptoms arise when persons with dementia have one or more unmet needs or goals (Algase et al., 1996). These needs can be physical, environmental, emotional, social, as well as internal or external to PWDs (Snow & Jacobs, 2014). Additionally, this model includes four categories of background factors that

explain the uniqueness of each PWD's behavioral symptoms: (1) neurological/cognitive abilities and impairments, (2) physical/affective/functional abilities and impairments, (3) premorbid personality, and (4) premorbid interests and abilities (Algase et al., 1996; Snow & Jacobs, 2014). Behavioral symptoms result from unmet needs in three ways: (1) attempts to meet the unmet need (e.g. pacing), (2) attempts to communicate the unmet need (e.g., repeated vocalizations), or (3) outcomes of having the unmet need (e.g., screaming and agitation due to poorly managed pain) (Cohen-Mansfield, 2015). The unmet needs model provides a useful framework for addressing problematic behaviors (e.g., aggression). If PWDs' aggression is due to the unmet need or goal of having more personal space, caregivers could work to provide the PWDs with more personal space, and, hopefully decrease their expression of aggression (Algase et al., 1996).

Learning/Behavioral Model

According to this model, also known as the ABC model, behavioral symptoms are influenced by their antecedents and consequences (Cohen-Mansfield, 2015). In other words, problematic behaviors have been inadvertently reinforced and/or desirable behaviors have not been reinforced or rewarded. Training caregivers of PWDs who are demonstrating frequent agitation how to use behavioral techniques and identifying the "A" (antecedent or trigger event of the problematic behavior), the "B" (behavior of concern), and the "C" (consequence of the problematic behavior) has been found to be an effective way of reducing the PWDs physical and verbal agitation behaviors (Sato et al., 2013).

Environmental Vulnerability Model

The premise of this model is that as personal competence decreases (as the dementia disease progresses) the external environment becomes a stronger determinant of behavior (Lawton & Simon, 1968). As such, PWDs have a lowered ability to cope with environmental

stimuli. Consequently, PWDs are more likely to perceive relatively minor pressure from their environment as stressful compared to cognitively intact individuals. The implication of the model is that distress behavior can be prevented or attenuated when the stimulation level of the environment is matched to a person's abilities and needs. Essentially, care must be taken to not create an environment that understimulates or overstimulates PWDs (Cohen-Mansfield, 2015).

Informal Caregivers' Understanding of Dementia

Despite the majority of PWDs receiving care from informal caregivers (Alzheimer's Association, 2020), most informal caregivers do not have any special training in how to care for PWDs as their dementia progresses. Moreover, the typical course of dementia involves progressive declines in cognition and overall functioning that increase in severity, leading PWDs to require increasingly greater amounts of care and supervision (Gallagher-Thompson et al., 2020). Thus, it is important to summarize the evidence regarding laypersons' beliefs about dementia, including common misconceptions, in order to better understand the perspective of the informal caregivers.

A literature review that examined familial caregivers' understanding of dementia found that these caregivers often receive little or unclear information about dementia from the PWDs' doctors or other healthcare providers (Stokes et al., 2015). This included both information about the disease itself and information about its progression, and the review concluded that these caregivers often have poor understandings of dementia. A more recent qualitative analysis of 50 familial caregivers of PWDs explored these caregivers' illness representations and found that they primarily attributed the PWDs' dementia to uncontrollable factors (e.g., biology) (Quinn et al., 2017). These caregivers also described significant uncertainty regarding the expected timeline for the progression of PWDs' disease. This may be due to PWDs' healthcare providers

downplaying the severity of the condition and/or avoiding prognosis when delivering the diagnosis. A study examining video recordings of 20 doctors at two memory clinics delivering dementia diagnoses to PWDs and their healthcare appointment companions (family members or friends) found that these providers stressed that the severity was mild and often softened the prognosis, likely to preserve hope (Dooley et al., 2018).

Further evidence that laypersons, including informal caregivers, have a poor understanding of dementia is the high prevalence of the misconception that Alzheimer's Disease and other dementias are a normal part of aging (Lowe et al., 2015; Seo et al., 2015; Werner, 2005). In fact, 2 in 3 people globally think dementia is caused by normal aging, which includes 62% of healthcare practitioners (ADI, 2019). Additionally, a qualitative study of 92 familial caregivers examined these caregivers' explanatory models about the nature and cause of dementia found that most explained the cause of dementia as a mixture of biomedical and folk models (Hinton et al., 2005). Folk models included attributing dementia to normal aging or psychological stress, and ethnic minority (Black, Hispanic, and Asian) caregivers more commonly provided folk explanations for dementia than non-Hispanic White caregivers. The misconception (or folk explanation) that dementia is a normal part of aging may lead informal caregivers to delay seeking treatment. This may actually harm their loved ones with dementia by delaying their access to pharmacological treatments that could slow the progression of their dementia.

Relatedly, another common misconception held by lay people is that dementia is not treatable (Seo et al., 2015). While there are no treatments that can change the course of dementia progression (ADI, 2016), there are pharmacological treatments that can delay the onset of dementia (ADI, 2019). Psychosocial interventions for caregivers of PWDs, such as the parent

study of the present qualitative analysis, can improve the quality of care provided, reduce caregiver burden and depression, and delay PWDs' transitions to long-term care placements (ADI, 2016).

Furthermore, one study found that helpful memory aids, like reminder notes around a home, were believed to cause further disease progression (Lowe et al., 2015). In sum, there is compelling evidence that laypeople (such as informal caregivers) lack knowledge and understanding of dementia as a disease (including the prevalence of pain among PWDs) and struggle to differentiate it from normal aging.

Theoretical Models of Pain

The present study is further informed by the biopsychosocial model. The following is a brief description of this model and evidence supporting its utility in understanding the etiology of pain in persons with and without dementia.

The biopsychosocial model of pain was proposed in 1977 as an alternative to the biomedical model (Engel, 1977). According to this model, health and illness result from the interaction of physiological, psychological, and social-cultural factors within a person and his/her surrounding environment. A large body of evidence supports the importance of psychological factors on pain experience, pain response, and pain treatment (Turk & Okifuji, 2002). For example, pain catastrophizing, defined as exaggerated negative thoughts and feelings about actual or anticipated pain, has been identified as particularly important for pain outcomes (Quartana et al., 2009).

The biopsychosocial model of pain can be contrasted with the biomedical model, a conceptual framework widely accepted since Descartes proposed that the human body functions like a machine in the 17th century (Melzack, 1996). The biomedical model posits that pain is

experienced as the result of physical tissue damage and that the severity of pain equates to the severity of the tissue damage. However, pain in both persons without and persons with dementia frequently persists in the absence of a physical cause or with greater severity than the physical tissue damage suggests. Over 100 million Americans suffer from chronic pain (Institute of Medicine, 2011). For these individuals as well as others suffering from chronic pain worldwide, the source of their pain is not an acute injury, and the biomedical model fails to capture the variability in pain sensitivity, pain intensity, and pain chronicity. Despite overwhelming evidence that the biopsychosocial model of pain better explains the complexities of different pain experiences, the biomedical model is still a predominant conceptual framework in many medical settings.

Informal Caregivers of PWDs and Pain Management

While no studies have yet explored the mental models of pain held by informal caregivers of PWDs (including spousal caregivers), previous research has examined some aspects of caregiver experiences related to PWDs' pain management. Specifically, this research has examined aspects of how PWDs' caregivers assess or identify pain as well as how these caregivers manage or treat their pain. Both pain assessment and pain treatment are critical to effective pain management in PWDs (Tarter et al., 2016).

Pain Assessment

For effective pain management to occur, pain must first be accurately identified (Horgas & Elliott, 2004). The underdetection of pain is the greatest reason for its nontreatment in PWDs (Zwakhalen et al., 2006). Multiple studies have identified "knowing the person" with dementia as an important factor in accurately recognizing when PWDs are experiencing pain (Bullock et al., 2020; Falls et al., 2004). Due to their familiarity with PWDs, including invaluable

knowledge of the PWDs' typical verbal and nonverbal behaviors with and without pain, informal, familial caregivers are uniquely able to identify when PWDs are experiencing pain. As such, multiple studies have found that general practitioners value and utilize informal caregivers' proxy pain reports when assessing pain in PWDs (Bullock et al., 2020; Jennings et al., 2018).

Although caregivers' importance in pain assessment in PWDs has been established, the mechanisms by which caregivers determine their loved ones are in pain are only beginning to be understood. For example, a qualitative investigation of caregivers' pain assessment in PWDs found that these caregivers reported that they "just knew" when PWDs were in pain (Falls et al., 2004, p. 7). Deeper investigation did identify some specific elements, including that caregivers of PWDs utilized behavioral indicators of pain unique to their loved ones' expressions of pain (e.g., facial expression, agitation, and vocalizations). However, the investigators noted that caregivers of PWDs did not tend to use a common set of pain indicators, only the previously mentioned unique indicators (Falls et al., 2004). Other evidence suggests that caregivers of PWDs do not utilize the nonverbal behavior of PWDs when assessing pain of PWDs (Eritz & Hadjistavropoulos, 2011).

Past research has found that caregivers of PWDs report high levels of confidence in their ability to detect pain in their loved ones (Falls et al., 2004; Weiner et al., 1999), and some research does indicate that these caregivers adequately assess PWDs' pain due to moderate concordance between caregivers' proxy report of PWDs' pain intensity and PWDs' self-report of pain intensity (Shega et al., 2004) and a significant positive correlation between caregivers' proxy report of PWDs' pain interference and PWDs' self-report of pain interference (Amspoker et al., 2020). However, caregivers' high levels of confidence in their ability to identify pain in their loved ones may not be fully justified. Weiner et al. (1999) found low levels of concordance

between PWDs' self-reported pain intensity and caregiver proxy reports of PWD pain intensity, despite caregivers reporting high levels of confidence in their ability to detect pain in PWDs. Similarly, Thuné-Boyle et al. (2010) found that caregivers of PWDs felt confident in their ability to recognize pain but did not believe PWDs were in pain, despite PWDs having painful diagnoses (e.g., arthritis, pressure sores). Additionally, caregivers of PWDs do not utilize validated pain assessment tools (Falls et al., 2004). Validated pain assessment tools exist for assessing pain in PWDs (e.g., the pain assessment in advanced dementia scale [PAINAD]) and can be effectively used by laypeople (e.g., informal caregivers) to assess pain in PWDs (Ammaturo et al., 2017). Informal caregivers of PWDs with pain also indicated that uncertainty regarding the etiology of the PWDs' pain is a barrier to effective pain management and may fail to accurately identify pain in PWDs due to lack of training in pain assessment and inconsistent guidance from formal care providers (Tarter et al., 2016).

Pain Treatment

Successful pain management in PWDs also requires that informal caregivers engage in behaviors that promote effective pain treatment. "Knowing the person" with dementia has also been identified as an important factor in providing PWDs with effective pain treatment (Corbett et al., 2016; Falls et al., 2004). Familiarity with PWDs allows caregivers to determine whether the PWDs' pain has changed. In other words, due to their knowledge of the PWDs with and without pain, caregivers can establish whether pain treatment has effectively reduced pain in PWDs and respond accordingly. Furthermore, informal caregivers of PWDs are often responsible for managing PWDs' pain treatments (Bullock et al., 2020).

Families of PWDs prefer that nonpharmacological treatments be utilized first when treating their loved ones' pain (Bullock et al., 2020; Corbett et al., 2016; Martin et al., 2005).

These nondrug treatments include physiotherapy, warmth, massage, and distraction (Bullock et al., 2020). Furthermore, informal caregivers expressed concerns regarding the use of pharmacological treatments for PWDs' pain. Specific concerns expressed by these caregivers include potential side effects of medications, interactions with PWDs' other medications, and increased number of total pills taken by PWDs (Bullock et al., 2020).

Previous research has identified numerous barriers for informal caregivers of PWDs to achieving effective pain management for PWDs. One barrier is caregivers' difficulty communicating with PWDs (Tarter et al., 2016). Caregivers cannot rely on PWDs' self-reports of pain alone and must use other indicators of pain to determine whether pain treatment has been effective. This is true even for PWDs with mild dementia who can verbally self-report pain (Snow et al., 2004). Another barrier is that informal caregivers of PWDs have reported inconsistent guidance from formal care providers in how to treat PWDs' pain (Tarter et al., 2016), and there is evidence that caregivers have limited understanding of pharmacologic pain treatments and pain etiologies, which leads to missed opportunities for effective pain treatment (Gillespie et al., 2014). For example, when caregivers do not understand the etiology of their loved ones' pain, they may reject pharmacological treatments that providers view as necessary (Tarter et al., 2016). Caregivers of PWDs have reported difficulties administering "as needed" or PRN pain medications and concerns with the side effects of pain medication (Martin et al., 2005). Some caregivers may be skeptical of the efficacy of nondrug treatments for pain, including acupuncture and mindfulness (Bullock et al., 2020). The ability of the caregiver to fully understand pain treatment options is critical because effective pain treatment requires a careful risk/benefit analysis of both non-pharmacological and pharmacological treatments. Ultimately, the existing research on the ability of caregivers of PWDs to effectively treat pain in

PWDs indicates that they desire and need more education and resources regarding pharmacological and non-pharmacological treatments of pain in PWDs.

Goals and Research Questions

While some research has examined the experiences with pain management of informal caregivers of PWDs, the author's careful review of the literature has not yielded any studies exploring the mental models of pain used by informal caregivers, including spousal caregivers, of PWDs. Existing literature suggests caregivers of PWDs may be overconfident in their ability to assess pain in PWDs (Thuné-Boyle et al., 2010; Weiner et al., 1999). Additionally, caregivers seem unaware of the schemas that they are utilizing to identify pain in PWDs (Falls et al, 2004). Caregivers may also lack the knowledge and resources necessary to provide PWDs with effective pain treatments (Gillespie et al., 2014; Tarter et al., 2016). As such, research on the mental model(s) of pain of caregivers of PWDs is critical to improving pain management in PWDs.

The purpose of this study was to identify and describe the mental models of pain of spousal caregivers of community-dwelling veterans with dementia and pain. Exploring spousal caregivers' mental models of pain is important as these mental models influence how these informal caregivers conceptualize pain generally and how their conceptualizations of pain affect how they assess and treat pain in PWDs. Furthermore, spousal caregivers' mental models of pain impact how they perceive PWDs' pain behaviors, especially nonverbal pain behaviors, and guide their responses to these behaviors and their own concerns about PWDs' pain and other problems. Existing research on the experiences of informal caregivers with pain management suggests caregivers' mental models of pain may be ineffective due to lack of understanding and/or experience with pain. Exploring spousal caregivers' mental models of pain will allow for

the identification of areas of intervention (e.g., pain psychoeducation for caregivers), leading to better, more effective treatment of PWDs' pain.

METHODS

Participants and Procedures

Overview

This qualitative study uses secondary data from a randomized controlled trial comparing the efficacy of a home-based 8-week psychosocial intervention (Preventing Aggression in Veterans with Dementia [PAVeD]) to enhanced primary care in reducing aggression in persons with dementia and pain (Kunik et al., 2017). The institutional review boards (IRB) of the Baylor College of Medicine and the University of Alabama approved this secondary study. The parent study enrolled 203 dyads consisting of community-dwelling veterans with dementia and their informal caregivers. Of the 203 recruited PWD-caregiver dyads, the PAVeD research team randomized 101 into the PAVeD intervention. Thirty of these 101 dyads comprise the sample for the present research.

For the parent study, the PAVeD research team identified potential participants through (1) a provider referral, (2) an active prescription of a medication for dementia, or (3) a search of the Veterans Health Administration (VHA) outpatient database for persons with a dementia diagnosis. Eligible individuals were aged 60 years and older, had a documented diagnosis of dementia, had mild to moderate dementia, had clinically significant pain (self- or caregiver-report), and had no history of aggression in the past year. Additionally, eligible individuals had to be receiving their primary care treatment from the VHA, dwell within the community (i.e., reside outside of a nursing home or other long-term care facility), and have an English-speaking unpaid caregiver involved with the veteran's care for at least 8 hours per week across two or

more days per week. In order for PWDs to participate, their unpaid caregivers had to agree to co-enroll in the study. Individuals with advanced dementia, with a history of aggression within the past year, and/or lacking clinically significant pain were excluded from the study.

Research staff obtained written informed consent from the veterans and caregivers in person or by mail for the parent study. PWDs and their caregivers provided consent separately, which included consent for the audio recording of the PAVeD treatment sessions to monitor treatment fidelity. When PWDs were unable to understand or remember the content of the informed consent, research staff obtained their assent. After the PAVeD research team completed data collection for the parent study, they obtained a waiver of informed consent and HIPAA authorization for performing the present qualitative analyses using these audio recordings of treatment sessions from the Baylor College of Medicine's IRB.

During the parent study, the PWD-caregiver dyads randomized into the PAVeD treatment condition received six to eight weekly 45-minute in-home psychoeducational sessions. A master's-level research clinician led the sessions. The PAVeD intervention provided psychoeducation in three areas: Module 1 – improving understanding and skill in pain and distress assessment and management, Module 2 – improving patient/caregiver communication, and Module 3 – increasing pleasant activities. Each dyad received the four “core” PAVeD sessions (i.e., “Recognizing Pain” (Module 1:1), “Recognizing and Responding to Pain and Distress: How to Look, Listen, Guess, and Respond” (Module 1:2), “Enhancing Communication” (Module 2:1), and “Making Daily Activities More Comfortable and Enjoyable” (Module 3:1)). At the beginning of the first session the caregiver completed the pain assessment interview and the dyad engaged in collaborative goal-setting with the research clinician to choose two to four elective sessions. The elective session options included: “Medical

Treatments and Talking to Your Doctor” (Module 1:3), “Rest and Relaxation Strategies You Can Use at Home” (Module 1:4), “Communication Problems and Challenges” (Module 2:2), and “Increasing Pleasant Activities” (Module 3:2).

The present study is a qualitative thematic analysis of the existing audio recordings of the PAVeD treatment sessions. These sessions took place between September 2011 through January 2014. The first PAVeD session (i.e., “Recognizing Pain”) (see Appendix A), which includes a pain assessment interview, is the primary focus of the present study. The review of the home practice assignment from the first PAVeD session (which occurs at the start of the second PAVeD session (i.e., “Recognizing and Responding to Pain and Distress”)), is also included in the analyses.

Participants and Sample

The sample size for this study is 30 informal caregivers. Previous qualitative research has determined sample sizes of approximately 30 to be sufficient to reach theoretical saturation. The sample included approximately equal numbers of Black, Hispanic, and non-Hispanic White caregivers (see below for further information on sample stratification). The sample consisted exclusively of spousal caregivers (including ex-spouses), because spousal caregivers are different from nonspousal informal caregivers in numerous ways.

Previous research has documented that, unlike other types of informal caregivers, spouses are more likely than nonspousal caregivers to aid with medical/nursing tasks (e.g., medication management) and are less likely than other types of informal caregivers to receive additional support from others, including informal sources like family and friends and formal sources like healthcare professionals (Reinhard et al., 2014). Thus, unsurprisingly, spousal caregivers of PWDs are also at greater risk of developing depression and loneliness (Shim et al., 2012).

Furthermore, a synthesis of 16 qualitative studies examining the experiences of spousal caregivers of PWDs identified “loss of partner” as the central theme, including difficulties related to loss of identity and reciprocity in their marital relationships (Pozzebon et al., 2016). Spousal caregivers also face unique challenges as caregivers for PWDs because they are typically older adults, often having their own chronic health conditions (Shim et al., 2013). Finally, spousal caregivers of PWDs have different professional support needs (e.g., need more emotional support) than other types of informal caregivers (e.g. adult children) (Peeters et al., 2010). Given the significant differences between spousal and nonspousal caregivers, and the limited capacity of this study to conduct between-group comparisons, the sample for this study is limited to only spousal caregivers.

Of the caregivers represented in the 101 audio recordings of session one, 71 were spouses. The 71 spousal caregivers included 32 non-Hispanic White caregivers, 23 Black caregivers, and 9 Hispanic caregivers. (Seven spousal caregivers were eliminated from the sample due to missing data on race or small sample size (e.g., one Asian caregiver).) Stratified random sampling was used to create the final sample. The website Random.org was used to randomly generate ID numbers for 10 non-Hispanic White caregivers and 11 Black caregivers. Since there were only nine Hispanic dyads, all were included in the final sample. Two of the originally selected Black dyads were replaced due to (1) not having a recording of the session 2 home practice review, or (2) having poor sound quality which made transcription impossible. Random.org was used to identify the two replacement Black dyads.

Materials

PAVeD Recognizing Pain Session, Pain Assessment Interview, and PAVeD Recognizing Pain Session Home Practice Review

The “Recognizing Pain” session is the first of six to eight weekly in-home PAVeD treatment sessions (see Appendix A and Appendix B). The goals of this session include (1) identifying PWDs’ experiences with pain, (2) understanding the definition of pain, (3) understanding the effects of pain, and (4) learning about behaviors that indicate pain. The caregivers reported on the PWDs’ experiences with pain during a structured pain assessment interview (see Appendix A). The data collected via the pain assessment interview included pain duration, pain location, pain quality, and pain interference. The interview questions as well as the session content were primarily addressed to the caregiver. During the session caregivers also completed a “Checklist of Nonverbal Pain Indicators” (see Appendix B). They were asked whether PWDs expressed pain through nonverbal vocal complaints (e.g., moans and groans), facial grimaces or winces, bracing, restlessness, or verbal vocal complaints (e.g., cursing). When caregivers endorsed witnessing any of these nonverbal pain indicators, they were asked whether they observed these behaviors when the PWDs were at rest, with activity, or both. At the end of the session, caregivers were asked to complete a home practice assignment in which they recorded the PWDs’ pain level at least once daily in the pain diary, using a pain thermometer with six pain levels ranging from no pain to “almost unbearable” pain (see Appendix B). At the start of the second session (i.e., “Recognizing and Responding to Pain and Distress”), the research clinician reviewed the home practice assignment with the caregiver. The home practice reviews were typically 5 to 15 minutes in length. Transcriptions of the “Recognizing Pain” session, including the pain assessment interview and home practice review at the start of the

following session, provided information regarding the pain mental models held by spousal caregivers of PWDs.

Data Analysis

Demographic Data

All demographic data were collected via self-report during the parent study. The author compiled the demographic data for the present study's participants in an Excel file. She obtained this data from a de-identified master Excel file from the parent study that included all demographic data for all 203 dyads (or 406 participants). The demographic data gathered for this study included the age, race, education level, and annual income for the spousal caregivers and PWDs. The author used Excel to calculate the mean age (and standard deviation) of both the spousal caregivers and the PWDs.

Audio Coding

After the author transcribed five sessions verbatim, it was determined that significant portions of the sessions were irrelevant to this study's aims because the sessions were created for the parent study. She then piloted the feasibility of audio coding the remaining 25 sessions. She did this by using an audio coding technique on five additional transcripts. The author found that she still reviewed all data, but saved significant amounts of time not having to transcribe irrelevant dialogue. As a result, the author used an audio coding technique rather than transcribing the remaining sessions verbatim in their entirety. When audio coding, the investigator listens to each session in its entirety, making notes with time stamps every time dialogue germane to the study's aims is heard. The investigator then listens to that same session's recording a second time, performing more in-depth coding and either transcribing verbatim or summarizing the coded material (Hartmann et al., 2018). In this study, the author

transcribed germane content verbatim (i.e., any dialogue relevant to the spousal caregivers' mental models of their own pain and/or the PWDs' pain). As coding proceeded through subsequent iterative cycles (see qualitative thematic analysis section below), the author returned to the recordings as needed.

Qualitative Thematic Analysis

The present qualitative research utilized thematic analysis. The six phases of thematic analysis are: (1) familiarizing oneself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing a written report (see Table 1) (Braun & Clarke, 2006). Phase 1 involves immersion in the data and began with the author listening to the 30 recordings of the “Recognizing Pain” session in addition to the home practice review from that session at the beginning of the “Recognizing and Responding to Pain and Distress” session (i.e., the second session of the PAVeD treatment). This phase continued until the author had listened to all recordings at least once before coding any data. Verbatim transcription of content germane to the study's aims also occurred during this phase. Phase 2 consisted of producing a list of initial codes. Codes are “researcher-generated constructs,” often words or phrases, that label and assign meaning to a piece of data, and “coding is analysis” (Miles et al., 2020, p. 62-63; Saldaña, 2016, p. 4). Dual-coding was also completed during this phase. Phase 3 involved distilling codes into possible themes and compiling all data germane to each possible theme (Braun & Clarke, 2006). Themes are patterns observed within the data relevant to a study's goals. During phase 4, each coded datum related to each possible theme was reviewed to determine whether it formed a meaningful pattern. Acceptable themes were then reviewed for how well they reflected the entire data set. Phase 5 consisted of refining the acceptable themes that were determined to be valid, accurate representations of the data in

phase 4. The author generated clear definitions for the acceptable themes, including each theme's scope and content. Phase 6 occurred once the themes had been finalized and is represented in this report. The written report produced during this final stage describes the data while providing a justification for the inclusion of each of the final themes. Data extracts that provide evidence for the final themes are included.

The actual qualitative analysis occurred primarily at the Tuscaloosa VA Medical Center (TVAMC) with select tasks occurring at the Michael E. DeBakey VA Medical Center (MEDVAMC), the lead site of the parent study. Pre-coding data preparation activities were completed by the author and a member of the secondary analysis research team (UA graduate student Julia Loup). Initial coding was completed by the author and three members of the parent study's research team (Dr. A. Lynn Snow, Dr. Sheila Richey, and Tracy Evans). ALS and PB (the author) completed all tasks for the present study at TVAMC, whereas SR and TE completed theirs at MEDVAMC.

The addition of a second audio coder improved the study's dependability or "reliability," which in qualitative research refers to quality and consistency of the study's design and methodology (Miles et al., 2020). The same individual (JL) served as the confirmatory coder for all sessions, providing consistency in the transcription process. Both the author and confirmatory coder used the study aims and research questions to guide what session content was determined to be relevant and, thus, included in the transcriptions. Anything verbally expressed by the spousal caregivers that related to how they generally conceptualize pain or distress, how they assess and treat pain (both in themselves and PWDs), their perceptions of the PWDs' pain behaviors (especially nonverbal behaviors), and how they respond to PWDs' pain behaviors was included and transcribed verbatim. Any of the research clinician's scripted language for the

session's intervention was excluded (see Appendix A). Excluded scripted data included the statement regarding the limits of confidentiality read at the beginning of the first intervention session, the questions guiding the selection of two to four elective treatment sessions, and psychoeducation on pain, including its prevalence in older adults, except when followed by direct responses from caregivers or PWDs. These direct responses occurred most often following scripted psychoeducation related to pain management in PWDs, including the tendency of PWDs to underreport their pain. The author listened to all of the audio recordings, transcribing only relevant portions of the recordings of the "Recognizing Pain" session and the home practice review of that session at the start of the second session using Microsoft Excel. After all relevant data for a given dyad was transcribed, the confirmatory coder (JL) separately listened to all sessions and concurrently reviewed the author's transcriptions, always keeping the study's aims and research questions in mind. She confirmed and/or refuted that the author had accurately transcribed all relevant data verbatim from that session.

To reduce any bias in audio coding and ensure this project had high confirmability, it was agreed to (1) have a second person serve as a confirmatory coder for all sessions and (2) include the home practice review from the start of the second PAVeD session in the data analyses. Confirmability or "external reliability" in qualitative research involves efforts to safeguard against author bias (Miles et al., 2020). Efforts to improve confirmability are intended to ensure that a qualitative study's findings are based on the participants' actual words and stories rather than the researchers' assumptions, values, or biases. Maintaining an audit trail by documenting all data processes and decisions through all stages of data analysis is a commonly used method to assure a study's confirmability (Creswell & Miller, 2000), and the author kept an audit trail throughout all phases of this project. Having a second audio coder also increased confirmability

of the project as this coder listened to all sessions, reviewing the data identified and transcribed by the author. She confirmed and/or refuted that the author had captured and accurately transcribed all germane data verbatim for all of the 30 sessions. Any disagreements were discussed between the two audio coders until consensus was reached. This ensured that the author was not the sole person deciding what to include/exclude in the analyses.

Moreover, adding the home practice review to the data included in the analyses further improved the study's confirmability, providing an additional opportunity for the caregivers' knowledge and beliefs regarding pain assessment and pain management to be voiced and incorporated into the final analyses. As mental models are "personally constructed, internal conception[s], of external phenomena" (Rook, 2013), some caregivers may not have been able to easily and readily describe their knowledge and beliefs regarding their own personal experiences with pain or those with PWDs' pain. Since the home practice assignment involved actively and deliberately measuring PWDs' pain on a daily basis, the author hypothesized that these caregivers might be better able to speak to their knowledge and experiences about pain after completing the daily pain assessments for at least one week. The author listened to a few second sessions which provided evidence that her hypothesis was correct for at least some of the caregivers. In the selected second session recordings caregivers provided additional rich details regarding their observations and experiences with PWDs' pain during the last week. This helped assure that the study's findings were indicative of these spousal caregivers' pain mental models, rather than the author's potential biases.

During the initial open coding, PB, ALS, SR, and TE each individually audio coded the same three sessions, which included one session from each of the three races represented in this study. Consensus meetings were held after each round of coding. Next, the data from six dyads

(20% of the overall sample) were transcribed by PB (the author) and confirmed by JL. These six transcripts included two dyads from each of the three racial groups represented in this study. These transcripts were dual-coded by PB, ALS, SR, and TE. Each coder completed open or free coding, generating their own novel codes for each section of transcribed text. Each coded between two and four transcripts. Consensus meetings were held after each round of coding. This initial open coding phase gave the author an opportunity to develop the overall coding approaches for this study in consultation with other experienced qualitative researchers and geriatric clinicians. Once the initial open coding phase was completed, the author moved forward as the sole primary coder for the remainder of the data.

For the next phase of coding, the author led the coding process with regular intercoder agreement checks from other research team members. This first occurred after the completion of the initial open coding. The author then combined the six transcripts jointly completed by PB, ALS, SR, and TE into one Excel file, placing the codes for each block of text in columns side-by-side for comparison. PB then reviewed these comparisons and began generating new microcodes informed by these comparisons into a series of two joint coding meetings with Dr. Michelle Hilgeman. PB developed microcodes with MH for two of the six previously dual-coded sessions. PB completed this process alone for the remaining four transcripts. ALS then confirmed and/or refuted the microcodes of two of the transcripts (one coded by the PB and MH together and one coded by PB only), generating new microcodes in any instances when she disagreed with the microcodes developed by PB and MH. PB and MH then together reviewed ALS's recommended changes to the microcodes. All discrepancies were discussed until consensus.

The author then combined these microcodes into the first version of the codebook (i.e., master list of codes and definitions). The author then reviewed all of these microcodes, consolidating and refining the codes to achieve a balance of parsimony of description and complete description of all identified phenomena in the transcripts. The resulting codebook included 184 microcodes, falling into 6 broad categories: (1) how caregivers assess, identify, and describe their own pain, (2) how caregivers assess, identify, and describe PWDs' pain, (3) how caregivers manage or treat their own pain, (4) how caregivers manage or treat PWDs' pain, (5) caregivers' general pain-related beliefs, and (6) contextual information. The contextual information comprised all data that was relevant to the study aims, but was expressed by someone other than the caregivers, usually the PWDs themselves.

After the codebook was completed, the author used it to code the remaining 24 transcripts. She continued to consolidate and refine the codes to succinctly and accurately describe all identified phenomena or concepts. She also created new codes for any additional phenomena described in these transcripts, updating the codebook as she coded each of them. After she coded these 24 transcripts, she recoded the 6 transcripts whose codes comprised the preliminary codebook. In recoding the first 6 transcripts, the author was able to demonstrate that data saturation had been reached, meaning the inclusion of additional sessions resulted in few or no changes to the codebook (Guest et al., 2006). In fact, due to further refining the codes, the total number of codes decreased from 401 microcodes prior to recoding the initial 6 transcripts to 395 microcodes after they were re-coded. The 395 microcodes in the updated codebook remained clustered in the same 6 broad categories as the first version of the codebook (see above). The majority of these microcodes fell into the two categories related to pain assessment in PWDs (135 codes) and pain treatment in PWDs (105 codes).

Additional intercoder agreement checks occurred after the author coded the remaining 24 transcripts using the preliminary codebook. ALS dual-coded 10% of these transcripts. The author used Random.org to identify 10% of each transcript's content for ALS to dual-code. The author then hid the data excerpts (rows in Excel) that were not randomly generated by Random.org (i.e., the remaining 90% of each of these transcripts). These transcripts varied in length, due to caregivers' varying degrees of talkativeness and engagement with session materials. ALS dual-coded between 1 to 3 quotations or excerpts from these 24 transcripts with 2 excerpts being most common (16 of these 24 transcripts). Similar to the steps taken by PB and JL during audio coding, any disagreements between PB's and ALS's dual-coding in this round were discussed until consensus was reached. To assist in reaching consensus regarding coding disagreements, PB combined all of the dual-coded excerpts (44 total) into one Excel file. After consensus had been reached for 38 of the 44 excerpts, the author created a new file of the 6 excerpts for which consensus had not been reached. She collated all of the excerpts from all 30 transcripts that used these codes into this document. This allowed PB and ALS to reach consensus on these codes. The author updated the codebook as well as the microcodes in the individual dyads' transcripts when it was agreed that the wording of a particular microcode needed to be changed, updated, or removed. In total, ALS dual-coded the equivalent of five transcripts (or 16.67% of the overall sample), coding 2 transcripts in their entirety during the open coding of the 6 transcripts included in the preliminary codebook as well as 10% of the 24 transcripts not included in the preliminary codebook.

The author then began phase 3 of the qualitative thematic analysis, searching for themes. During the previous phase of coding, the author concurrently engaged in memoing, writing reflections on the data analysis process, including the potentially emerging themes (Saldaña,

2016). Some of the topics on which the author engaged in analytic memoing were (1) observed discordance between the caregivers' mental model(s) of their own pain and their mental model(s) of PWDs' pain, especially how pain should be managed or treated in themselves versus in PWDs, and (2) how a poor or insufficient mental model of dementia could negatively impact caregivers' abilities to help PWDs manage their own pain, even in instances where caregivers demonstrated consistent or concordant mental model(s) for pain in themselves and for pain in PWDs. To further identify potential themes, the author began grouping codes into categories. For example, the broad category relating to how caregivers assess, identify, or describe PWDs' pain was broken into three smaller categories (i.e., how caregivers identify the presence of pain in PWDs, how they describe the intensity of PWDs' pain, and the extent to which they perceive PWDs' pain to interfere with or hinder their ability to engage in a range of activities). Each potential theme or category became a separate Excel worksheet. The following workbooks were created: (1) how caregivers assess their own pain (16 codes), (2) how caregivers treat their own pain (22 codes), (3) how caregivers identify the presence of PWDs' pain (54 codes), (4) how caregivers describe PWDs' pain intensity (22 codes), (5) how caregivers describe PWDs' pain interference (19 codes), (6) how caregivers treat or assist the PWDs treating their pain (97 codes), (7) caregivers' general beliefs about pain (4 codes), and (8) caregivers' beliefs about dementia (13 codes). The author first gathered all of the microcodes related to each of the 8 categories in their separate workbooks. She then gathered all of the data excerpts from all transcripts for each microcode. While completing this step, she continued to further refine and clarify codes, including collapsing some codes which were found to be have too much overlap in the phenomena described. An example of a code being further refined was the microcode for the excerpt below.

E37:

RC: Is there anything that makes the pain better? Like medication or...?

CG: He's never been on nothing so far.

The microcode generated by PB and MH was “CG does not give PWD any medication to reduce pain,” and it became “CG denied current regular PWD use of pain medication” during this phase.

Reviewing themes (phase 4) was the next phase of the thematic analysis. The author read the excerpts related to every code, and she noted any newly observed patterns in the data (e.g., some spousal caregivers reported that PWDs’ pain prevented them or limited them from many daily activities, but they did not believe PWDs needed any additional pain treatments). She also reread each of the 30 dyads’ transcripts in their entirety, again noting any observations regarding patterns of caregivers’ behaviors in response to PWDs’ pain. During this phase, PB and ALS also met multiple times to discuss the emerging themes identified by PB, with the author describing various examples of potential themes observed in the data. This phase concluded with the author drafting a thematic map of the analysis with three themes identified: (1) pain assessment, (2) pain management, and (3) barriers to effective pain assessment and pain management.

The author then began to define and name the themes (phase 5). She reread all of the 30 individual transcripts at this time and pulled all excerpts of data related to the three identified themes, organizing them according to observed subthemes. These subthemes helped the author further define and describe each of the initial three themes. The subthemes of pain assessment included (1) the importance of knowing the person, (2) understanding of PWDs’ pain language, and (3) explanations of the cause(s) and location(s) of PWDs’ pain. The subthemes of pain management were (1) concerns regarding analgesic and pharmacological pain treatments, (2) preference for nonpharmacological and complementary and alternative medicine (CAM) pain

treatments, and (3) perception of their role in PWDs' pain management. The subthemes of the theme of barriers to effective pain assessment and management were (1) poor understanding of dementia disease process, (2) belief that pain is a normal part of aging, (3) attributing PWDs' possible pain behaviors to comorbid health conditions or other factors, (4) prioritizing treatment of PWDs' other comorbid health conditions, and (5) difficulties accessing appropriate medical care for PWDs' pain. The author then began writing these results, continuing phase 5 while starting the final phase, producing the report (phase 6).

In writing the results, the author identified the best exemplar excerpts for each theme and subtheme. PB also confirmed that a given excerpt was only used to demonstrate one theme or subtheme and that every dyad had at least two excerpts included in the results to ensure that the story of the analysis reflected the full sample of caregivers. She shared this draft with ALS, who after reviewing the results, suggested reorganizing the results into two themes (1) pain assessment beliefs and knowledge and (2) pain management beliefs and knowledge. The subthemes for each of these themes are described in detail in the following section (i.e., results). The author continued to update the exemplar quotations, removing some and adding others in order to better describe the themes and subthemes of the data, which included re-reading all of the individual transcripts to ensure that all relevant data was represented. The step of phase 6, involving relating the analysis back to the research questions and literature, occurs in the following sections of this dissertation.

In addition to the previously described steps taken to improve the confirmability and dependability of the present qualitative analysis, the author's regular consensus coding conversations with ALS, TE, SR, and MH across the stages of data analysis assured that she continued to approach coding and the thematic qualitative analysis in a manner consistent with

and informed by the perspectives of experienced qualitative researchers and psychology (ALS and MH) and nursing (TE and SR) clinicians. These conversations also helped increase the credibility or “internal validity” of the analyses (Miles et al., 2020). The author viewed the data in multiple ways, including by codes, by themes, by individual dyad transcripts, and by counting the frequency of certain phenomena (e.g., different types of nonverbal pain behaviors). Furthermore, PB made efforts to improve the study’s transferability or “external validity” (Miles et al., 2020). For example, individualized demographic data for all study participants, including their race, age, current painful conditions, and relationship to the other member of the dyad, are provided in the results (see Table 2).

RESULTS

Characteristics of Study Participants

In the final sample of 30 dyads, the caregivers were all female and the PWDs were all male (see Table 3). The 30 spousal caregivers were 36.67% Black, 33.33% non-Hispanic White, and 30% Hispanic. The mean age of the caregivers was 72.33 ($SD=7.29$, Range 57-86). The PWDs were older with a mean age of 77 ($SD=7.02$, Range 63-91) and had fewer Hispanic participants (23.33%). The majority of the caregivers completed high school or some college (93.33%), and half (50%) had an annual income of <\$10,000 (Range <\$10,000-\$39,999). Over 46.67% of the PWDs had at least some college, and their annual income tended to be higher than the caregivers' income with 83.33% reporting an annual income of \$10,000 or greater (Range <\$10,000- \geq \$60,000). Per the inclusion criteria of the parent study, all PWDs had clinically significant pain (self- or caregiver-reported), and 40% of the spousal caregivers reported having a current painful condition themselves (see Table 2).

Main Results

Two themes were identified (see Figure 1). The first theme is Pain Assessment Beliefs and Knowledge (PA). This theme has four subthemes: (1) understanding of the dementia disease process, (2) importance of knowing the person, (3) understanding of PWDs' pain language, and (4) attributing PWDs' pain behaviors to causes other than pain. The second identified theme was Pain Management Beliefs and Knowledge (PM). This theme has seven subthemes: (1) belief that pain is a normal part of aging, (2) understanding of the cause(s) of PWDs' pain, (3) perception of their role in PWDs' pain management, (4) prioritizing the treatment of PWDs'

other comorbid conditions, (5) difficulties accessing appropriate medical care for PWDs' pain, (6) concerns regarding analgesic and pharmacological pain treatments, and (7) preference for nonpharmacological and CAM pain treatments.

These 2 themes and their 11 subthemes are illustrated below with exemplar quotations. The dyads are identified by their study ID numbers. When the quotations include dialogue from the PWDs or master's level research clinician, the following abbreviations are used: CG for caregiver, PWD for person with dementia, and RC for research clinician. Also, when mm-hmm and uh-huh are used, they indicate a response of "yes."

Pain Assessment Beliefs and Knowledge (PA)

The first theme covers how spousal caregivers determine whether PWDs are presently experiencing pain. It contains the caregivers' knowledge of the PWDs' history with pain, duration of PWDs' pain, and how PWDs have responded to or behaved when experiencing pain and/or distress in the past. This theme further includes the verbal and nonverbal behaviors that notify spousal caregivers that their husbands are experiencing pain as well as which activities or situations cause PWDs to feel more pain.

Understanding of the Dementia Disease Process. The first subtheme of PA was spousal caregivers' understanding of the dementia disease process, including its etiology. This subtheme details how caregivers' knowledge and/or beliefs regarding the expected course or progression of their spouses' dementia (or memory impairment) impacted their perceptions of when the PWDs were experiencing pain. Many caregivers expressed surprise in response to psychoeducation regarding dementia's impact on language and the ability to self-report pain. One caregiver also described believing that her husband's dementia-related cognitive decline could be reversed, with his memory returning to his pre-dementia functioning. Present

pharmacological treatments for dementia can slow its progression, but they cannot prevent dementia from ultimately worsening (ADI, 2016). A poor or incomplete understanding of dementia may have led spousal caregivers to incorrectly believe that the PWDs had more control over their dementia-related cognitive decline than they actually had. For example, in response to getting the instructions regarding the home practice assignment, including the pain diary, one caregiver (E135) told her husband that he had to “push his brain,” disagreeing with him as to whether he did this. She further overestimated his ability to stop or slow his dementia’s progress, implying that his memory would continue to decline since if he did not use his brain/memory, he would “lose it.”

E135 [to PWD]: You can help me on that too. When you get up in the morning, you can tell me about your pain. If it’s bad on a scale of 1 to 10 how bad it is in the mornings when you get up. And when you have those excruciating headaches, there you tell me that it’s a 10. But when...every day is not exactly the same amount of pain in your head. You have different degrees of pain on different days. You think you can remember to tell me when you get up in the morning how bad the pain is?

PWD: I can tell you, yes.

CG: You think you can remember to take your medicine at night?

PWD: [laughs] I’ll try to.

CG: You’re gonna have to practice and push your brain.

PWD: Well, I do.

CG: No, you don’t. You depend on me to do your thinking for you. Listen to me. And you have to learn to push your brain. Otherwise, if you don’t use it, you lose it.

Another caregiver expressed confusion regarding the etiology of her husband’s dementia. She reported that his healthcare providers thought that his chronic pain had caused his memory loss. Although chronic pain has been found to negatively impact working memory and the retrieval of long-term memory (Mazza et al., 2018), there is no empirical evidence that chronic pain directly leads to the development of dementia. While this caregiver expressed some uncertainty regarding whether she agreed that her husband’s pain had caused him to have

memory loss, she clearly demonstrated an incomplete understanding of dementia and memory loss and their relationship with chronic pain.

E209: They [PWD's doctors], I think, [are] about to decide that he may have early stages of Alzheimer's. And, of course, they say [it's] probably all the pain he's been through and everything is what's brought it on the memory loss and everything. I'm not sure that it's all that [that caused the memory loss].

As previously mentioned, a significant area in which many spousal caregivers demonstrated poor understanding of dementia was through their lack of awareness of its negative impact on PWDs' ability to process and produce verbal language.

E198:

RC: But it [dementia] also causes a loss of language. 'Causes a loss of language.

CG: I didn't know that.

RC: So, dementia reduces the ability to understand others. So, it really reduces the ability to process language. So, it may cause difficulty in understanding questions. Or even understanding what pain like the word pain or the concept of pain means.

CG: I've noticed that. I have to say the same question several times to him now.

Dementia's impact on language and memory are both reasons why PWDs become unable to accurately self-report their pain and/or distress. As such, caregivers' incomplete understanding of dementia's negative impact on PWDs' verbal abilities may lead them to underestimate the presence of PWDs' pain. In response to psychoeducation that it becomes harder for PWDs to express that they are in pain as their dementia progresses, one caregiver (E198) asked the research clinician whether PWDs really felt "all the pain."

E198:

RC: As dementia progresses it becomes harder and harder for people to express that they are in pain.

CG: Well, do they really feel all the pain?

RC: That's a good question. Yes. However, with dementia, especially with moderate to severe dementia, it can become difficult to really know how to interpret your internal cues. [...]

CG: Okay. So, the brain doesn't transmit that information back to them?

RC: It may transmit it. They just may not be able to interpret it.

CG: Interpret it.

RC: And then also dementia really impacts language. So, they may not be able to communicate it.

CG: Hmm. Okay.

Furthermore, multiple caregivers expressed continued reliance on PWDs' verbal self-report of pain to inform them of when their spouses were experiencing pain. In doing so, these caregivers have continued to rely on their spouses' pre-dementia pain indicators. In response to psychoeducation regarding the importance of viewing PWDs' pain in the context of dementia, one caregiver shared that she forgets to do this.

E02: I forget about that part. That's what I have to concentrate on too because I'm still thinking he is like he used to be.

Another caregiver reported that she did not ask the PWD further questions when he verbally stated that he was presently experiencing "a little bit" of pain.

E19: I'll say, "How are you feeling?" [PWD's response] "Well, arthritis is bothering me a little bit today." And then usually I don't go any further then just hearing him say, "Just a little pain."

Other spousal caregivers continued to provide PWDs with analgesic pain treatments only when they directly complained that they were having pain. One such caregiver shared that she only gives her husband pain medication "when he complains." If he had pain but did not verbally report it to her, he would not receive any pain treatment. This is concerning given that this caregiver had previously reported in the session that her husband was "in the middle stage" of dementia severity, and thus may not have had the cognitive abilities necessary to initiate requests for needed pain medication.

E51: Tylenol when he complains. But most of the time he don't do that much work. But then I give him the Tylenol.

Additionally, at least one caregiver did not change how she administered her husband's pain medication, despite his verbal complaints in the morning that he had been experiencing untreated

pain overnight. This was at least partially due to her report that the PWD denied needing pain medication the previous evening. Still, she explained her inaction and failure to provide her husband with the evening dose of Tramadol as the fault of her husband. He had not come and asked her for pain medication.

E53: I've tried to get him to take his Tramadol. I ask him every night before he goes out, "Do you need any pain medicine?" "No, I don't." But then he...the next morning, he may say, "Well, I ached all over all night." Well, he didn't come and ask for any pain medicine.

Another way in which caregivers demonstrated continued reliance to PWDs' pre-dementia pain indicators was in their expressed confusion (and sometimes expressed frustration) when PWDs verbally denied recent experiences with pain. Some of these caregivers appeared to believe that PWDs were deliberately denying their pain, in order to make their caregivers appear ill-informed in the presence of the research clinician. These caregivers either did not know or, if they knew, they did not believe that the PWDs may have been unable to verbally self-report their pain due to dementia-related language and memory impairments. It did not occur to these caregivers that the PWDs may have been unable to remember their recent pain and, as such, could not verbally report it to the research clinician.

E19:

RC: Did you have any pain this morning? No?

CG No pain yet?

PWD: Nope.

CG: Well, early in the morning when the temperature drops...

PWD: Yeah, when it gets cold. [...]

CG: But you were cold this morning. Didn't you say?

PWD: Yup. Turned my heater on this morning.

CG: Oh my word. Here I am...

PWD: I've been cold-natured all my life.

RC: But your knees don't hurt? You didn't have any pain?

PWD: Yeah, they hurt.

CG: You just told her that you didn't have any pain.

PWD: Well, if I turn the heat on, they don't hurt.

RC: It hurt when you woke up?

PWD: Yeah.

E51: Yesterday he was complaining. How'd you[r] pain go in his legs? He can't...he say[s] he can't do much because it hurts his legs. Yesterday when you walked. When you walked you said, "My pain...my leg hurts."

PWD: Well, if I walk too much, yeah.

CG: You didn't walk that much, okay.

PWD: You get tired if you walk too much.

RC: So, do you have pain from it?

PWD: No. No. No.

CG: You said you had pain last night when you came inside. You said you had pain last night, didn't you, when you came inside?

PWD: Why it's...this morning...

CG: You said, "My leg hurts. I don't know why." You said that.

Another spousal caregiver (E37) seemed surprised to learn that when someone with dementia tells you that they are in are pain that there is something wrong.

E37:

RC: The important thing to remember is that when someone with Alzheimer's or dementia tell you they're in pain there's something wrong.

CG: There is?

The research clinician provided that caregiver with additional psychoeducation on this, using the example of hunger as another internal experience that becomes difficult for PWDs to verbally self-report as their dementia progresses. In response, this caregiver shared that her husband was "never hungry." Interestingly, she then said, "he'll tell you that [he is never hungry]," suggesting that she had some continued reliance on the PWD's ability to verbally report his needs to her. As such, she displayed a poor understanding of how dementia makes it increasingly difficult for PWDs to verbally describe their internal states, including when they were hungry or experiencing pain.

E37:

RC: And that's kind of similar with the pain, [it] becomes more difficult, especially as the dementia and Alzheimer's progresses, to recognize your own internal needs. So, it becomes harder to know, to recognize to verbalize when you're hungry.

CG: He's never hungry. He'll tell you that.

RC: Right. He may just not be able to recognize or express it.

CG: Oh, okay. Just...

RC: It's the same with pain.

CG: Yeah.

One caregiver (E07) demonstrated her lack of knowledge regarding dementia's impact on PWDs' language abilities by failing to connect the change in her spouse's "negative" mood to his dementia's progression. She shared that her husband had been very negative when his memory problems began. She further explained that she used to ask him why he was "always talking about this in a negative way" during that time, indicating that she was aware of his mood due to what he verbally told her. This caregiver then described a reduction in the PWD's negativity over time. Importantly, she did not report that her spouse had received any treatment or intervention to help him with his negative mood or express any known reason for the improvement in his mood. As such, the reduction in his verbally expressed negativity may have been due to dementia-related declines in his ability to verbalize his thoughts, rather than an indication of true change or improvement in his mood.

E07: Before when I when he first started having problems with his memory, he was very negative. So, I don't know if it had anything to do with pain or just the difference space that it was taking him through. But his mood was never low, but he was very negative. And all the sudden I would ask him, "Why are you so always talking about this in a negative way?" But then his mood seemed to have calm down a little. More than it has before. And it's not really negative anymore, like he was before.

In contrast, other spousal caregivers demonstrated awareness of PWDs' difficulties understanding and verbally responding to questions. One caregiver reported that her husband was having difficulty verbally expressing his pain due to his dementia.

E135:

RC: But as the disease progresses it may be difficult for him to find words to express his pain.

CG: He's already...

RC: Even if you ask him.

CG: It's already...

RC: You feel like it's already happening.

Another caregiver (E07) described her husband's dementia-related difficulties in self-reporting his pain. She compared her husband's pre-dementia ability to self-report his pain intensity on a 1 to 10 scale to his inability to do the same task now. She described her husband clearly responding with a number to indicate his pain intensity level before his memory problems began. In contrast, she reported that now when he was asked to rate his pain on a scale from 1 to 10, his response was unrelated to the question. As a result of this knowledge, she also described monitoring his nonverbal behaviors (i.e., rubbing or complaining) and using them to identify when the PWD was experiencing pain.

E07: And before he started having the memory problems, you know, every time he would go into the doctor, because he go[es] to the rheumatoid doctor also, and they would always ask him, "How's your...what's your pain level?" He would always say 6 or 7. So it was always up there.

RC: Yeah, so it's there, and I think the medication is controlling it. But it's still a good idea to know how bad he's rating it even without the medication so that you know, and it seems like you do know, when he complains that it's probably pretty bad.

CG: Yeah, 'cause right now if you ask him, you know, when you ask him, "On a scale from 1 to 10, what is your level of pain?" He really can't tell 'em. Because he'll say something, he talk[s], he'll say something else that's not pertaining to what the question [asked] at all. So, he really can't tell 'em what the pain level might be.

RC: So that's why in the future it will be important for you to be able to monitor that and let the doctors know how bad that is. So that if there comes a point where that medication isn't enough for him.

CG: If he starts rubbing or complaining then I'll know that, you know, it's not working. But, right now, it is.

A different caregiver described a recent experience where she left her husband at home alone, only to have him attempt to cook bacon while she was gone. She explained that he had burned it, thrown it away, and then forgotten that he tried to cook by the time she returned from the grocery store. She linked his difficulties with remembering his recent cooking to him possibly having similar difficulties with remembering and processing his pain.

E90: Maybe he feels it [pain], but then it just goes in to, you know, a hole or something. Last week I was gonna fix beans, but I had to go to the grocery store to buy beans. So, I left the bacon on the counter, and I came back and the bacon was gone. And I said,

"Where's the bacon?" He says, "I don't know." and "I don't know." and "I don't know."
[...] So that's a scary thought. That when I went to the grocery store...

RC: He was cooking, especially bacon of all things.

CG: And he burnt it. He burnt it, and he put it in the trash. And he forgot about what he had done. He could not remember. And I could see that he was trying to remember something, you know, but he couldn't. And that's easily with pain or anything else, you know. He's had the pain, but he just can't process it.

An additional caregiver (E33) stated that her husband could not express himself, including how badly he felt, as a result of his dementia. She explicitly connected his difficulties self-reporting and describing his pain and distress to his dementia diagnosis.

E33: I don't even know what he feels. But it must be bad. Because...I don't have it. But some people that has it and they don't have dementia, they tell me it's very bad to have ringing. It'll drive you crazy. One lady at the senior center she wears a little radio here. He don't want to wear one. I told him I'd get him one. But driving and coming to the senior center, she wears it all the time. It must be very noisy. But he...

RC: He doesn't want to.

CG: But he has dementia [and] he can't express himself sometimes how bad he feels. Sometimes he say[s], "I guess I might." I guess he says, "I guess continue to moan." He says. I guess because he feels so bad he says [that].

She also expressed awareness that her husband repeated his verbal, vocal complaints of pain and distress due to his dementia-related memory impairment.

E33: He repeats himself constantly. It's repetition constantly. He's just got through telling me, "I've just got dizziness and ringing on the ears." And then a little while longer he says that again. If I says hi to him or hello, [he'll respond] "Oh, hello, I've just got dizziness." He[ll] tell me [again].

RC: Yeah, that's the dementia.

CG: Yeah, dementia.

Notably, this caregiver's awareness of the PWD's difficulty in verbally expressing himself led her to identify actions she could take in order to better understand her husband's pain and distress. Specifically, she described observing and discussing her husband's painful conditions with cognitively intact individuals with the same conditions (i.e., ringing in the ears and hemorrhoids). In addition to this helping her to better understand what her husband likely experienced on a daily basis, she discovered additional pain management strategies that the

cognitively intact individuals had shared with her that had been effective in helping them better manage their painful conditions. She reported encouraging the PWD to utilize these techniques, including wearing a radio to help with his distress due to the ringing in his ears and dizziness and using a non-squat portable bidet with their toilet to help him to avoid irritating his hemorrhoids. She also learned that some treatments can cause an increase in pain in the short-term and, thus, described using the pain management techniques that would cause him to experience the least amount of pain and distress when possible (e.g., avoid using suppositories for his hemorrhoids if possible).

E33: Also, he has hemorrhoids pretty bad. And he gets up at nighttime. And one time he got up and say, "Call the ambulance. My..." He was hurting and itching very bad from the hemorrhoids. I call my friend, and she said, "Oh, my...they are terrible." She can express herself and tell me about it 'cause she don't have dementia. It is a very terrible thing. Well, the doctor at the VA gave him suppositories. But [she] was telling me, my friend, she said, "Oh, he puts it in, he's going to [have his hemorrhoids go] bonkers a bunch more, and they hurt more." I don't know. The VA doctor told me to give him suppositories. But they can't do surgery or nothing. He suffers a lot from that.

E33: My friend told me. I called her. I said she's around my age, and she suffers from that. I put him in the toilet, and, after a while, I couldn't get him up. I mean I'm up in age too. But he say[s that] he couldn't get up. So, I said no more to [that]. So, she say[s], "Alright, it's hard to him to get up. Well, they sell this little thing at Walmart." She say[s], "I bought it years ago." And she puts it on the toilet. We got one of those highest toilets [non-squat portable bidet].

Ultimately, this caregiver demonstrated how caregivers having better understanding and knowledge of the dementia disease process could allow them to help PWDs manage their pain more effectively.

Importance of Knowing the Person. Most spousal caregivers described the importance of knowing the PWDs in order to identify when they were experiencing pain and/or distress. Due to their familiarity with the PWDs, these spousal caregivers expressed high levels of confidence in their knowledge and understanding of the PWDs' behaviors, including those they

exhibited when feeling pain. All reported living with the PWDs and spending significant amounts of time with them daily for years. As a result of their long-standing daily interactions with the PWDs, almost all of these caregivers reported that they knew the PWDs better than anyone other than the PWDs themselves.

E07: Well, since you're around a person every day, you really get to know what that person is like.

E135: He usually don't tell me when he's feeling bad, but I can tell.

E181: He doesn't have to tell me. That's why I tell him, "Don't do nothing." 'Cause then I can see. "Oh, my back hurts. Or I have pain." He doesn't have to tell me after being married for 51 years.

A few spousal caregivers even claimed to know PWDs better than they knew themselves.

E19: I know more about him than he probably knows about himself.

E181: I don't even have to ask him. I know him better than myself. I tell him I know you better than anything.

PWD: Better than my mother, you said.

CG: Yes.

Most spousal caregivers described long-term knowledge and understanding of the PWDs' responses to pain and/or distress, including their responses to pain prior to their dementia diagnoses. Many caregivers reported that the PWDs' typical responses to pain were minimizing it. Thus, these PWDs avoided making verbal, vocal pain complaints.

E25: He tries to hide stuff from me. He's not a complainer. You know, you have some people that complain about everything? "My this hurt!" He's not one to let you know that anything is bothering him. He never has been a complainer.

E100: He is not a person that complains. It's not in his nature to complain. This is why I say I'm gonna have to...it's up to me to really determine when he's in chronic pain.

E195: I know better. He's a macho man. He won't tell.

Additionally, some of these caregivers further shared that PWDs would not tell them about their pain unless they were explicitly and directly asked about it. These wives reported that this was the only scenario in which the PWDs would tell them about their pain.

E117: I can tell, and I ask him. Whenever I ask him, then he'll tell me. And I'll say, "What's the matter?" [PWD's response] "I'm just hurting real bad." But I have to ask him.

Another caregiver (E73) reported knowing that her husband had long-term chronic pain as well as a high pain tolerance. Her familiarity with her husband had given her the knowledge that she had to ask him about his pain in order to get him to self-report it to her.

E73: He can tolerate a lot of pain. He's had it for so long. So, I have to ask him.

Furthermore, due to their awareness that the PWDs tried to hide and/or minimize their pain, many spousal caregivers described recognizing when PWDs had pain as a result of understanding the meaning of their nonverbal pain behaviors. These caregivers endorsed various nonverbal behaviors that alerted them that PWDs were experiencing pain. Some caregivers described their husbands isolating themselves and/or avoiding speaking to them or others when they were experiencing pain.

E44: He usually just pretty much isolates himself [when he's in pain]. He's done it ever since I can remember. It's an escape.

E90: He just kinda shuts down. And I can tell that he's not complaining, but by his not being responding, responding real good. It's just something he's just not.

E135: And he doesn't do it out loud or anything. But I can tell. He goes straight to the chair over there. He leans back. He closes his eyes. And I'll ask him if he's feeling all right. And he'll [respond], "No."

RC: And are you noticing that when he's doing something? Or when he's just resting? Or both?

CG: Well, when he gets up there and has a vicious headache, he is...he comes straight out and goes over there. He will get his little half cup of coffee, and that's when I'll notice that's he's really looking...I don't know how to express that. But he doesn't actually moan or groan out loud. He just collapses over there.

Other nonverbal behaviors reported by caregivers were those listed on the “Checklist of Nonverbal Pain Indicators,” which they completed during the first session (see Appendix B). These pain indicators included facial grimaces or winces, nonverbal vocal complaints, and verbal vocal complaints. Facial grimaces and winces also included other types of facial movements such as narrowed eyes, tightened lips, clenched teeth, and/or distorted expression. These were endorsed by 22 (or 73.33%) of the spousal caregivers.

E19: I can tell actually by the expression on his face. When he walks in that door first thing in the morning, I can tell if he's mad, sad, [has] pain, or whatever it might be.

E33: The dissonance is sometimes is badder [worse] than other days. He reflects on his face how bad he feels. You can tell, and then other the days it's not as bad. His face don't look as bad. So, I can tell it's not as bad.

E71: I see how he squinch his eyes and he hold his head. [You] can tell when a person is in pain if you know them.

Nonverbal vocal complaints of pain such as moans, groans, or cries were also recognized by many spousal caregivers. Twenty-one (or 70%) of the spousal caregivers reported witnessing PWDs' nonverbal vocal complaints.

E54: He's a good groaner. Yes. Getting up. Sitting down. Just when he starts rocking up to get up is when it's strong.

In addition to nonverbal vocal complaints, caregivers endorsed that PWDs made verbal pain complaints, including cursing, using words that expressed pain or distress (e.g., “ouch”), and making exclamations of protest (e.g., “stop”). More spousal caregivers reported observing this pain behavior in PWDs than any of the other behaviors listed on the “Checklist of Nonverbal Pain Indicators.” Eighty percent (or 24 of the 30) spousal caregivers reported witnessing PWDs make verbal, vocal pain complaints.

E89: Yeah, "Ouch." Sometimes it will happen when he's changing position in bed. Sometimes when he's trying to get out of the chair. And many times, when he's walking [he] has to go, you know. Not necessarily at home. But even out.

E117: He goes, "Ow! Oh!" And I can hear him. And I know whenever he does that...

RC: It's bad.

CG: Right.

E195: I can read his body language. When he wakes up cussing, then I know he's in bad pain.

A few spousal caregivers also described specific past instances where they observed a discrepancy between the PWDs' nonverbal pain behaviors and their verbal denials of pain. These caregivers reported noticing that the PWDs were displaying nonverbal pain indicators (e.g., limping or moaning). After observing these behaviors, they asked the PWDs about them, including whether they were experiencing pain. Despite the PWDs denying that they were experiencing pain, these caregivers did not ignore these nonverbal behaviors, which deviated from the caregivers' knowledge of the PWDs typical behaviors when pain-free. One of these caregivers (E201) described continuing to ask her husband about his atypical nonverbal behaviors, including asking different and more specific questions, until she had an explanation for them that matched her understanding of the PWD's past behavior.

E201: He'll start moaning or something, and I'll go, "What's wrong?" You know? He goes, "Nothing." [CG then asks] "Then why are you vocalizing? Why are you [CG makes moaning sound] like you're hurting?" [PWD then responds] "Well, my neck is hurting." And then he'll open up and tell me. But it's usually his back or his neck that he has the biggest issues [with]. And it gets very intense usually before he'll tell me. I've realized that.

In addition to continuing to ask her husband about his nonverbal pain behaviors despite continued verbal denials of pain, another caregiver (E122) described pursuing medical treatment for her husband. She reported continuing to observe her husband's nonverbal behaviors (i.e., limping), which were discrepant with his denials of pain and/or injury. This led her to take the PWD to the doctor. Furthermore, when his limping persisted despite his having been examined by a doctor, she pursued a second and a third medical opinion. Without her familiarity and

knowledge of her husband's typical behavior (i.e., walking without limping), she would not have been alerted that something was wrong with him and may not have persisted in seeking an answer for why her husband's verbal and nonverbal behaviors did not match. She reported that her husband was ultimately diagnosed with rheumatoid arthritis and that she now gives him acetaminophen twice daily for his pain. During the home practice review at the start of the second session, this caregiver described her evidence for the effectiveness of the acetaminophen in treating her husband's pain, which included the absence of nonverbal pain behaviors (see excerpt on page 70).

E122: That's how I found out that something was wrong with his knee because he started limping. And I [was] thinking, "He didn't fall." 'Cause I'm here all the time with him. And he didn't hit his leg on anything. So, what's going on? So, I guess like week passed, and it was the same thing. And I'm thinking, "Something is [wrong]." And I asked him. I said, "Did you hit your knee? Your knee hurting?" And he kept telling me that it wasn't hurting. But I kept telling him, "Something is wrong with your knee." I say, "You['re] limping." I say, "Hit your knee on something?" I said, "Did you fall?" [He'd respond] "No, I didn't fall." It was puzzling to me. So, then I thought, "Okay. I don't really in [the] medical field know what's going on. So, I'm gonna have to take him to the doctor." So, I did, and that's when...it was like I had to take him 2 or 3 times before they actually find out what was going on. So, you know, it was hard for me to just look at him and tell. [...] Rheumatoid arthritis is what he had.

RC: Well, you did it perfectly then.

CG: So, I knew it was...

RC: Knew something was going on.

CG: Something was going on that I had to know about. I had to try to, you know? And it was puzzling my brains. And I'm thinking, "Oh, my." You know, so I need[ed] medical attention. Medical help here.

CG: What he had in the past when it first started it was...yeah, it was knee pain. But I didn't realize what it was like I mentioned before. So, when I took him there to the doctor, and they was telling me it was like that arthritis that he had. They gave him some medicine. Gave him Tylenol to take. And I usually give it to him twice a day.

Understanding of PWDs' Pain Language. The next subtheme consists of spousal caregivers' knowledge of the words used by PWDs when they are experiencing pain and/or distress. Caregivers expressed varying degrees of awareness and mental flexibility in describing

or identifying the words their spouses used when they were experiencing pain and/or discomfort. Some caregivers demonstrated inflexibility or rigidity in their understanding of which words the PWDs voiced when they were having pain. In these instances, these caregivers could not identify any words other than “pain” that notified them that the PWDs felt pain, discomfort, and/or distress.

E14:

RC: How about doing social things with other people?

CG: Yeah, if you're tired and you don't feel like going would that be considered that?

PWD: Yeah, because sometimes...

CG: 'Cause if he's tired and goes, “Ugh, I don't feel like going. I’m tired.” Would that be the same as [him not doing social activities because of his pain/distress]?

RC: Yes.

E69: Do you want more information about getting treatment or care that your husband needs? And this would be for pain and distress.

CG: Would anything actually help the distress?

RC: Um, well that's what we're hopefully trying to do. We'll see if it works or not.

CG: Okay, that would be nice.

One caregiver (E93) in particular expressed annoyance and confusion regarding her husband’s continued complaints that his shoulder was “swollen” and “tight.” She described asking him whether what he was experiencing was pain and his response being that it was “a little pain, but not really pain.” This caregiver expressed uncertainty regarding how to respond to her spouse’s complaints as a result of his continued use of words other than “pain” to describe his shoulder-related pain and distress.

E93: What's bothering me with my husband is...and it goes back I guess [to] communication. He constantly...well, not constantly...but he complains about his right shoulder. So, I'll say it him, "Is it pain?" And he says, "Well, a little pain, but not really pain. And it's tight. It's swollen." And I just cannot figure out what he's actually, what he's actually trying to say to me.

Interestingly, in subsequent conversations with the research clinician, this caregiver reported that the PWD previously experienced a shoulder “strain” and had received a cortisone injection in

that shoulder, effectively treating the related pain and discomfort. He had not been scheduled for further treatments, and the one-time injection that he received in his shoulder had been over one year prior. Despite her knowledge of the PWD's past pain and its effective treatment, this caregiver was unable to conceptualize the PWD's shoulder problem as pain, instead preferring to describe it as "bothersome."

E93:

RC: I would definitely talk to the doctor, and say, "Hey, whatever you did last time, that worked well. I've noticed now though the pain's come back."

CG: But see it's not...he's saying that it's not pain.

RC: Or the swelling has come back, and it's bothersome.

CG: Yeah.

A different caregiver (E02) demonstrated similar inflexibility regarding which words when used by the PWD indicated pain. She described frustration regarding her husband's behavioral withdrawal, explaining that it made her angry. Furthermore, she reported that she did not ask him why he was withdrawing to their bedroom and/or lying down. However, in contrast to the previous caregiver that was unable to adjust her understanding of which words indicated that the PWD was experiencing pain or distress, this caregiver responded positively to the example provided by the research clinician. Specifically, the research clinician described her experiences working with another gentleman who continuously denied having "pain," instead reporting that he felt "tired." The caregiver then applied this language to her own experiences with her husband. She described a recent experience where the PWD had to sit for a long time at the doctor's office and complained about his back. She reported that she asked him what was wrong, and he responded that he was "just so tired."

E02: I'm listening to and applying it to myself as well so I can understand what's happening with him too. That's like what you say, I can get up and take care of myself, but just like him going back in that room.

RC: And lay down.

CG: Won't say anything. Won't talk.

RC: I always use an example [of] a gentleman that I see, he has a lot of pain, but he won't admit it. Every time I say the word pain. He'll say "I don't have pain. I don't know what you're talking about." But he would describe he's feeling tired and fatigued. And he'd say, "My back..." (severe back pain) he'd say, "Well, my back just gets tired." So then when I started using tired instead of pain then he would be able to tell me. We could really get an understanding of his pain. He wouldn't use the word pain.

CG: Oh, okay. He say[s] that all the time. He's always tired. He's always tired. When we went to the doctor the other day, he complained about...well, he's always upset when he has to sit a long time anyway. But he was complaining about his back. I said, "Well what's the problem?" [PWD] "I'm just so tired."

Other caregivers demonstrated mental flexibility in which words when used by PWDs indicated that they were experiencing pain or distress. These caregivers reported PWDs used words like "tired," "uncomfortable," and "hurts." They also expressed awareness that the PWDs had difficulty describing variations in their pain's intensity and/or location and could only confirm or deny the presence of pain and/or discomfort.

E69: I'll ask and say, "Is it hurting real bad?" And then he'll say, "Yes" or "No, not too bad." He just say[s], "It hurts."

E73: When I ask him, he says, "Ask me where it doesn't hurt."

E84: He'll say, "I'm tired. Oh, I hurt."

E209: He'll just say, you know, "I hurt" or "I'm uncomfortable." And then I usually probably just try to guess by how he's acting whether he's in a lot of pain.

E209: If I said, "How much pain are you in?" He'd probably just goes...he'll tell me, "I just don't feel well." I don't think it's as far as pain goes...like I said we're not at these [severe] levels as far as pain. 'Cause he just doesn't...and that's what I actually have to do that already 'cause he doesn't give me straight answers.

Furthermore, one caregiver (E51) described being aware that the PWD was feeling pain when walking around a store due to him telling her that he needed to get a beverage or some candy. This caregiver expressed understanding that her husband's statements were motivated by a desire get some pain relief through sitting down and taking a break from walking. She did not need the

PWD to use the word “pain” in order to understand that his actions and behaviors were pain-related.

E51: He wants to sit down. When we got in the store [he'll say,] "I need a Coke. I have to sit down there at McDonalds." Sometimes we make him walk a little bit. But he[']s just like, "I need a candy" or "I need Coke. You go get what you have [to get]."

Given the impact of dementia on PWDs' abilities to verbally express themselves as well as the long-standing tendency of many of these PWDs to minimize their pain, caregivers with greater mental flexibility regarding which words might have indicated the PWDs had pain were better able to recognize when the PWDs were experiencing pain and/or distress, and then act to help them manage their better.

Attributing PWDs' Pain Behaviors to Causes Other Than Pain. This subtheme involves the tendency of several spousal caregivers to believe that some of the PWDs' pain behaviors were caused by things other than untreated pain. The reported nonpain causes of possible pain behaviors included both those perceived to be out of the PWDs' control (i.e., comorbid conditions) and those perceived to be within the PWDs' control (i.e., personality-driven factors).

Various comorbid conditions were reported by caregivers as reasons for the PWDs' engagement in certain pain behaviors. Dementia-related memory impairment was identified by multiple caregivers as the cause of at least some of their husbands' possible pain behaviors. One caregiver (E209) expressed that her husband had stopped doing activities, but that this was not due to his pain. Instead, she attributed this change in his behavior to his memory problems and his related fears if he was away from his home without his wife.

E209: I think he stopped doing anything or going out because of his memory problems, and not feeling secure. I think he gets...actually I think that would be when he's scared. I think he gets scared at times if he's out and not...unless I'm right there with him. He's fine if I'm there with him. He doesn't want to be anywhere without me.

Similarly, another caregiver (E135) stated that the PWD stopped participating in activities due to his memory impairment, in addition to his vision and hearing loss. When directly asked by the research clinician whether pain also played a role in reducing his engagement in activities, this caregiver responded, “Probably.” As such, this caregiver may have attributed her husband’s lack of activity to multiple causes while also believing the non-pain causes played a greater role.

E135: There's no activity that actually he could participate in because of the memory loss and the vision and hearing.

RC: What about the pain? Do you think that plays a role also? Or no?

CG: Probably.

This same caregiver implied that her husband demonstrated restlessness due to boredom caused by his inability to “do the things he’d like to do.” While she did not specify what was preventing him from getting up and doing the activities that he wanted to do during this portion of the session, this caregiver previously identified the PWD’s memory impairment, vision loss, and hearing loss as what stopped him from participating in activities. She also reported that her husband had Parkinson’s disease during the session, but it was unclear what impact (if any) she believed that this had on his inability to do the activities that he would have liked to do.

E135: No, his is just because he can't get up and do things like he'd like to do.

PWD: Yeah.

RC: It sounds like you've noticed that, but you don't feel like it's related to the pain.

CG: No, because the pain is always there. Gets restless anyhow. I'm just saying.

RC: Okay. So, you have noticed restlessness, but for you it feels like it's not related to pain.

Another caregiver (E69) whose PWD also had Parkinson’s disease suggested that this was the cause of some of his pain behaviors. This caregiver reported that her husband sometimes seemed like he could not walk and described him as sometimes needing to be pushed by her in his walker in order to make it to the bathroom.

E69: Sometimes to get him into the bathroom I have to get him in the walker, when you sit on it and push him around 'cause it seem like he can't walk. Like as I said it could be related to Parkinson's 'cause sometimes he act like [he] just can't walk.

Two other caregivers reported that their husbands engaged in bracing in order to “avoid falls” and that this behavior was unrelated to their pain. One of these caregivers (E53) did not specify a reason for her husband’s bracing beyond to “keep from falling.” However, she previously shared that her husband had arthritis and knee pain and reported that his current pain treatment (Tramadol) was ineffective. Furthermore, a robust body of research supports the relationship between chronic pain (including arthritis) and increased risks of falls in community-dwelling older adults. For example, a meta-analysis of 21 studies that examined the relationships between pain and falls risk in older adults found that 50.5% of adults with pain had at least 1 or more falls while 25.7% of adults without pain had at least 1 or more fall during the past 12 months (Stubbs et al., 2014).

E53: Yeah, he does that [braces], but it’s not necessarily for pain. It's just to keep from falling.

A different caregiver identified the PWD’s low blood pressure as the reason that he was prone to falls and, thus, needed to engage in bracing.

E209: He has to do this holding on because of the [low] blood pressure. He has to brace himself to avoid falls.

A few caregivers attributed some of the PWDs’ pain behaviors to personality-driven causes. As a result, these caregivers indicated that the PWDs could control or limit them. These caregivers described multiple motivations for their husbands’ behaviors. One of these caregivers, who had previously reported that the PWD’s behavioral withdrawal and isolation made her angry (see excerpt page 94), shared that her husband wanted to withdraw when things

became “busy and loud.” She further expressed that she had never associated that behavior with his pain.

E02:

RC: I always use the example of a headache. You know, loud noises? Maybe there's a constant ringing in the house or something. That could cause him to have a headache.

CG: I noticed that when things get busy and loud, you know, that he wants to withdraw again. He wants to go back to the room. [CG described birthday party they attended where there were many people present.] He wanted to go back. When they came to the house, he wanted to go into the room. He'll sit for a minute, but then he goes. The loud noises...I never associated that with [pain].

Another caregiver (E198) reported feeling confusion regarding the cause of three of the PWD's pain behaviors (lying down, moans, and bracing). She first asked the research clinician whether her husband's “wanting to lie down” could be a nonverbal indicator that her husband was having pain. Then in response to the research clinician asking her what else wanting to lie down could mean, this caregiver suggested that laziness or fatigue could also be the cause of this behavior.

E198: Would one of the signals be just wanting to lie down?

RC: Could be. Yeah. Or what else could it be?

CG: Well, could mean that he's tired.

RC: So, you have to get to be able to figure out...

CG: Are you lazy?

RC: You in pain or are you tired?

CG [laughing]: Or lazy? Okay.

Later in the session, this same caregiver described confusion regarding why her husband moaned every time he passed her in the house as well as sometimes when she joined him in bed even though he appeared to be asleep. She posited that her husband might be doing this to get her attention or to “irritate her.” The research clinician helped the PWD explain to his wife that he did this to communicate to his wife. He further clarified that he always experienced pain when walking. This appeared to surprise his spouse, who expressed that she had not known that walking always caused him to experience pain.

E198: Well, if I don't know he's in pain, but he doesn't appear to be in pain, whenever he passes me in my presence, he moans. So, I don't know if that's an attention getter. Or like don't ask me to do anything because I'm hurting. This is a trick. But it is...he can be in the bed just no moaning, but when I...the minute I get in the bed, there's a moan.

PWD: How do I describe that? Sometimes it's just to let her know that I am awake. Or it's more or less a signal in some kind of way. Yeah, and I don't know exactly how to describe [it]. Like I said sometimes it's to let her know I am awake. I may be laying in bed still, and she may think that I'm sleeping. That may be an indication that I am awake. But other than that, I couldn't describe.

CG: What about just normally walking through the house and stuff [and] when I pass you moan?

PWD: I couldn't describe why I do it. Yeah.

RC: Well, maybe it is the pain. You know, you said...well, pain causes...he gets a lot of pain while walking. Maybe his way of letting you know he is in pain.

CG: Okay.

PWD: Well, I'm always in pain when walking. Always in pain when walking and standing.

CG: Always? Okay.

PWD: Yeah.

CG: I thought [you were] just trying to irritate me. Okay. [CG, PWD, and RC all laughed.]

Finally, this caregiver reported that her husband sometimes engaged in bracing. Instead of believing that this behavior was the result of his pain, she suggested that his bracing was one of his “nervous habits.” Despite acknowledging that it could be pain, she continued to question the reason why he regularly leaned on things (e.g., the sideview mirror of her car) and braced. In suggesting that this behavior was a “habit,” she implied that it was under his control and something that he had the ability to change.

E198: Like breaking your sideview mirror off the car when you pass it in the garage. He leans on things.

RC: That makes sense if you've got a lot of pain walking.

PWD: Yeah.

RC: Or standing to get extra support.

CG: How can that support you? Just the mirror on the car is really no support.

PWD: Well, the closeness of the car to other stuff that's in the garage. It's not like I can just walk through wide space like this not having to hold anything. But it's so close to [other things] feet is gonna bump against it or whatever. I'm gonna touch it for support, you know? But I just...sometimes I think some things are just out of habit. When you pass the wall, [you] just touch it. I think it's just one of his nervous habits. So, I don't know. Maybe it is pain. I don't know.

RC: It could be. But I would say, if he has pain all the time while walking, it's probably the [way he] gets relief.

CG: Okay. So, what do you say it is [to PWD]? When you just touch everything?

PWD: That's just for bracing. That's all. Supporting myself.

Both of these caregivers attributed some of PWDs' pain behaviors to personality-driven causes that they believed were under the control of their husbands and expressed negative emotions regarding their caregiving experiences with their husbands. Caregiver E02 reported feeling "angry" when her husband withdrew to his bed and isolated himself. Whereas caregiver E198 suggested that the reason for her husband's pain behavior (moaning) was to "irritate" her, indicating that she may have found this behavior to be annoying. Interestingly, both of these caregivers reported that their husbands experienced significant daily pain interference in their general activity but avoided providing them with pain medication.

Spousal caregivers described differing levels of success in identifying when the PWDs had pain due to their pain assessment beliefs and knowledge. Poor understanding of dementia's etiology, disease progression, and impact on language likely leads to missed opportunities for pain treatment. In contrast, knowing the PWDs, including awareness of their pre-dementia responses to pain as well as the words they currently used to convey that they were having pain, was reported by almost all spousal caregivers to aid them in accurately assessing the PWDs' pain. Some caregivers attributed the PWDs' pain behaviors to causes other than pain, which may have caused missed opportunities for pain treatment.

Pain Management Beliefs and Knowledge (PM)

The second theme involves how spousal caregivers decide to assist (or not assist) PWDs in treating or managing their pain. This covers the caregivers' general beliefs about pain as well as what they believe their role should be in their husbands' pain management. This further consists of what they believe or know to be the cause of the PWDs' pain, their understanding of

the location(s) of the PWDs' pain, and their perception of the intensity of the PWDs' pain. It also encompasses the caregivers' experiences with the PWDs' healthcare, including how they prioritize the treatment of the PWDs' comorbid conditions and barriers to accessing the necessary healthcare to effectively manage the PWDs' pain. This theme further includes the spousal caregivers' preferences for how their husbands' pain is treated, including pharmacological and non-pharmacological pain treatments.

Belief That Pain Is a Normal Part of Aging. The first subtheme of PM was the belief held by many spousal caregivers that pain was a normal part of aging. Similar to how the misconception that dementia is a normal part of aging leads to delays in seeking medical treatment for the PWDs' dementia (Hinton et al., 2005), caregivers' holding this belief about pain may postpone their pursuit of medical treatment for the PWDs' pain. If pain is a normal, inevitable part of aging, it is believed to be something that must be endured, rather than something to be treated.

E14: Yeah, you just learn to live with it because it's there constantly. You know, my back hurts right here? But, you know, what can we do?

E19:

PWD: She has more pain than I have.

CG: Well, you start recognizing pain when you get [to be] 68 [years old].

E89: It's a matter of when he wants to do something, he pushes through it [the pain]. But he does a lot of complaining. His hand hurts...his back hurts...everybody has that at our age.

Another caregiver (E209) explained that the lack of treatment for a friend's cancer-related pain was due to her age (83 years) (see excerpt page 67). This same caregiver also expressed that her own pain was always present, with just its intensity changing, and that ignoring it was the best way for her to manage her pain. She described having similar beliefs about the PWD's pain, which may indicate that she avoided asking him about his pain.

E209: 'Cause I think...like I said if I ask him about the pain, and he'll stop and think about it. And he'll say well he is in pain. He'll say, you know, "Well, my...it's not something." He probably doesn't think about it unless you really just ask him because it's always there. So, it's kinda like my arthritis with my fingers now...it's always there. So...
RC: You know, it's really a skill though to be able to divert your attention to other things when you're feeling the pain all the time. That's really good that you're able to do that.
CG: Well, yeah. Because I have arthritis bad, especially in my fingers. It's so bad. They ache all the time. You know, sometimes...like rainy weather or changing weather or cold weather. So, there are times when [my pain's worse], and you just go on about your business. You sort of ignore it. But it's always there.
RC: It's always there.
CG: But if somebody just asks you if they hurt then you will stop and think about it. So, I think a lot of it his [pain] is probably like that. Because I'm sure his lower back is always hurting.
RC: Somewhat.
CG: But not [unbearable/severe pain]...I mean somewhere in the middle of the scale. Moderate back pain, you know. It's probably [moderate] for the most part. There would be tasks where it would be up here in very bad.

Many caregivers (E14, E19, E89, E93, E209) who expressed beliefs that pain was a normal part of aging had chronic pain themselves.

E14: I feel like I have pain all the time, and [I] have to live with it. Like okay, my back hurts me all the time like this.

Interestingly, the two caregivers who expressed this belief but did not have chronic pain themselves reported dissatisfaction with PWDs' current analgesic pain treatments. One caregiver explained that his Tramadol did not "do much for him."

E53: He can't lift much that doesn't start the knee or the shoulder from hurting. And the knee, he can't get down on his knees and do anything. It's just...they've told him he's got arthritis in it, and we're trying to live that. But, you know, it's just get what you can out of it and bear the rest. They put him on Tramadol, but that doesn't do much for him.

The other caregiver (E63) who shared this belief despite not having her own chronic pain was dissatisfied with the PWD's pain medication, due to concerns regarding opioid pain medications. She feared that their use would cause her husband to "stay zonked out" (see excerpt page 90). Both of these caregivers (E53 and E63) may have been unaware of non-pharmacological pain

treatments, possibly due to lack of personal experience managing chronic pain. This may have contributed to their continued belief that pain was “something you have to endure” and “bear.”

Notably, the one caregiver (E93) that reported reading one the chapters from the optional self-help guide on pain management in older adults (Hadjistavropoulos & Hadjistavropoulos (Eds.), 2007) between the first and second sessions shared that she had learned from this resource that pain was not an inevitable, normal part of aging. She expressed that she now had new, more accurate beliefs about chronic pain, as well as a new understanding that things could be done to better manage chronic pain.

E93: Before all this happened, I read about Stan [character from optional readings] and the limp leading to this. And how he just I guess closed up to relationships or the whole bit. But what was interesting was the questions, you know. Like pain coming with old age or whatever. And how this myth...because we say it all the time. He and I say it all the time. We [are] getting old, and about the pain. And just reading about that...that it's really a myth, you know. Being older doesn't mean that...you're gonna have some pain. But it's not [that it] cannot be managed. So, it was interesting. The reading was very interesting.

This caregiver demonstrated how psychoeducation that dispels myths about pain, especially pain in older adults, can improve someone’s awareness that pain is treatable. Still, it is concerning that so many of the spousal caregivers (approximately a quarter of the sample) voiced this belief before receiving the PAVeD intervention. This likely led to missed opportunities to treat the PWDs’ pain.

Understanding of the Cause(s) of PWDs’ Pain. The next subtheme involves spousal caregivers’ explanation(s) of the cause(s) of the PWDs’ pain. These descriptions were often consistent with the biomedical model. Most caregivers reported that tissue damage from an injury or a medically diagnosed painful condition was the cause of the PWDs’ pain. Some caregivers even expressed confusion in response to psychoeducation on pain that was consistent with the biopsychosocial model. The reaction of two caregivers to psychoeducation regarding

“What is pain? (which included a handout with pain facts) was uncertainty (See Appendix A and Appendix B). During this portion of the session, the research clinician explained that “Pain isn’t just a physical experience; it’s an emotional experience too” in addition to describing the bi-directional relationships of pain with mood, thoughts, and behaviors. One of these caregivers (E93) stated that she “never related pain to emotion.” The other caregiver (E100) expressed that she was “trying to understand the word pain” due to the content included on the “What is Pain?” handout.

E93:

RC: Pain can cause depressed mood, negative thoughts, and behavior changes. But also, if you see the arrows, it's a 2-way street...

CG: Physical and...mm-hmm.

RC: Physical and emotional, right.

CG: Mm-hmm.

RC: So, when we have these thoughts like "I'm never gonna feel better" then that makes us not want to go out and do anything. Then our muscles atrophy, which makes them hurt more. So, it ends up being this cycle.

CG: [I] Never related pain to emotion.

RC: Mm-hmm.

CG: Oh, okay.

RC: Yeah.

CG: Hmm, okay.

RC: Yeah, especially when we feel like we can't do the things that we used to do, and we used to be really active. Or we used to... We can't do that. It gets to be... It makes us sad.

CG: Right.

RC: And depressed, and we feel like can't do things. And everyone has to help us. And...

CG: Yeah, that's an emotion though, right?

RC: Mm-hmm, exactly.

CG: But it's considered pain as well?

RC: No, it's considered emotional pain.

CG: Emotional pain. Okay. Emotional pain...

RC: But emotional pain...

CG: I can understand that.

RC: ...yeah, can be caused by physical pain.

CG: Right. Okay.

E100: We discussed this before when y'all came. And I'm trying to get in my mind exactly in what way you are referring to pain. Okay, I know, of course, about physical

pain. I know that. But now you were here before and the other young lady. We discussed this, and it seems as if to me... I want you to explain it to me if I'm wrong.

RC: Sure.

CG: That it could be pain in other ways, other than physical. Is this correct?

RC: That's correct.

CG: I mean I'm looking at this diagram here.

RC: Oh, sure.

CG: They say it's pain. Okay?

RC: You're ahead of me.

CG: Yeah, okay. But I'm trying to understand the word pain. Because I want to be sure that you are not referring to just physical.

RC: Correct. We're referring to...

CG: It could be either of these 3 things.

RC: Correct. It...well, what this diagram is telling you is physical pain...when a person has chronic physical pain...

CG: Mm-hmm.

RC: ...it can make them depressed because you feel that you're never gonna get better. I'm never gonna be able to do the things I used to do. You know, I'm never... I'm always going to be more limited in my activity. So, it leads to kinda this negative thoughts...

CG: Mm-hmm.

RC: ...which I was just saying. Which can make you depressed. Which can then lead to behavior changes, like you becoming more inactive [and/or] not going out as much.

Which then makes your muscles weaker and tighter, which then can lead to more pain.

So, this diagram here is really referring to physical pain. However, the same can be said if you do have...if he suffers...or you've got depression or anxiety. You know, that can cause negative thoughts as well, like I'm never going to feel any better. Or I'm not going to be able to do the things that I used to do. And that can lead to behavior changes like isolation, which then can create...make you depressed. So that can be a cycle as well.

CG: Mm-hmm.

RC: When I ask you about pain, what I'm really referring to right now is physical pain.

CG: Mm-hmm. Okay.

Interestingly, both of these caregivers subsequently asked the research clinician for clarification regarding whether the home practice assignment was meant to describe the PWDs' physical pain or emotional pain.

E93: This is where I'm getting (not confused), but I'm trying to understand. Are we talking about physical pain or emotional pain?

RC: This is physical.

CG: Physical. Okay.

E100: I'm looking at the [pain] thermometer here.

RC: Yes.

CG: And I'm going to ask him this [these] questions. I mean about pain.

RC: Yes.
CG: He's going to basically refer to his physical pain.
RC: That's fine.
CG: Is that correct?
RC: Yes.
CG: Because...
RC: That's what we want you to focus on this one.
CG: Yeah, his physical pain.
RC: Yes, that's what we want you to focus on.
CG: This thermometer is referring...
RC: Correct.
CG: ...to his physical pain.

One of these caregivers (E93) provided further evidence during the home practice review at the start of the second session of her prior lack of exposure to pain from the perspective of the biopsychosocial model. The conversation between this caregiver and research clinician appeared to have begun prior to the start of the session's audio recording, so there was no information regarding the specifics of the situation to which the caregiver was referring. Still, she clearly expressed that she found the psychoeducation provided to be helpful, as well as a change from how she had previously thought about pain and distress. Interestingly, as mentioned in the previous subtheme, she was also the only caregiver that specifically reported reading the optional material (i.e., Pain Management for Older Adults: A Self-help Guide (Hadjistavropoulos & Hadjistavropoulos (Eds.), 2007), which may have further aided her in developing new beliefs about pain (see excerpt page 59).

E93: You just really hit home. So, when you talked to me about this mental pain. And see [that] I was just dealing with just [the] physical [pain], and I didn't see how deep the mental pain could be. So, you really helped me with that.
RC: Often times they can be con...you know?
CG: Yeah.
RC: Kinda what our study is looking at is how the chronic pain can lead to mental pain.
CG: Mental. Yeah.
RC: And then how that can become a cycle.
CG: Mm-hmm.
RC: You know, when you're in a lot of physical pain, you get depressed.
CG: Mm-hmm.

RC: And when you're depressed, that makes your physical pain worse. But, of course, you can have the emotional pain...

CG: Right, with it.

RC: ...without having the physical [pain].

CG: Wow.

Many caregivers seemed to easily identify and describe the PWDs' pain if they had knowledge of an established physical cause. An example of this was observed in one caregiver's response to her husband being asked what year his pain started after he expressed that he could not remember that information. His wife quickly stated that he had been having pain for the past five or six years. She then reported that his pain was the result of a pinched nerve that had continued to worsen.

E14:

RC: And in what year did you start having pain?

PWD: I don't remember.

CG: It's been a good what 5 years, 6 years already. Five or 6 years. It's gotten worse.

PWD: Stayed with a headache...get headaches all the time.

RC: You get a lot of headaches?

CG: Mm-hmm.

RC: Okay, so it's on your back and shoulder?

PWD: Across here and on my shoulder.

RC: Was it caused by an accident? Or?

CG: Well, he had like a pinched nerve about 6 years ago. And from then it's never gotten any better. It's gotten worse and worse.

In contrast, a different caregiver expressed uncertainty when answering the research clinician's question regarding whether the PWD had arthritis, changing her response from "yeah" to "well, no." Her husband subsequently explained that he had previously had an MRI, but his doctors had not diagnosed the cause of his pain.

E195:

RC [to PWD] So, you have arthritis?

CG: Yeah. Well, no.

PWD: It really hasn't been diagnosed. They've taken MRIs and...

RC: All that, and they didn't find [the cause]?

PWD: Yeah. It's...I can tell you what it is. It's old age.

Another caregiver appeared to question the validity of some of her husband's pain and reported that she believed that his pain was caused by his failure to exercise. She explained earlier in the session that his pain included leg pain severe enough to lead to multiple falls. Still, she expressed that it was her husband's fault that he had pain due to his lack of exercise. However, after sharing this, she then brought up his stomach pain, resulting from a hiatal hernia. She described this pain differently, stating of his stomach pain that "it could be that he's telling the truth." This caregiver implied that the PWD's pain for which she could identify a specific physical cause was "true" or legitimate. When she could not identify a physical cause of the PWD's pain (other than his inactivity), she blamed him for it.

E37: One morning he got up, so he was hurting. I said, "What's hurting you?" He said, "My stomach. "And one day (I asked him every day), but one day he voluntarily... He was helping me in the kitchen, moving around. I was so glad. He said, "Oh, my legs hurt. I gotta go sit down." [CG sighs] So I said, "Go sit down." But I think that pain is because he do[es] not get exercise. I really believe that. I may be wrong. And the pain in his stomach it could be that he's telling the truth because he has a hiatal hernia. And I haven't heard from his primary care. They're going to take him in. That's what they're going to do about it. I don't think they'll do surgery. I think they'll probably bypass that and put him on some kind of medication.

Spousal caregivers rarely attributed the PWDs' pain to anything other than damaged tissue or a painful chronic health condition (e.g., gout, diabetes).

E90: That neuropathy in diabetics comes and goes also. He's sore. That's what he says. So, I guess it's pain.

Some caregivers described past causes of PWDs' acute pain, despite PWDs no longer experiencing pain related to those causes.

E02: He's had the hip replacements. He's had the ostomy. He's had a heart attack. And each time he had surgery for those. And he had the surgery for this burning pain that he had, and they found it was colon cancer because it was up here, way up high. And he used to complain about that all the time. But that was before the surgery. So, he's had, since we've been here, I think he's had 5 surgeries since [20]05.

E89: In 1978, he had his first heart attack.

RC: Oh, wow. Okay, and that caused a lot of chest pain, I assume.

CG: Oh, in the chest. That was an emergency. Eventually that. ...40 days later or so he had to have the bypass operation.

RC: Okay. Does he still have pain from that?

CG: No, not from that. But he also had...way before that in 1960-something, he hurt his leg, had that in a cast. I mean through the years he's had many instances of pain. Back related at various times.

RC: What does he have now?

CG: He has spinal stenosis. Gosh, I don't have his list in front of me, but he has back pain, leg pain, foot pain.

E209: He had quite a bit...probably about 4 years. He had terrible pain with his back. And then he had to have surgery on...he fell at the VA. And he had to have surgery on the back. And that did help some, but he always has back pain.

One caregiver expressed that she did not know that pain could persist beyond the healing of physical tissue damage. This was interesting given that the PWD agreed with the research clinician that pain could continue after the damaged tissue had healed.

E14:

RC: There are types of pain that occur long after the physical tissue has healed.

PWD: That's true.

CG: Really?

PWD: Oh yeah.

CG: I didn't know that.

Furthermore, an accurate medical diagnosis is an important component of the biomedical model. In this model an accurate diagnosis is needed to identify the appropriate treatment, which will then effectively heal the damaged tissue. One caregiver (E195) expressed a desire for the PWD to be “diagnosed better,” sharing that she did not want her husband to be on analgesic medication for “the rest of his life.” Her statement suggested that she believed an accurate diagnosis of her husband’s painful condition was needed for it to be effectively treated. This may have also indicated that she was unwilling to use analgesic medication to treat her husband’s pain.

E195: I don't want him to be on pain pills for the rest of his life. I'd just like for him to be diagnosed better.

Another caregiver (E33) described taking her husband to four different doctors, all of whom were unable to determine the cause of his pain and distress. Thus, the caregiver shared that “there’s nothing” that could “help him.” She seemed to suggest that a diagnosis for the cause of her husband’s ringing in the ears and dizziness would have enabled the PWD’s doctors to find an effective treatment, reducing his suffering. Notably, she was the spousal caregiver that demonstrated the highest level of understanding of the dementia disease process and described speaking with cognitively intact individuals with the same conditions (or constellation of symptoms) as her husband to better understand his pain and distress and identify potential pain management strategies (see excerpts pages 41-42). As such, caregiver E33 did not let the lack of diagnosis dissuade her from searching for ways to help the PWD better manage his pain.

E33: He started telling me about ringing on the ears and his dissonance. And it has been ever since then. And four doctors have seen him, but they just couldn't find anything wrong. They even checked his ears. So, I don't...he has to live with what he's got. They say there's nothing can help him. The ringing drives him crazy.

Multiple spousal caregivers reported long-healed physical injuries from years or even decades prior as the cause of the PWDs’ pain. Types of past injuries identified by caregivers included muscular tears and broken bones. In fact, no caregivers reported a recent injury as the cause of PWDs’ pain. This is significant as pain persisting beyond tissue healing is inconsistent with the biomedical model.

E44: Remember when you injured your back, and you try not to bend down? Or if you stand on your feet too long your back hurt? You know when you were trying to paint the old house when you had the big old ladder, the painting? You messed up your back, you were on your back for 2-3 weeks. I don't remember now how long.

PWD: Oh, yeah. I forgot about that.

CG: You pulled a muscle. It still bothers you.

PWD: Oh yeah, if I do a different function or something, I regain [the pain].

CG: He doesn't bend that much. He doesn't pick up stuff.

PWD: I use that little pick up thing.

E53: I guess when he fractured his knee and stuff like that. It's been about 5 years. They're giving him a shot at the VA in it. And he was getting it in both shoulders 'cause he hurt one shoulder, tore the rotator cuff about 3 years ago, I guess. The other one I think is just arthritis. He just gets a shot in both of them. I don't know what they call it, but it wasn't called cortisone. He gets it every 4 months right now, but he had some time in there when they had stopped them or a while. It works good for him. He doesn't complain of it hurting when they give it or when he gets home.

E93: 2001.

RC: Okay, so about...a little over 10 years ago.

CG: Yeah, and that was due to a fall, and he broke his hip.

Other spousal caregivers reported painful chronic health conditions to be the cause of PWDs' pain. These conditions included arthritis, gout, neuropathy, and cancer. These caregivers expressed varying beliefs regarding the severity of PWDs' pain. Some of these beliefs appeared to stem from the caregivers' understanding of the expected course of their husbands' painful condition. For example, one caregiver whose husband had bone cancer expressed multiple times and that she expected his pain to increase over time as a result.

E209: I know it's early stages as far as the pain goes. 'Cause I know with the bone...I know that with the bone cancer it will get bad as it progresses.

CG: You know, like I said, with this bone cancer, I know we're gonna get up to those [severe pain intensity levels], and I don't...I'm dreading that part.

Interestingly, this caregiver also explained that she recently had a friend that passed away from bone cancer. She shared that her friend had received no intensive treatment for her pain, which she believed was at least partially due to her friend's age (i.e., 83 years old).

E209: I just lost a friend recently, and she had cancer in all in her bones. And they didn't do anything. They pretty much...well, she was 83. They pretty much left her alone. Because I think everything hurts at that point.

At least part of caregiver E209's understanding of the severity and expected progression of her husband's bone cancer was due to believing that there were no effective treatments, especially

for older adults. Another caregiver (E71) reported that her husband's pain was severe, sharing that it was "almost unbearable" every day. She expressed that since his pain was caused by arthritis the only treatment available for his pain was medication, which her husband avoided taking and did not eliminate all of his pain even when he did take it. As such, her understanding of the PWD's pain severity may similarly have been due to her understanding and/or belief that there were no effective treatments available for his arthritic pain.

E71: They say it's arthritis in the head. That's what they're telling him. That's the reason they have no treatment except for pain pills. And he does take his pain pills.

Another caregiver reported that her husband sometimes had severe pain, which was also due to arthritis. She described him experiencing significant pain interference, including his being unable to drive as well as his having to retire 10 years earlier than he wanted.

E84: It'll be 15 years 'cause he retired at 65. He's gonna be 80 in November. He retired because of his legs. He couldn't stand on them. He's got arthritis, and it's really painful for him. Other than that, I think he would have kept on going.

A few other caregivers described the PWDs' pain as severe due to lack of cartilage between bones, identifying a specific area of damage in the PWDs' bodies.

E117: He had 3 disks. I think it was 3 disks that were...that were almost not there.

RC: So, it was just degenerative.

CG: Over time, yeah.

E54: [The] last 5 or 6 years have been the worst. Because what it is [that] he needed [was] knee replacements, and [he] didn't do it. So, he's bone on bone in his knees.

RC: And you're not going to do any replacements? Or that's not an option anymore?

CG: No.

PWD: I'm mobile enough, and I mean just the picture of the surgery, you know, where they go in there and tear up everything.

RC: Don't wanna [have knee replacement surgery]? So, knee pain is the primary.

CG: Yeah, I mean we're talking hard to get up and hard to get down.

RC: You have no cartilage in your knees? And is there anything they can do...? Short of a knee replacement?

CG: Yeah, that's all.

RC: Which isn't an option?

CG: No.

One of those caregivers (E54) also reported that knee replacement surgery was the treatment that would have eliminated the PWD's pain. In other words, she believed that her husband's worn out or damaged knee joints needed to be replaced in order to be repaired, eliminating his pain. This caregiver was further aware that the PWD was unwilling to have this invasive treatment. Interestingly, this caregiver also described pursuing the possibility of her husband having lap band surgery to help him lose weight. She reported that her husband had lost 45 pounds but was still over 400 pounds, and she expressed that his excess weight likely increased his pain. While lap band surgery is a much less invasive surgery than knee replacement surgery, it may indicate that this caregiver preferred traditional medical treatments (e.g., surgery and medication) to CAM treatments.

E54:

RC: And you have no cartilage in your knees, right?

PWD: I'm sorry?

RC: You have no cartilage in your knees? And is there anything they can do? Short of a knee replacement?

CG: Yeah, that's all.

RC: Which isn't an option?

CG: No, because... What I try and do because, like I said, he's lost 45 pounds, but that 400 and something pounds is a lot do, especially with all the pounding he did on the knees. And I kept trying to say (well, I'll tell you) "Why don't he have that, the stomach, the belt thing?"

RC: The lap band?

CG Lap band. And they said, "Well, we could do the other." I'm really concerned about that other because I've had lots of friends whose husbands have had that thing, and, if they don't stay on it, which he would not without constant supervision, he would be eating. And so that, they just kind of let it go.

Other caregivers indicated that the PWDs' pain was less severe when there were effective treatments, including pain medication and dietary changes. An example of this was observed in caregiver E122, whose pursuit of medical care for her husband's limping was described in the first subtheme (see excerpts on page 47). Due to her subsequent pursuit of medical care for the PWD, which included three separate visits to doctors, her husband was ultimately diagnosed

with rheumatoid arthritis and instructed to take pain medication twice daily. She reported that this treatment was successful in treating her husband's pain due to him verbally denying having pain, as well as her no longer observing him limping or engaging in any other nonverbal pain indicators (e.g., facial grimaces or winces).

E122: So far, he keeps saying he doesn't have any pain.

RC: No pain?

CG: So, I kinda charted it down. I couldn't see any signs of where...that he might have been [having pain]. When I asked him when he get up or sat down or start walking or anything. So...

RC: No pain. Well, I guess that's good. Did you notice any pain?

CG: Well, no. That's what I'm saying. I didn't see any signs where he might have been... Might of had some pain and didn't recognize it. Or anything in his face features or his body motions or anything.

RC: You didn't notice any.

CG: Uh-huh, I didn't notice any. And I even, you know, exercised his leg kinda 1 day. And stuff like that. And he didn't say anything that he had any pain, you know, after I did that. And moving it around or anything.

RC: Nothing. Well, that's good, I guess. What pain has he had in the past? Knee pain?

CG: Well, what he had in the past when it first started it was... Yeah, it was knee pain. But I didn't realize what it was, you know, like I mentioned before. So, when I took him there to the doctor, and they was telling me it was like that arthritis that he had. So since then...I mean they gave him some medicine. Gave him Tylenol to take, and I usually give it to him twice a day. So, I don't know whether that keeps it...

RC: Keeps it at bay.

CG: At bay, where he doesn't be able to feel it enough to say [he] is hurt or is uncomfortable or anything. Most times when I'm moving him around, getting him to bed at night, or when I first get him up in the morning, and with him sitting and me taking his leg out. I ask him about 3 or 4 times per day. And he usually say[s] he doesn't have any. So...and I can't see any facial features or movements. Or I mean anybody...

RC: Nothing indicates.

CG: Indicates that he have...is having any [pain].

RC: Well, that's good. I mean it's good that you're also...that the doctor gave him the Tylenol for the arthritis. You're still...

CG: Right. Right.

RC: ...giving it to him. And it seems to be controlling it.

CG: Right.

Most spouses of PWDs described causes of the PWDs' pain that were consistent with the biomedical model. Any caregivers who were unable to do so expressed a desire for a diagnosis and to know the physical cause of the PWDs' pain.

Perception of Their Role in PWDs' Pain Management. This theme consists of spousal caregivers' beliefs regarding their role in the PWDs' pain management. Specifically, it describes whether these caregivers believed that the PWDs were able to manage their own pain or whether they believed that the PWDs needed help to manage their pain. Caregivers who presumed that the PWDs had the capacity to manage their own pain took a passive role in the PWDs' pain management.

As a result of taking a passive role, some caregivers expressed that they did not know how much pain the PWDs usually experienced. For example, one caregiver (E68) expressed that she could not know how much pain her husband had and that he would need to provide that information to the research clinician himself.

E68: How am I supposed to know how much pain he has? I mean he has to tell you, doesn't he? Instead of me. All I know is he's very, very weak, and I guess he's in pain all the time. He doesn't talk. He says, "You talk enough." So, I don't talk.

Later, after the PWD had joined the session, this caregiver reported having poorly managed shoulder pain. She described plans to call the nonemergency police phone number to get a ride to the hospital for treatment for her pain. She expressed that she did not believe that she could do anything to help the PWD manage his pain (other than calling 911). This caregiver also reported that her husband had to help her with certain Activities of Daily Living (ADLs), including bathing. She further stated that she could not complete the pain diary due to being unable to write as a result of her untreated pain.

E68:

RC: What about getting instructions on how to help care for him?

CG: I don't know if that's gonna do any good or not because I can't do anything myself. The only thing I can do in helping him is call 911. I mean, right now I cannot help him.

RC: Yeah. Is that normally the case or is it worse because of your arm right now?

CG: I think it's normally 'cause he won't tell me anything. Or leave me alone I can do it myself sort of idea.

Whether it was due to her pain-related activity limitations, poor communication between her and her husband, or communication problems stemming from the effects of the PWD's dementia on his ability to process and produce language, this caregiver did not believe that she could do anything to help the PWD to better manage his pain and took a passive role in his pain management.

Other caregivers demonstrated taking a passive role in the PWDs' pain management in their lack of awareness regarding which pain treatments were being utilized by the PWDs. This included some caregivers sharing that they did not know which (if any) pain medications their husbands' took. One caregiver (E173) explained that she did not think that her husband took any pain medications, but she was not sure.

E173: I don't think he takes any medications. Sometimes he takes aspirin or something like that, but nothing that I know of.

Another caregiver (E89) similarly exhibited a lack of knowledge regarding the PWD's use of analgesic pain treatments, other than sharing that he would sometimes take acetaminophen for his pain. She did point out that acetaminophen did not need to be prescribed, which may indicate that she took a passive role in her husband's pain management due to believing over-the-counter (OTC) pain medication to be less dangerous than prescription pain medications.

E89: Well, I'm not sure how much pain medication he's taking, or what he's taking. I know he'll take...every once in a while, when the pain comes, he'll take acetaminophen, which doesn't have to be prescribed.

Another caregiver (E198) demonstrated a lack of knowledge of the PWD's PT for his knee pain, including the frequency of his sessions. The PWD shared that he was going to the VA for PT once a week, which conflicted with the caregiver's understanding. She disagreed with her husband, stating that he had not been going to PT weekly.

E198:

PWD: Well, I'm still taking physical therapy at the VA right now for my knee and my back. I have an appointment this week or next week.

CG: Is it once a week? Once a month?

PWD: Once a week.

CG: Once a week? You haven't been going every week.

PWD: I still am [going] once a week.

CG: Okay.

A different caregiver (E201) expressed surprise after hearing the PWD share that he took acetaminophen at least once every day. She stated that she did not know that he took this medication daily for his pain.

E201:

PWD: I take Tylenol at least...I take Tylenol like once a day. Okay?

CG: You take Tylenol once a day?

PWD: Every morning.

CG: I didn't know you were taking Tylenol.

Interestingly, this same caregiver asked the PWD whether he was okay with her getting more information regarding pain treatments from the research clinician. It was unclear whether she did this due to perceiving her role in the PWD's pain to be a passive one, or whether she did this because she had a person-centered approach to helping her husband manage his pain. She may have been taking an active role in some of his pain treatment, including identifying additional pain management strategies. She also reported that she planned to get heating pads for her husband, suggesting that it might "loosen up" his muscles (see excerpt page 98).

E201:

RC: Would you like more information about getting treatment or care that he may need for pain?

CG: How would you feel? I mean I think you need to have something with your back and your neck. [This] Is my personal opinion. But how do you feel about it? About getting more information about it.

PWD: Yeah, that's fine.

Caregiver E201 was also the only caregiver that tried to explain to her husband the tendency of PWDs to underreport their pain. She further told her husband that she believed he underreported his pain.

E201:

RC: People with dementia tend to under-report their pain.

CG: See that's what I was telling you earlier, honey.

PWD: Under-report the pain?

RC: Mm-hmm. Research has shown [that], yeah.

CG: Okay, we were talking earlier, remember? And I said because of the dementia and also the PTSD (which you have) [that you have] a tendency to under-report pain.

PWD: Hmm. Okay.

CG: And you told me that I was in more pain than you were.

PWD: Is that true? That's what I hear...

CG: I know.

PWD: ...all the time. You know, so I'm gonna ask questions.

CG: I have osteoarthritis. So, during cold weather it does hurt me.

Other caregivers described taking active roles in the PWDs' pain management. This included taking active roles in the PWDs' healthcare appointments. One caregiver (E100) asked the research clinician whether the pain diary home practice was something that she could share with her husband's doctor, indicating that she desired to advocate for her husband and ensure that he was receiving any pain treatments that he needed.

E100: Is it okay to mention this particular item [completed pain diary] to the doctor when we go? Because I have no way of keeping up with his physical...I'm trying to keep up with his physical health also. If he's having pain in a certain area more than, you know, I think he should.

RC: Sure. Absolutely.

CG: Because I have no way of keeping up with his physical...I'm trying to keep up with his physical health also. if he's having pain in a certain area more than I think he should.

RC: No, definitely.

CG: In this...yeah.

RC: One of the things we encourage is take[ing] these to your doctor. Write down the things that you see. Because often times when we get in to see our primary care doctor, whatever doctor, we have a really limited amount of time with them. They've got a really limited amount of time.

CG: 30 minutes.

RC: And then you forget what you want to ask.

CG: Right.

A different caregiver (E117) described taking active role in her husband's pain management through tracking and monitoring his analgesic medication use. She shared that she kept track of when he took medication. This allowed the PWD to be able to ask her whether he was able to safely take more medication when he continued to have pain after taking one of his pain pills.

E117: I'm just keeping everything in my mind. "Well, go ahead and take the pill." But [or] "You're going to have to wait until a little bit later." And he'll listen to me. Whenever. [He may say] "But I only took one of [the pills]." [If so, I respond] "Well, you can go ahead and take another." But see I'm here. I don't work. And I've got time to do that.

This caregiver also reported that the PWD did not voluntarily tell her when he was hurting. She explained that she was aware that he was having pain due to his moans and his facial expression. When she observed those nonverbal behaviors, she asked her husband whether he was feeling well. If he responded that he was not, then she would ask him whether he had taken his pain medication. If he had and was unable to safely take more pain medication, the caregiver described using other strategies to manage his pain, including massaging areas where he was having soreness with horse liniment.

E117: Why he moans...he moans and...when whenever...he doesn't tell me he's hurting or anything. He just moans. So, I know. And like you said the expression on his face, you know. I said, "[Are] You feeling okay?" [He'll respond,] "No, I'm not." Otherwise he won't tell me. Well, [I ask PWD] "When did you take your hydrocodone?" [He may respond] "Well, I can't take that. I already took it." I say, "Well, alright." Then I've got this liniment that I massage him with, you know, for like the muscles, you know, and the bones. And it doesn't take all that away. But it helps him. In fact, I had to do that yesterday, you know, right around his back across there. And then his legs on both sides, all the way down. And so, I massage him real good with that stuff. And then he forgot. I want him to tell me, "Well, how does it feel?" You know, but he forgets. So, I say, "So how? You never did tell me. So how do you feel?" He says, "Well, you know, yes, it helps." It helped him some. Not completely.

Another caregiver (E33) expressed openness to different strategies for pain and distress management. Specifically, she spoke of her husband's desire to have something to chew (i.e.,

gum or animal cookies). She reported that chewing might help the PWD relax, and she had previously shared that her husband experienced constant ringing in his ears and dizziness. This caregiver also described being aware of her husband's difficulty expressing himself due to his dementia, and spoke with cognitively intact individuals with his same conditions in order to better understand and better help him manage his pain (see excerpts pages 41-42). She further shared that she tried the pain management strategies recommended by those cognitively intact individuals (e.g., playing a radio to help with the PWD's ringing in his ears). As such, this caregiver demonstrated consistently throughout the session that she took an active role in her husband's pain management, desiring to do anything that she could to reduce his pain and distress.

E33: But everywhere he goes [he likes to have gum]. So, he's washing his clothings, he likes to have gum. So maybe that's a way of relaxing I noticed. Or animal cookies. Sometimes he'll say, "Can I have [an animal cookie]?" He likes animal cookies. So, I started buying them. He likes to chew them really while he's watching TV. Maybe it's part of his relaxation

Spousal caregivers varied in their involvement in the PWDs' pain management. Some caregivers described playing a passive role, where their husbands managed their pain themselves, including their pain medications. Other caregivers reported playing active roles in the PWDs' pain management, tracking their husbands' pain medication usage and seeking additional pain management options.

Prioritizing Treatment of PWD's Other Comorbid Health Conditions. The next subtheme contains spousal caregivers' reports of prioritizing the treatment of the PWDs' other health problems over their pain. Some caregivers did not specify a particular comorbid condition for which they were pursuing treatment rather than pain. One such caregiver (E90) shared that she had not put much effort into trying to get more effective pain treatments for the PWD's pain

due to his having “so many other issues.” Some of the issues she described separately during the session included significant memory impairment (including him cooking bacon, burning it, and forgetting that he had done this) and diabetes (see excerpts pages 40-41 and 64).

E90: Not with the pain. Not like I said we really haven't addressed it so much. 'Cause there are so many other issues.

Interestingly, this same caregiver also expressed that her husband’s pain interfered with many of his daily activities. For example, she reported that her husband avoided walking across the street to play with his grandchildren in order to prevent increased levels of pain.

E90: He doesn't expose himself to that [situations that would cause pain].

RC: He doesn't? Okay.

CG: There's no length. The other day, when he was mixed emotions about going, he says, "I'm dying." I said, "Well, you have a choice. You can lay there and die. Or you can get up and go play with the grandkids." I knew where he was, and I said, "They're over there across the street." [PWD responded,] "Oh, that's too far. I'm not gonna walk over there." But I knew he was just kinda like...and he knew it was gonna exert him once he got over there. To keep up with all the grandkids.

She further described believing that the PWD’s pain was “24/7,” or constant, occurring every hour of every week day.

E90: I think the pain is there 24/7. Like I said, he's got it somewhere back here in the back burners or something.

Despite reporting that her husband experienced significant pain interference and constant pain, this caregiver also stated that she did not think he needed pain medication.

E90: My daughter spends a lot of time with him, and she says when it's time for them to do something that involves physical walking he says [that] his feet hurt.

RC: And he has neuropathy?

CG: He really does. I've tried walking with him too, but...and discussing it as we're just gonna be shopping. And then he'll say, "My feet hurt." And he boom stops, no more.

RC: Okay.

CG: That's it. You know, there's no more going forward. It's just back-track back, and that's it. It's over.

RC: Does he take pain medications?

CG: No, no. I don't think he needs it.

While this caregiver (E90) did share that she sometimes rubbed her husband's feet to give him some pain relief, she shared that she had also considered getting the PWD a massage for pain management at a local college but not followed through on this due to her numerous and time-consuming caregiving tasks.

E90: He's sore. That's what he says. So I guess it's pain. I was wondering if I need to take him to a massage. There's a college over here. And if that...I know it would help him, but, gosh, to fit in all these things into my [day].

RC: I know.

CG: And then when he was working...you know, he's only been retired 2 years. But now it's the three squares [meals], the medicines...if I can do that, I'm doing good. And [with] the doctor appointments, you know? [I do not have enough time.]

As such, she clearly expressed that better managing his pain was not her priority in terms of his health.

In response to psychoeducation regarding the negative consequences of undertreated and overtreated pain, one caregiver (E100) described the PWD as having all four of the side effects of overtreated pain (i.e., sleepiness, difficulty thinking, increased risk of falls, and low activity level), despite him taking no pain medications (see Appendix B for the “Why it is important to recognize and treat pain” handout). Interestingly, she then reported that her husband took Risperidone, an antipsychotic, because of his “tendency to move around at night.” She further expressed that she did not want to decrease that medication, stating that he needed it. She then shared that he once had prescription pain medication, but she did not think it was a “good idea” for him to take it with his other medications. As such, this caregiver was clearly prioritizing treatment of her husband's behavioral and psychological symptoms of dementia (BPSD) over pain. (BPSD include agitation, depression, sleep problems, and various inappropriate behaviors (Kales et al., 2015).) She did not report considering that his BPSD could have been caused by

his pain, nor did she express any concerns regarding the potential serious side effects of using antipsychotics in older adult populations.

E100: He actually has all 4 of those [symptoms of over-treated pain]. The sleepiness all day. Difficulty thinking. When he starts talking, he just...I don't know. I don't know what I was gonna be say...I did not want to want to decrease the Risperidone because he has the tendency to move around at night. He needs that. He definitely needs that. As far as the...he's so afraid of falling. It's ridiculous. He already doesn't walk. He creeps. So, I'm saying actually he has all 4 of these at this particular time. He really does.

RC: Well, seniors tend to be at an increased risk of falls in general. I didn't see that he's on any pain medication. Is that correct?

CG: No pain medications. Because she [PWD's doctor] did give him pain [medication] for his knees at one time. But we don't take it on a daily basis. We really don't because he doesn't like to take many pain medications. With his other medications, I didn't think it was a good idea anyway.

Another caregiver (E54) shared that her husband's dementia had been the priority and focus of all of his recent medical treatment. She explained that they had not "really gotten into" working with the PWD's doctor to more effectively treat his pain, instead prioritizing getting treatment for her husband's dementia. She also reported that she had to start the PWD's dementia-related medical treatment a second time due to having a bad experience with his previous doctor. As a result, her husband was able to see a previous primary care doctor who had seen him prior to his dementia diagnosis.

E54: I don't think we've really gotten into that with [PWD's doctor]. It was mainly...I was so concerned about the dementia. And I was getting no satisfaction, so we just started all over, and we were lucky enough to get him as his primary care doctor because he had him before. And I'd never met him. See I never...wives should be more involved 'cause they don't always tell you everything.

This caregiver did express that she intended to discuss pain treatments for the PWD with his doctor at an upcoming appointment. She also reported giving him OTC pain medication as needed as well as using lotions and massage to provide her husband with pain relief (see excerpt on page 97). Still, she downplayed the urgency of the PWD needing alternative pain treatments, sharing that there were few days when he told her that he really needed a pain pill. This seems

out of sync with her acknowledgement that the PWD was previously on prescription pain medication. Additionally, she reported elsewhere during the session that the PWD would need knee replacement surgery to effectively treat his pain (see excerpts pages 68-69).

E54: I think part of it is we started over like off of all this stuff. And but he did at one point have pain pills, and so we're gonna see [PWD's doctor]. It's about time again. And so, I will talk to him about that. But I give him Tylenol and Aleve and sometimes that helps, but there's not many days where he says, "I have...I really need a pill."

Still, caregiver E54 was the only caregiver to report previous dementia caregiving experience, sharing that both of her parents had dementia. Instead of making her more knowledgeable of the dementia disease process, this experience may have made her more concerned about and eager to get treatment for her husband's subsequent dementia diagnosis.

E54:

RC: Today we're going to talk about how to recognize signs of pain and distress.

CG: I kind of got a leg up on this because I went through this with my parents.

RC: You did?

CG: I wasn't living with them 24/7 but, you know, I got an overview from that. Because theirs is just totally different, it seems like they're all just totally different, the awfulness of dementia. It's never...it's signs [are never the same for different people].

RC: Its true, it's a very individualized disease which is why it is hard to kind of generalize for people.

CG: Right.

Some caregivers expressed that comorbid health conditions were the priority of the PWDs' recent healthcare. Sometimes this was related to the comorbid conditions being numerous, and other times this was related to concerns regarding dementia as well as BPSD. In these instances, the PWDs may have experienced untreated pain and distress as a result.

Difficulties Accessing Appropriate Medical Care for PWDs' Pain. This subtheme involves barriers to accessing the needed healthcare to treat the PWDs' pain as reported by spousal caregivers. These caregivers described various reasons for their difficulties accessing medical care for the PWDs' pain. Some of the barriers endorsed were communication

difficulties with the PWDs' healthcare providers, having to see numerous doctors (including various specialists) for the PWDs' comorbid conditions, the cost of pain treatments, and lack of transportation to healthcare appointments.

Spousal caregivers provided various examples of poor communication between the PWDs' healthcare providers and themselves. One caregiver (E63) described one of her husband's doctors recommending pool PT as a pain treatment. (This PWD had arthritis, back pain, and leg pain.) She expressed that she thought that doctor was going to put in an order for that PT, but she and the PWD had not heard anything subsequently. This caregiver stated that she needed to follow-up with that doctor in order for her husband to get that treatment.

E63: I don't know why we haven't heard anything, but the doctor...I'm gonna have to call the doctor because he had said he was gonna...the surgeon recommended water therapy. And I was under the impression that he was gonna follow through on it, but so far, we haven't heard anything.

Another caregiver (E84) reported that there was an effective treatment for the PWD's pain but that it was not available in the United States.

E84: He's disgusted with it. I wouldn't say depressed. Well, he gets down with it, I guess, because he's tired of it. He wishes there was something that would relieve the pain. There was something we did find that would relieve the pain. It would not cure him, but it would help him. But we can't get that medication here in the States. It came from Europe.

Interestingly, when her husband briefly joined the session, he similarly reported that there was a medication that was "guarantee[d]" to help pain like his. This prompted the caregiver to name the medication, which was Cymbalta, a medication available in the United States. The research clinician provided psychoeducation, and this caregiver reported that she would speak to the PWD's doctor at the VA regarding the possibility of him trying that medication. It was possible that this dyad had heard about Cymbalta recently, and the PWD had not yet had a doctor's appointment. However, even if this was the case, it seems clear that the PWD's doctor had not

explored the full range of pain treatments with him. Furthermore, this caregiver also described her husband having to retire a decade earlier than he had planned (see excerpt page 68). The significant pain interference experienced by the PWD for over a decade indicated that his pain had been poorly managed for a significant amount of time.

E84:

PWD: But there's some medication that they advertise on TV that I'm hoping to tell the doctor about. 'Cause they say...they guarantee that.

CG: You're not gonna get that from the VA, Cymbalta.

RC: You might get Cymbalta, an antidepressant that can help with pain. You could.

CG: Yeah, we can ask. Oh, too next month when we see go see [PWD's doctor], we're going to talk to her about changing your medications over.

A different caregiver (E14) reported that one of her husband's doctors had told them that Naproxen was a good option to treat his pain, but another doctor (likely a gastroenterologist) told them that it was not a good treatment option. She reported that they had ultimately switched to acetaminophen. Still, she expressed confusion regarding why they had received this contradictory guidance, stating that the PWD had taken Naproxen for "a period of time" (see excerpt page 87).

E14: Like I told you they always wanted to put him on those Naproxen. And it's like, well, you don't know who to listen [to] 'cause one doctor is saying "It's not good," and the other one saying "Yeah, it's good."

Other caregivers described confusion regarding with which of the PWDs' doctors they should discuss pain treatment options. These caregivers reported that the PWDs saw multiple specialists in addition to their primary care doctors.

E89: This is one of his issues. He has a primary doctor. He has a cardiologist. He has a neurologist. He has a sleep doctor, a dentist, a gastroenterologist. To whom would he be reporting pain? Pain in his leg...in his back.

RC: I would start with your primary care doctor. No?

CG: He's not that good. He uses him for a cold. Or he's gonna give him his flu shot.

RC: Well, you could also get a referral from the primary care doctor for a pain specialist.

CG: Pain specialist? Okay.

RC: Who prescribes his pain medication now?

CG: I guess his primary.

Another caregiver (E53) expressed concern regarding when certain pain treatments were terminated due to the PWD's pain improving. This caregiver shared that her husband had previously completed PT for his knee and his shoulder as well as some kind of injection for his shoulders (see excerpt page 67). She described worrying about his pain returning if he needed to resume that treatment again due to having to see multiple healthcare providers (e.g., primary care doctor and physical therapist).

E53: Well, that's like, you know, you're thinking all the time when they'll say [the doctors will say], "Well, we're gonna stop this treatment now for a while. He seems to be doing okay." Well, the first thing that runs through my mind, "Well, what if it starts back up again?" You know, you gotta go all the way back through and back, all the arrangements, through two or three doctors, to get him treated again.

Other caregivers reported difficulty accessing certain treatments due to cost. One caregiver (E195) reported that their dog had destroyed their heating pad, so it needed to be replaced. She expressed that it would be difficult to afford this unexpected, additional expense.

E195:

RC: Have you been treating it with anything? I know you said you're taking pain killers.

PWD: Heat.

CG: But our heating pad rubbed the cord [dog chewed the cord]. We have to get a new one. It's just affording it.

Another caregiver (E181) reported that they had found an effective treatment for the PWD's pain, Lyrica, but their insurance would not cover it. There also appeared to be poor communication between various VA healthcare providers and the dyad. They described having to speak to multiple doctors in addition to a pharmacist and a nurse when trying to obtain Lyrica, only to be told that the medication was not covered by their insurance. The caregiver and her husband both confirmed that paying for Lyrica out of pocket (i.e., \$450 per refill) was not something that they could afford. Therefore, the PWD was stuck with using a less effective pain

treatment (acetaminophen). Notably, this caregiver also reported that her husband had developed Barrett's esophagus due to having to take so much acetaminophen to manage his pain (see excerpt page 88).

E181: We had a problem with...two doctors had recommended that he take Lyrica, which he had taken before for the other surgery, and it controlled his pain. We went to two doctors, and, I mean, I had a mean streak due to this thing that happened. He got so upset 'cause he went to a doctor, and they gave him the prescription. And then we called VA, and the pharmacy said for us to... somebody take it down there, and the nurse would approve it or something like that. Okay, it has to be approved by them. Well, they didn't even want to see him for the prescription or anything. So, in the following appointment that we had we asked why they had denied that. And then they brought in [PWD's doctor], and she said the reason they didn't do it 'cause it was too expensive. He was in so much pain.

PWD: And then my insurance the same thing over here. So, I'm not gonna pay \$450 for the medication. I'd rather take aspirin. But that was another thing that made me sleep well. And the pharmacist told me they had it in the VA, but they wouldn't give it to me.

CG: She said 'cause he was like HMO. And it's too expensive.

A few other caregivers reported having no transportation, including being unable to drive. One of these caregivers (E68) reported needing to call the non-emergency police number in order to get to the hospital to get her shoulder pain treated. She previously reported that the only thing she could do to help the PWD's pain was call 911 (see excerpt pages 71-72). In addition to not having transportation, this dyad did not appear to have any social support, including family or friends that could give them a ride to a healthcare appointment. Nor did this dyad appear to be able to afford paying for a taxicab ride to the hospital.

E68: We can't get to anything. No transportation. I was gonna call an ambulance service. The nurse said don't call 911 call 311 first and see if they'll...I don't want the whole shebang to come out here. I just want transportation really. So, I don't know how to do it. I've never done it before. The other times when we've called 911 is when the fire department and everyone has come out here to help me. But today I don't need that kind of help. I just need to get over there and let them x-ray or probably do a CAT scan it or something to see what's going on.

Another caregiver (E181) similarly reported difficulties accessing healthcare due to not driving. She shared that they had to get one of their two sons to give them a ride, both of whom had jobs.

These jobs likely had typical workday shifts, overlapping with the hours of many doctors' offices. She expressed that their lack of transportation was especially challenging when the PWD had a health emergency, such as his recently having a "minor heart attack."

E181:

CG: He tried to make an appointment with the VA. And they told him he could not have an appointment until October, and this was June. And he was desperate. I mean he didn't even know what to do with the pain. '[O]Kay. And then he had a minor...

PWD: Minor heart...

CG: ...little heart attack

PWD: ...attack. I had a [minor heart attack].

CG: 'Cause he was so...

PWD: And I called VA, and I asked them, "What do I do?" He said to go to the nearest facility. So, I went to the nearest facility. So, it's kinda hard sometimes dealing with the VA because they have so many, many, many patients. So that's why when I have an emergency or I'm really hurting.

CG: We don't know what to do, you know. It's very hard. Especially that I don't drive, you know. We have to get our sons to get up for work to drive.

Spousal caregivers reported various barriers to accessing the healthcare needed to effectively treat PWDs' pain, which included poor communication with healthcare providers, conflicting guidance from different providers, costs of some treatments, and lack of transportation. These barriers may have led to these PWDs having less effectively treated pain.

Concerns Regarding Analgesic and Pharmacological Pain Treatments. Many spousal caregivers expressed concerns regarding treating the PWDs' pain with pain medications. The reported concerns involved both OTC pain medications (e.g., acetaminophen) as well as prescription pain medications (e.g., Tramadol). Areas of concern regarding analgesic pain treatments involved side effects, dependence, overdosing, and tolerance. These caregivers tended to err on the side of underutilizing pain medications for the PWDs' pain, including giving them pain medications "as needed" or PRN rather than as prescribed. Some caregivers further reported using nondrug treatments (e.g., rubbing or massage) for the PWDs' pain in order to use pain medications more sparingly.

E209: I think he has a high tolerance for pain. Because he doesn't take a lot of pain medication. So, like I've said I've resorted to things like doing the rubs. If a scenario where I can put a rub on that's gonna make it feel better, but I don't give him more medicine than I do.

However, some caregivers did not supplement their low utilization of pain medications with any additional nonpharmacological treatments. One such caregiver (E02) was giving her spouse one acetaminophen tablet daily rather than three times daily as prescribed by the PWD's doctor. This persisted despite the PWD disagreeing with her, believing his doctor had instructed them to have him take acetaminophen three times daily.

E02: I've just been giving it once. He [PWD] said 3 times. He said I didn't understand it, but I think he [PWD's doctor] said one time a day. Although I don't think he would be giving people 3 times a day.

RC: Yeah, Tylenol.

CG: Yeah. Well, maybe he did say [to give him one pill 3 times daily].

RC: It's just over-the-counter Tylenol?

CG: Yeah. Pain reliever. He said rather than giving him a whole lot at one time just giving him one.

RC: Right. Would be one [tablet], 3 times per day.

CG: I have Walgreen's pain reliever.

RC: Yeah, it's acetaminophen, and that's about every four hours you can give that to him.

CG: Okay. Maybe it is 3 times. Because I didn't want to give him like the lady, I didn't want to give him too much.

RC: It's just over-the-counter Tylenol?

CG: Yeah. He [PWD's doctor] said rather than giving him a whole lot at one time, just giving him one. Because I didn't want to give him like the lady, I didn't want to give him too much.

RC: Yeah, and she was only giving him acetaminophen. It wasn't some crazy pain medication, but, yeah, she was concerned...and even that you do need to be concerned about. But if you're giving it as prescribed by a doctor and they're following up and, you know, it's safe to do. Tylenol wears off every 4 hours. So, I wouldn't be surprised if it was morning...like breakfast, lunch, and dinner.

CG: That's what he [PWD] said.

This same caregiver also reported awareness of the PWD's previous pain due to his verbal vocal pain complaints. Despite this, she confessed that she "did not think" about giving him any pain medication or any other pain treatment in response to this. Interestingly, she further reported that

she did not believe that her husband's recent PT had been effective due to his verbal pain complaints after sessions.

E02: We just finished a physical therapy.

RC: Did that help with the pain at all?

CG: I think it caused it to be worse.

RC: Really?

CG: Yeah, because at the time we would leave he really would complain. They would try to make him stand up. And I think we were going too fast. That was my concern. You know, they started gung-ho trying to get him to walk, but he couldn't. And, of course, then he would get swelling in the left ankle. So, I say let's just try to do the strengthening and then move to that.

RC: Right, and then go for it.

CG: They wanted to go straight to trying to get him to stand up and walk, before he had the strengthening exercises. But he always did complain about that toe. With that therapy, it was constantly.

RC: And they didn't recommend pain medication before they came or anything to help with that?

CG: No. And I didn't think about giving it to him. You know, the Tylenol.

Other spousal caregivers described concerns regarding side effects from regular use of analgesic pain treatments. These were described for both OTC pain medications and prescription pain medications. One caregiver described receiving guidance from the doctor who had given her husband a colonoscopy, explaining that she was told that his use of Naproxen was not advised. However, she did report switching to a different OTC pain medication (acetaminophen) in response rather than stopping the PWD from using any further pain medications.

E14: He stopped taking that Naproxen. Yeah, because the doctor when he had a colonoscopy said that medicine was not good, it was going to mess up his stomach. He says, "I wouldn't recommend it." But he had taken it for a period of time. 'Cause he had been taking it for years. But since he had that, you know, so he says, "I guess I'll deal Tylenol now."

Other caregivers reported specific side effects experienced by the PWDs due to their use of a specific pain medication in the past. One explained that her husband had previously taken hydrocodone for his chronic pain. She shared that the PWD's doctor believed that this

medication could be having a negative impact on his memory and, thus, had switched him to a different prescription pain medication (Tramadol).

E53: And then sometimes I'll give him two of the Tramadol, which it calls for one, but there's no drug interaction in it. It's just like Tylenol. It doesn't have any codeine or anything like that in it. It's just strictly a like an Aspirin or a Tylenol. He had for a while they had given him some hydrocodone, and his primary doctor had thought that might be making his memory worse. So, she suggested that they just give him the Tramadol. But there's no drug in it at all. It's just...it's not over the counter, but it's...I don't know the word that they call it. But, anyway, it doesn't have any narcotics in it, you know.

Another caregiver (E181) explained that the PWD had developed Barrett's esophagus, a condition involving acid reflux and chronic heartburn due to his overuse of acetaminophen after his recent back surgery. She did not report that he had been provided with prescription pain medication while he was recovering from this surgery. She also described that he still sometimes took acetaminophen when he felt that he needed medication to manage his pain. In contrast with the two other caregivers that expressed concerns regarding the side effects of analgesic pain treatments, this PWD had not been provided with an alternative medication for this pain, despite being diagnosed with Barrett's esophagus.

E181: He was in so much pain. I mean, he was taking six Tylenols about 500 milligrams a day. Now he has that Barrett syndrome due to taking so much.

Another caregiver (E195) described concerns regarding dependence on pain medication. Other than expressing that she did not want the PWD to take pain medication "for the rest of his life," this caregiver did not report that the PWD regularly utilized analgesic pain treatments. Instead, she expressed concerns that she herself might become dependent on prescription pain medication.

E195: I've been off and on pain medication for over 13 months. [...] I'm so afraid of being hooked on them that I don't take them like I'm supposed to.

One caregiver (E117) reported monitoring her husband's use of pain medication due to concerns regarding overdosing. She described encouraging him to abstain from taking his pain medication unless he was currently experiencing pain or "hurting." She expressed worries that he might "take too much" of his pain medication, leading to an overdose.

E117: He needs it now. That's for the pain. Because I say, "Don't take it if you're not...if you're not hurting." He [says,] "No, I'm not [taking it when I'm not in pain], but I am [in pain now]." So, he'll go [a]head and take it. [I'll ask,] "When did you take it?" I want to know when because I don't want him to take too much. I don't want him to OD.

Other caregivers described concerns regarding PWDs' tolerance to their analgesic treatments. They reported believing that their PWD's pain medications would no longer be effective if they took them more frequently, even when this was how the PWD's doctors had prescribed them.

E53: I've been giving it to him as needed because I don't want him to get to where it doesn't do him any good if he takes it all the time. I gave him...

RC: How's the doctor prescribed it?

CG: One every 6 hours.

RC: Generally, pain medication actually works better if you give it...

CG: Yeah, I've heard that.

RC: ...every 6 hours.

CG: I don't want him to.

RC: What happens is, if you only take it when you think he really needs it, usually a higher dose is required to control the pain.

CG: But don't you get to the point where it doesn't do you any good after you take it for so long?

RC: Not necessarily.

CG: Okay, well...

RC: Especially Tramadol is kind of a lower level pain med. It's on the...

CG: Yeah, it's not a narcotic.

RC: Uh-huh, so I wouldn't worry about that.

CG: Okay. So, you can take one every 6 hours?

RC: Yes. I'd try that and see what his pain rating is.

CG: Okay.

RC: See if it helps it. 'Cause moderate pain is still a pretty high level of pain to constantly have. If he was taking the Tramadol every 6 hours, and it was only a little pain probably okay. But if it's a moderate amount, I...I mean I would definitely do every 6 hours like the doctor said.

CG: Okay.

E63: The pain is so bad this morning. And I said, "Well, get back in bed!" I gave him his medication, and he lay back down. So sometimes he can take that medication and lay down for a while. It [the pain] subsides. This morning I gave him codeine. So that should really kinda help. Take the edge off anyway. His back and down, down his leg. I think it's that sciatic nerve. 'Cause he have arthritis all over his body. So, it may be from that. It's very bad. He was feeling good yesterday. Well, he started out with quite a bit of pain. And he'd taken his medication, and we got up and drove around for a while. And he say he began to feel better. And this morning he got up, and we had...you know, I helped him with his shower and everything. He said, "Oh, my leg hurts me so bad! I can hardly walk. My back hurt." I say, "Babe, lay down. Let the pill take effect." You know? And then he'll feel better. So, a while ago he said he was feeling somewhat better. As long as he's laying still. It's just one of those things. Something you have to endure. Especially until they can find something to really stop it, and I don't think they want to put him on any real, hard pain medication. You know, I don't want him to stay zonked out. Because once he lay down for a while, I think he's gonna start feeling better 'cause I asked him a while ago. He said he felt somewhat better. So, we'll just wait and see.

RC: Oh, well, that's...does he take the codeine regularly?

CG: Well, he takes that and the tramadol. Because he doesn't take the codeine every day. You know, I kinda alternate.

RC: Is that what the doctor told you to do?

CG: Yes, he said when it's real bad...he told me to actually give him the codeine at night, but, if he's hurting real bad, he can take it during the day. So, he don't take that as much as he does the tramadol.

Another caregiver (E84) expressed beliefs that the PWD had become “immune” to his prescription pain medication. She explained that he had been on the same pain medication (Tramadol) for an extended period of time, and it no longer effectively treated his pain.

E84: He doesn't say, but I would say throbbing because it's always there. Always there. There's nothing that he can take that will calm the pain, not even the pain pills.

RC: What pain pills is he on?

CG: Uh, I'll have to give it to you [later].

RC: Oh, that's okay. Maybe I have it written down. Tramadol?

CG: Yeah. I don't believe it's very strong, but I don't know. Maybe he's had it so long that he's immune to it. That's why I need to talk to [PWD's doctor].

It is notable that when her husband briefly joined the session, he also reported believing that he had become “immune” to his pain medication. He had not been present when the caregiver expressed her concerns regarding her perception that his current prescription pain medication

was no longer effective. He further described having similar experiences with other types of pharmacological pain treatments in the past.

E84:

PWD: What happens is I start taking them too long, that I've become immune to them. They don't work as good as when I first started taking them. And so, they keep changing from some type of pill to another type of pill. And that work the same way here. And after a while... I've been doing this, for what about 7 years?

CG: You've been doing it for longer than that.

PWD: Oh, yeah because I got out of the service in '53, and I didn't start hurting...my knees didn't really start hurting until about 6 or 7 years after I was out of the service.

This dyad (caregiver and PWD) also reported that they were aware of a medication from Europe that would help the PWD's pain, and it was identified as Cymbalta (see excerpts pages 81-82).

The caregiver shared inaccurate beliefs that this medication was unavailable in the United States.

The caregiver further expressed that while her husband's Tramadol was ineffective in treating his pain, he received cortisone injections in his knee, which effectively treated his knee pain.

E84: He takes pain pills twice a day, but they don't help. The only thing that...there is something that helps. When they gave him an injection in the legs. In the knee. He's had cortisone. [Of] course they only let him have it about once a year. There is another one that they give. I think there's a series of 3 on that one.

Interestingly, this caregiver also reported that her husband would not have knee replacement surgery. Taken along with her shared beliefs that certain medications and injections were other ways that she thought the PWD's pain could be effectively managed, this caregiver may not have been open to non-pharmacological treatments (other than surgery) or CAM treatments for his pain.

E84:

RC: You said he has pain in his knees?

CG: Mostly in his right knee. That's why he walks with a cane.

RC: Okay. Mostly...and that's arthritis?

CG: Right, and he won't have a knee replacement.

Spousal caregivers expressed various concerns regarding pharmacological and analgesic pain treatments, including side effects, dependence, and lack of efficacy. Instead, many (but not all) caregivers voiced preferences for non-pharmacological and CAM pain treatments.

Preference for Non-Pharmacological and CAM Pain Treatments. This final subtheme details the preference of many spousal caregivers for managing the PWDs' pain using non-pharmacological and CAM treatments. These treatments include exercise, adjusting body position, massage/rubbing, heat/warmth, dietary supplements, and pleasant activities.

Some caregivers reported encouraging PWDs to move their bodies in order to reduce their pain. One caregiver (E100) described encouraging her husband to “move around a little bit” when he complained of hip pain.

E100: This morning his hip was bothering him. But it's not to the place where [he'd say], "Oh god, the pain!" It bother...when he gets ready to stand, he say, "Oh, this hip. That's part of the arthritis." Which it probably is. And I just say, "Move around a little bit." And I had him [do that] last night. It was bothering him some.

Other caregivers shared that they urged PWDs to engage in exercise, especially walking, in order to manage their pain effectively. One caregiver shared that she and her husband went for walks together in order to maintain their independence, as well as to reduce her husband's pain.

E14: I keep telling him we have to do that exercise like that. We have to. I don't want to be one of those people that people come and do things for me. I wanna be independent as long as I can. I don't want to depend on anyone.

Another caregiver (E19) complimented the PWD on not giving in to his pain and maintaining regular physical activity. The PWD shared that he took the stairs rather than the elevator. This caregiver added that the PWD went for daily walks with his dog, walking further than she would. This dyad's session also began with the PWD sharing that the caregiver had more pain than he did (see excerpt page 57).

E19: But you're one of those, that doesn't give in to it. I mean, you try to keep going.

PWD: That's right. Instead of riding the elevators. I take the stairs.

RC: Good.

CG: Well, most of the time. And too, your pet, you have to get up and walk him. And that's...I know when I have my granddog, he gets me up. And I take him out. Where otherwise, I might not. So, pets can be a good thing in many ways for an older person. Um, but [PWD] doesn't give in, you know? I sit and watch him walk way over there, and I'm thinking, "Oh, my gosh!" You know?

PWD: I walk all the way around the hospital parking lot.

CG: Yeah.

PWD: And all the way around.

CG: And how...

RC: That's good.

CG: That he don't just sit in his chair and give in to pain, which is great.

However, the caregiver's emphasis on how great it was that the PWD did not give in to his pain and maintained regular physical activity may indicate that she discouraged him from pacing himself in his physical activities, which could have led him to have more pain. This caregiver also reported that she told the PWD to not complain about his pain around her because of her having "enough of" her own pain. Her discouraging him from voicing when he was having pain may have further hindered his ability to manage his pain effectively.

E19: Yeah, because he is the type, unfortunately, to really, get really crazy with his pain, you know. So, I used to tell him, "Don't complain about your pain. I have enough of my own." So, because he can get carried away with, what you call them, hypochondriac about pain.

A different caregiver (E37) reported using exercise and physical activity to manage her own arthritic shoulder pain. She shared that, in addition to helping her manage her pain, she believed it kept her mind, bones, and muscles young.

E37: I hurt in my shoulders from arthritis, but I move around so much [that] I don't have time to have pain. I just keep moving. My doctor said, "You [are] doing real well." The secret is you keeping busy. It keeps my mind young and my bones, and my muscles.

She similarly reported that she encouraged her husband (who also had arthritis) to walk regularly and expressed beliefs that his pain was caused by him not exercising.

E37: I think, I try my best to keep him going walking. Because I think, I believe, the pain in his back, too [also] hurt[s] down low, and I think the pain is coming from not exercising.

Another way in which some spousal caregivers helped the PWDs manage their pain using non-pharmacological strategies was recommending that they change or adjust their body position. Some caregivers actively helped the PWDs change their body positions. For example, one caregiver reported putting a pillow behind her husband in his wheelchair, trying to make him more comfortable. Interestingly, in sharing this with the research clinician, she hypothesized that this might have actually been making it less comfortable for him, making him less likely to stay at the table.

E02: I put the pillow behind him. He has that cushion. It looked like to me that cushion might be a culprit now that we've been talking. It could be causing some problems, and maybe that's why he doesn't want to sit there.

This caregiver had started the session by sharing that it made her angry when her husband would not stay at the dinner table, instead choosing to go back and lay down in the bedroom.

E02:

RC: So how to identify his pain when he's not telling you that he's in pain.

CG: What it does to me...I get angry when he wants to go back into bed.

RC: Right. Right.

CG: Instead of asking him.

As such, it is meaningful that she was questioning previous strategies intended to make her husband more comfortable. A different caregiver (E100) described suggesting that her husband try to sleep in different positions if he woke up experiencing pain. She reported that her husband may have been sleeping on his side and arm where he had pain, leading to his having more pain.

E100: But like I told him this morning, "Are you sleeping on that side? Where you're having the pain?" I said, "It could be...maybe you should try to get [in]to different positions at night when you're sleeping. You know, if you think [about it]." If he thinks about it and try not to lay on that side where the arm bothers you.

Some caregivers specifically encouraged PWDs to move their legs to reduce their pain. One caregiver reported that her husband had lost mobility due to his lack of activity. She described that she continued to recommend that he move his legs to prevent further muscle deterioration and related pain.

E07: I have to tell him to move his legs. You know, his muscles like deteriorated 'cause he sits all the time. [...] He just can just with me there. He can transfer himself from one place to another. But as far as, oh no, he cannot walk.

A different caregiver recommended that her husband change the position of his leg after hearing him share that he felt “a little bother” in his leg.

E44:

RC: Your legs are hurting now?

PWD: Well it's sort of having a...

CG: Tingling?

PWD: Not a tingling.

CG: Stiffness?

PWD: Just sort of sensation that's kind of a little bother, but not painful.

CG: Can you raise your leg? Want to raise your leg?

PWD: I can do that. If I just maybe sit a certain way. I don't know.

Other caregivers encouraged PWDs to lie down in order to manage their pain. One caregiver reported doing this when she knew that her husband had spent much of the day sitting up.

E07: I tell him during the daytime when he's here or even when he comes back from the senior [center], I say, "Now you've been sitting up all day. Why don't you go lie down for a little while?" I say, "Maybe give your back some rest." Take some of that pressure off. And he'll do it. So, I tell him that during the daytime also. And usually during the daytime he has that reclining chair so... It's a lift chair. I say, "Well, sit in there in a relaxed position get that pressure of your back."

Similarly, a different caregiver shared that when she observed the PWD's nonverbal pain behaviors that she tried to get him to lie down. Notably, this caregiver also encouraged the PWD to utilize analgesic treatments along with changing his body position to manage his pain. She

expressed that lying down helped her when she was experiencing pain, which was why she recommended that he do the same.

E71: He'll tell me, "Oh my God, the pain is here." He catches [touches] his neck. He catches [touches] his head. You know, like he'll hold his head with his hand. And I try to get him in a position, if he's not sitting. 'Cause most of the time when we eating, we're sitting up. But then I try to get him to lie down, switch position. And I'm not sure if that's better for him, but I know it's better for me. I don't want him to fall. So, I try to get him to where he can go and just lie down and relax a while. And pop that pill.

Another caregiver shared that her husband lay down (without her suggesting it) to reduce his back pain. She expressed that this did help reduce the PWD's pain.

E53: Like for instance he'll say, "My back is hurting." And he'll lie down. And I'll say, "Do you need to go to the doctor?" [PWD responds] "No, not yet. Let's wait a while." Well, finally it will quit hurting, and he'll forget it ever hurt.

A different caregiver (E63) similarly described her husband lying down without her suggestion for additional pain relief after she used other non-pharmacological and CAM treatments (e.g., massage).

E63: When I say almost unbearable, it was. And after showering I rubbed him down and put him back...he got back in bed. Now it may subside, and he'll be okay. But it just depends.

Massage or rubbing was another CAM treatment that many spousal caregivers reported using to provide their husbands with pain relief. Some caregivers described using different types of lotions, oils, and gels when they massaged their husbands in order to increase the effectiveness of the pain treatment. One caregiver did not specify which type of lotion she used, but she did state that it helped her husband's pain "a lot."

E209: I bought a cream. That my sister told me about. That I actually have used, which helped him. Which helps a lot. Just a rub on his back. So, we do that.

Another caregiver (E54) shared that she had used various types of lotions as well as a therapeutic massage oil, Pain's All Gone, stating that rubbing her husband gave him "a little" pain relief.

E54: I think the choosing medications would be good because there are times when he really, really needs something better than Tylenol or something. I've got all sorts of lotions and potions and Pain's All Gone and all this stuff we're rubbing on and that gives him a little...you know, a little [relief from the pain].

One caregiver (E117) expressed enthusiasm for using horse liniment when massaging her husband, reporting that it helped the PWD's pain "a lot." She further shared that she recommended this treatment to others trying to better manage chronic pain. Despite this, she made sure to tell the research clinician that it helped the PWD's pain but did not completely take it away (see excerpt pages 75). This caregiver also described using massage and the horse liniment when hydrocodone alone was not managing his pain well.

E117: We found some liniment for horses that we found out that it's very good, you know, to use it on yourself. And that works. It helps a lot. It's a lotion. And it's for horses whenever they get hurt, you know, you massage them, you know, real good with that liniment. And he...I don't know. And somebody heard...he heard from somebody that it works real well with [massage for pain relief]. We went over there to the tractor supply, and they had it. And so, we've been telling everybody to use it. And it works. Now it's not gonna cure you, but it gives you...it helps. It helps so maybe you can eat in peace. Or just a little something, you know. So, I massage his back, all the way down sometimes. And sometimes across like that. And I said, "Well, I need to massage it really, really good." You know, and I do. And you got to kinda press. Press some. Make sure the liniment goes into the system.

A different caregiver (E90) described using rubbing to provide the PWD with some pain relief, but she did not specify whether she also used lotions or gels. Still, she reported that massage was an effective pain reliever.

E90: If I rub his feet and stuff. But that helps me too. Last week I got a pedicure, and oh it was so good to have my calves worked on.

One caregiver (E63) shared that she massaged her husband after he showered, which may indicate that she was also using warmth to further provide him with some pain relief. She reported that she used lotion when massaging him. Similar to caregiver E117, she described doing this when the PWD's pain medications were not effectively providing pain relief.

E63: Unbearable pain is really like this morning and yesterday. And when I say unbearable, I mean I have to...we got out of the shower, and I just rubbed him down with lotion. And he said it was feeling better. So that's what I call unbearable. It's just almost..."oh, just, just rub my back. Just rub my back." But other times, he can take his medications okay.

While caregiver E117 did not use massage and warmth together like caregiver E63, she did also report that the PWD got pain relief from taking a hot shower.

E117:

RC: What else makes the pain better?

CG: Oh, taking a shower. Like a hot shower.

Another caregiver (E93) shared that the PWD's pain was reduced by taking a hot shower, allowing warm water to cover his knees. She reported that this, along with OTC pain medication, were used to treat her husband's pain.

E93: He's on acetaminophen for just pain. And warm water when he, just in the shower. Warm water on his knees or whatever.

Some caregivers described using heat or warmth to treat the PWDs pain (without massage). These caregivers described using heating pads (or intending to try to use them) to provide warmth to the locations of their husbands' pain.

E195: Here's [PWD's] pain relief. The heating...

RC: The heating pad?

CG: Which his dog steals.

E201: I told him today (I have hip pain), and I said after you left, I was gonna get the heat pads and get him to sit in his recliner. And I thought maybe it might loosen up the muscles and everything if he'd sit there a little bit with it. So, we're gonna try that.

One caregiver (E53) agreed with the PWD that he used a bone stimulator to treat his pain. Bone stimulators emit low intensity electrical and electromagnetic, ultrasonic, or extracorporeal shock waves to aid in bone healing.

E53:

PWD: In reference to that, I have a little box kit here to put some...

CG: Gels.

PWD: Gels on there, and keep it on there for...

CG: 20 minutes.

PWD: 20 minutes.

RC: Does that help?

PWD: It supposed to be for the bone.

CG: Yeah, he had a fracture there, and it's never closed up. It's been like that for years.

RC: Oh, wow.

CG: It never had closed. They found that out when his knee started hurting him real bad again. And back about 6 months ago, I guess, they did an MRI, and, uh, so he got back on that thing. And keeping him steady on doing what he's supposed to be doing is hard because I forget too. You know, I'm not that great of a rememberer, but he'll remember that most the time.

Another CAM treatment that two spousal caregivers (E33 and E181) reported PWDs using was dietary supplements. Interestingly, both were Hispanic. One of these (caregiver E33) was the caregiver that demonstrated the highest level of knowledge and understanding of the dementia disease process, speaking to cognitively intact individuals who shared her husband's conditions in order to better understand and treat them (i.e., ringing in the ears and hemorrhoids) (see excerpts pages 41-42).

E33: At GNC I buy [the supplement] 'Ringing in the Ears' is the name on the capsules. In fact, I will buy some tomorrow. It comes in a bottle, a month's supply [of] 'Ringing in the Ears.' As far as I can tell myself, I don't think it helps him. But he say[s], "I have to have it," because it helps him. So, it helps him.

E33: Right now, he's alright taking ginger. [He says,] "I'm taking ginger for I'm dizzy."

The other dyad that reported using dietary supplements included a PWD who had obtained a Ph.D. earlier in his life and had a career in medical research. Consequently, he likely had a high level of health literacy and more awareness of CAM treatments. In fact, this PWD expressed frustration at the start of the second session due to the simplicity of the pain-related psychoeducation provided during the first session.

E181: You started taking turmeric for the...

PWD: Inflammation. I take naturally healing medications like turmeric or...

CG: Fish oil.

PWD: Fish oil.

Some caregivers described their husbands participating in pleasant, enjoyable activities to aid in their pain management. In some instances, it was the PWD that decided to engage in such activities.

E89: For years, I've noticed that he...when he is doing what he likes to do, he pushes through the pain. But if he's just sitting around. And, maybe he'll get up, and, as he gets up, he feels it. And he shows it.

One pleasant activity that multiple caregivers reported that the PWDs did was spending time every week (sometimes multiple days a week) at a senior center. In addition to caregiver E07 (see excerpt page 95), caregiver E33 also shared that her husband was better on days in which he went to the senior center. She further described having difficulties managing her husband's pain and distress during the weekend when the senior center was closed, and stated that she had made plans for him to start spending time with one of his friends on Saturdays.

E33: Saturdays I don't know what it is. When we home, he seems like he's worse than when we get out of the house. That's why I started getting out of the house because the doctor told me years ago get him out of the house. It helps him better. It helps him just to get out and not be locked in this house. So all morning he plays pool and everything [at the senior center]. Seems like if he's [in the] house and [in] the room, [he'll say,] "Oh, I feel lousy. I feel bad. My hemorrhoids." You know, "I'm itchy," he says. "Itchy," he says, "I'm itchy." So I know it's his hemorrhoids.

RC: 'Cause you say he does better during the week. 'Cause you guys have a schedule during the week. And you get out.

CG: Right.

RC: So we might watch to figure out. And we have a whole module on this. But figuring out something for him to do Saturday...

CG: Yeah, I already...

RC: ...that's not too much for you.

CG: Yeah. We joined. We have [inaudible] with his friend. And we gonna start...I'm gonna start taking him.

Going to church was another activity that spousal caregivers reported that their husbands liked and appreciated. One caregiver explained that her husband enjoyed church so much that he got himself up to get ready for the Sunday services.

E71: He goes to church every Sunday. And I mean he gets up on his own. I don't have to get him up because he's energetic. He love to go to church and hear the word. And the thing is we do that. He love his church.

Another caregiver (E100) described plans to take her husband to church for the first time in a while. She implied that he used to enjoy church and reported that many church members were interested in seeing him. Importantly, she admitted that she was unsure how he would respond to attending church again, but she wanted to get him to return to participating in once enjoyable activities. She shared that it bothered her seeing him sit all day due to his pain-related mobility limitations.

E100: I know he's having it in his knees. Like I said this has limited his mo[bility]. That bothers me a lot to see him sit like that. [...] I told him Sunday...I go to church. I leave him. I say, "This week I want..." (He's lost a lot of weight.) "I want you to try on your clothes." ('Cause he's lost weight.) "I want you to try on your suits. We're gonna see if we can find one." And I'm gonna take him to church Sunday. I plan to do that because some of the church members called and inquired about him. I don't know how he's going to respond when we get there. But I'm gonna try it.

This same caregiver described other efforts to get her husband involved in activities outside of the home. Most recently, she reported that she had taken him to the store to get dessert, but her husband had been unwilling to get out of the car when they arrived. Still, despite having some failed attempts to get him engaged in activities, she continued to try to find pleasant activities that her husband would enjoy, including taking him to church the upcoming Sunday.

E100: And you see this is what he does daily. This is where he stays most of the day. I try to get him out. He went to the store with me two days ago I think it was. He wanted something sweet and so did I. So, I said, "Let's go get something quickly to snack on." But that's the only way he will get up. He will not get out of the car when we go out.

Other caregivers detailed efforts to get their husbands involved in pleasant, meaningful activities.

One caregiver shared that she encouraged her husband to play dominos.

E37: Well, he play dominos when I put him out and make him go.

She expressed that the PWD had a history of enjoying dominos and that she continued to recommend that he play, even after having him express that he did not want to be around others.

E37: Like last week [...] He has a cousin. She and her husband has [have] a big house out here on the river. [...] Beautiful place, million-dollar home. And she has two brothers [that] live out here. And she had 'em over, and they played dominos right on the water. Beautiful place. And he used to like to do that, he don't do none of that. But they called him, she called her brother, and tell [told] him to bring him. But he makes every kind of excuse not to go. But last Friday when they called he made an excuse said he didn't feel good. But I said you're going, because it works the mind. You know playing them dominos, they play dominos.

Another caregiver (E71), who also shared that her husband enjoyed church, reported other prior attempts to get the PWD engaged in pleasant activities. She explained that he used to be a professional bowler. She had gotten him a lighter ball and gone to the bowling alley with him, but she discovered that this made him sad due to his being aware of his lost physical abilities.

However, she did still report that she encouraged her husband's weekly church attendance.

E71: He was a pro bowler. So, he said he going to the bowling alley to "Just throw the ball." So, I say, "Okay, I'll go with you." But, yes, he's a good bowler. He used to be the best.

RC: Do y'all ever go anymore?

CG: Uh, it's so depressing to him when he go[es], and he can't do what the others are doing. That's the reason, you know, I don't take him at lunch because he gets very upset. Imagine that big ol' ball. Like I told him. I got him a smaller ball, but when he threw the ball, he goes for the ball.

A few caregivers reported utilizing CAM pain treatments, including seeing a chiropractor. One caregiver (E195), who thought that visits to a chiropractor had helped her own pain, asked the research clinician whether VAMCs had chiropractors. However, her husband expressed that he thought all chiropractors were "quacks," indicating that he was less open to CAM treatments than his wife.

E195: Does the VA have chiropractors?

PWD: Have what?

RC: I don't know if they have...

CG: Chiropractors.

RC: I don't know if they have chiropractors. They do have pain management specialist though which are doctors. But I don't think they have chiropractors.

PWD: I don't think so either. I think chiropractors are quacks for the most part.

CG: Oh, no. They've helped me tremendously.

Spousal caregivers described differing levels of effort and success in helping the PWDs manage their pain due to their varying pain management beliefs and knowledge. These caregivers' actions (or lack thereof) to help the PWDs manage their pain were informed by their general beliefs about pain in older adults, their understanding of the cause(s) of the PWDs' pain, their understanding of their role in the PWDs' pain management (i.e., passive role or active role), how they prioritized the treatment of the PWDs' various health conditions, difficulties they had experienced when trying to access medical care for treatment of the PWDs' pain, and their preferences regarding which pain treatments to use for managing the PWDs' pain. All spousal caregivers seemed to understand pain as explained by the biomedical model. They believed pain was caused by tissue damage or a painful condition, which once accurately diagnosed could be effectively treated, eliminating all pain. This is problematic given that chronic pain's persistence past when tissue had healed is inconsistent with this model and may have further impaired caregivers' abilities to help the PWDs effectively manage their pain. Some caregivers also prioritized the treatment of the PWDs' other health conditions over pain, including BPSD and dementia itself. These caregivers had not pursued medical treatment for the PWDs' pain as a result. Caregivers further described various barriers to obtaining the necessary medical treatment for the PWDs' pain due to communication problems with the PWDs' healthcare providers, the cost of pain treatments, and lack of transportation to healthcare appointments. Many caregivers expressed concerns regarding the use of analgesic, pharmacological pain treatments for the PWDs' pain and avoided giving such treatments to the PWDs due to fears of side effects, dependence, overdosing, and tolerance. Instead, caregivers generally expressed a preference for

using non-pharmacological, CAM treatments for the PWDs' pain (i.e., movement, exercise, changing body position, massage/rubbing, heat/warmth, dietary supplements, and pleasant, enjoyable activities). All of these things contributed to caregivers' decisions to act (or not act) to help the PWDs manage their pain and the particular pain treatments they used when they decided to act to help the PWDs' in their pain management efforts.

A Proposed Mental Model: Results Related to Research Questions

Introduction

In this section, the author proposes and provides justification for a pain mental model of spousal caregivers of PWDs. Spousal caregivers' action(s) in response to the PWDs' behavior(s) are influenced by Pain Assessment Beliefs and Knowledge (PA) and Pain Management Beliefs and Knowledge (PM) as follows: PA and PM affect the ways these caregivers answer for themselves (implicitly and/or explicitly) two PA-related questions (*1: Is there a problem?, 2: Is this problem pain?*) and three PM-related questions (*1: Is the pain treatable?, 2: Is it worth treating?, and 3: How do I prefer to treat it?*), and their answers to these questions determine the likelihood that these caregivers will act, or not act. It is proposed that caregivers are moved to action in response to the PWDs' behavior(s) when they "connect the dots" in their understanding of the behavior by identifying a problem, labeling the problem as pain, and identifying a response (i.e., a treatment approach) they believe is worth trying. However, disconnects in understanding of the PWDs' behavior(s) are common in this study sample, and predictably lead to inaction. A disconnect is defined as when the caregiver identifies the PWD pain behaviors yet does not act in response to those behaviors because the caregiver fails to correctly answer yes to one or more of the PA or PM questions. In the next subsection (Subthemes) the author will demonstrate how the two PA questions play out within each of the four PA subthemes by

providing multiple examples of caregivers' responses to the two PA questions. The author will then repeat this process for the three PM questions within each of the seven PM subthemes. In the next subsection (Synthesis), the final proposed mental model of pain is provided. The author will provide multiple examples demonstrating how missed connections lead to inaction (and conversely, how successful connections lead to action).

Subthemes

Pain Assessment Beliefs and Knowledge (PA). When prompted by PWDs' pain behavior(s), spousal caregivers of PWDs first answered (implicitly or explicitly) two PA questions: (1) Is there a problem?; and (2) Is this problem pain? Caregiver interview data revealed a consistent pairing of: (a) the first two PA questions with the PA subthemes of (1) understanding of dementia disease process, (2) importance of knowing the person, and (3) understanding of PWDs' pain language; and (b) the second question also often paired with subtheme (4): attributing PWDs' pain behaviors to causes other than pain.

Understanding of the Dementia Disease Process. The first PA subtheme is about spousal caregivers' knowledge of dementia, including its etiology, symptoms, and expected progression. Lack of dementia understanding can result in a "no" response to the first and/or second PA questions (*Is there a problem?, Is this problem pain?*) when there is actually a problem and/or the problem is pain. This was observed in multiple caregivers (e.g., E37, E51, E53, E135, E198) who were unaware that dementia negatively impacted PWDs' abilities to produce and process language, making it more difficult for those PWDs to process and self-report their internal states (e.g., pain and hunger) to others. These caregivers continued to rely solely (or mostly) on the PWDs' verbal self-report to inform them of problems, including pain, likely causing multiple missed opportunities to help the PWDs manage their pain and distress.

For example, one caregiver (E198) questioned whether PWDs “really feel all the pain” due to their cognitive difficulties and then expressed uncertainty regarding the meaning behind the PWD’s multiple novel post-dementia behaviors (e.g., moaning whenever he passed her) (see excerpts pages 35-36 and 54-56). Another caregiver’s interview (E19) revealed that she did not ask any confirmatory follow-up questions or observations once the PWD confirmed that he was not having pain (see excerpt page 36). Caregiver E37 questioned the research clinician’s assertion that when PWDs told you that they were in pain that something was wrong and responded to psychoeducation on PWDs’ self-report using hunger as an example by stating that her husband was “never hungry” and would “tell you that” (see excerpt pages 38-39). Her continued reliance on the PWD’s verbal self-report to identify when he had pain or distress led her to answer the first PA question (*Is there a problem?*) with “no” in the absence of the PWD’s verbal complaints of pain or other types of discomfort, taking no action. Caregiver E51 shared that she only gave her husband OTC pain medication when he “complained” and explained that her husband did not do so very often, sharing that she believed that he did not often engage in activities that would have caused him to experience pain and thus did not often need pain medication (see excerpt page 36). Caregiver E53 reported the PWD regularly declined his evening dose of his prescription pain medication, and she did not subsequently encourage him to take this dose of medication despite his morning reports that he had pain during the night (see excerpt page 37). A couple of these caregivers (E19 and E51) also expressed frustration regarding the PWDs’ inability to verbally recall their recent pain, implying that they believed the PWDs were actually able to remember and yet were deliberately denying their recent pain in front of the research clinician (see excerpts pages 37-38). In sum, lack of dementia knowledge

may result in inaccurate caregiver answers (implicitly or explicitly) to the PA questions (*Is there a problem?, Is the problem pain?*).

Conversely, a more complete understanding of the dementia disease process may enable spousal caregivers to more accurately identify when PWDs are experiencing problems such as pain. For example one caregiver (E90) shared a recent experience with her husband in which he cooked bacon, burned it, and forgot this had happened while she was on a quick trip to the grocery store (see excerpt pages 40-41). She identified that her husband's forgetfulness as demonstrated in the cooking example was likely also applicable to his ability to remember his pain when asked to self-report. While receiving psychoeducation about language problems in dementia, another caregiver (E135) identified that her husband had difficulty finding words to express his pain (see excerpt page 39). The caregiver that perhaps demonstrated the best understanding of the dementia disease process (E33) shared that her husband "constantly" repeated himself and could not "express himself sometimes how bad he feels" because he had dementia (see excerpts page 41). Rather than relying on her husband's verbal self-report, she shared that she had reached out to cognitively intact individuals with her husband's conditions (i.e., ringing in the ears, dizziness, and hemorrhoids) so that their descriptions of these conditions could inform her understanding of her husband's experiences. She described awareness of how painful and distressing his conditions were as a result. She further reported trying solutions for her husband's various conditions (e.g., using a radio for ringing in the ears and using a non-squat portable bidet for hemorrhoids) based on the recommendations of her acquaintances with these conditions. These examples suggest that a more accurate and comprehensive understanding of the dementia disease process allows caregivers to better identify problems and pain in their PWDs.

Importance of Knowing the Person. The second subtheme is about caregivers' understanding of their spouse's pain behaviors as informed both by their current knowledge of the PWDs' patterns of responses as well as historical knowledge of their pre-dementia responses to pain and discomfort experiences. This familiarity might facilitate caregiver accuracy in answering the PA questions (*Is there a problem?, Is the problem pain?*). For example, multiple caregivers reported having knowledge that pre-dementia their husbands would minimize their pain (e.g., E25, E100, E195; see excerpts page 43), and this knowledge helped them know they needed to be vigilant about monitoring for pain. Two such caregivers (E73 and E117) explained that their husbands had never tended to spontaneously talk about their pain, so now post-dementia they had to be sure to ask them directly about it (see excerpts page 44). Many caregivers reported a reliance on understanding the meaning of nonverbal behaviors to determine whether their husbands were having problems and, if so, whether that problem was pain. Commonly reported nonverbal behaviors that were understood as pain indicators included facial grimaces and winces (e.g., E19, E33, E71), and moans and groans (e.g., E54) (see excerpts page 45). Most spousal caregivers also reported using the PWDs' verbal pain complaints to notify them when the PWDs had pain (see excerpts pages 45-46), particularly words like "ouch" (E89) and "ow" (E117) and cursing (E195). A couple of caregivers (E201 and E122) reported observing discrepancies between their husbands' nonverbal pain behaviors and their verbal denials of pain; these discrepancies prompted these caregivers to determine that something was a problem for their husbands, motivating them to take action. One of these caregivers (E201) shared that when she heard her husband moan she asked him what was wrong, and if he denied having any problems (including pain) she continued to query the PWD until he provided her with an explanation that matched this behavior, sharing that it was usually his back or his neck where

he experienced pain (see excerpt page 46). The other caregiver (E122) described observing her husband limping, despite not witnessing any type of injury or fall and his subsequent denials of pain (see excerpts on pages 47). She took him to the doctor three times to identify a cause (i.e., rheumatoid arthritis) and an effective solution (i.e., OTC pain medication), eventually resulting in successful treatment of the limp. Caregivers' familiarity and knowledge of their spouses likely helps them more readily identify and recognize when they have pain; however, accuracy may be hindered when caregivers have not adjusted their historical understanding to accommodate existing changes in behavior due to the effects of dementia.

Understanding of PWDs' Pain Language. The third PA subtheme is about caregivers' knowledge and awareness of the words used by their spouses when they are experiencing pain and/or distress. A narrower, more inflexible approach to the types of language that might indicate pain or distress could hinder caregiver accuracy in answering the first two PA questions (*Is there a problem?, Is the problem pain?*), whereas a broader, more flexible approach might facilitate accuracy. For example, caregiver E93 reported that her husband regularly complained about his shoulder, making her aware that there was a problem (see excerpt page 48). However, she expressed frustration that the PWD denied that his shoulder problem was pain, when he explained that it was "tight" and "swollen." When the research clinician explored the issue further with the PWD and caregiver, it came out that the PWD had in the past gotten an injection in that shoulder that effectively reduced his discomfort, but the caregiver had on her own failed to connect the dots that her husband's current complaint could be related to the same or a similar issue. She ultimately agreed to speak to the PWD's doctor to see if it was possible to resume injections for his shoulder.

Conversely, other caregivers exhibited flexibility in which words they acknowledged as possible indications that their spouses were having problems and, furthermore, that the problems were pain. For example, one of the caregivers (E14) shared that her husband said that he was “tired” as a reason for not wanting to do social things and asked the research clinician whether this was the same as him not wanting to do social things because of his pain (see excerpt page 48). Other caregivers (E69, E73, E84, and E209) shared that their PWDs used words such as “tired,” “uncomfortable,” and “hurts” to communicate pain (see excerpts page 50). Caregivers’ flexibility (or lack thereof) regarding their understanding of their spouses’ pain language may impact their likelihood of acting in response to those communications.

Attributing PWDs’ Pain Behaviors to Causes Other Than Pain. The fourth and final PA subtheme is about the tendency of some spousal caregivers to credit PWDs’ possible pain behaviors to causes other than pain. When the caregiver believes the PWDs’ behavior has a cause other than pain, they are implicitly or explicitly answering the first PA question (*Is there a problem?*) with “yes,” but the second PA question (*Is the problem pain?*) with “no.” For example, some caregivers believed that their husbands’ possible pain behaviors were due to personal choices (e.g., E02 – withdrawing to bed to avoid caregiver and E198 – laziness). These caregivers expressed anger and frustration about these behaviors (see excerpts pages 54-56 and 94). Caregiver decisions to act to try to reduce pain in response to PWD behaviors may be the result of their beliefs about the causes of those behaviors, as well as whether those causes are seen as within or out of the PWD’s control.

Other caregivers attributed their spouse’s possible pain behaviors to a specific health condition for which the caregivers believed there was an effective treatment option. These caregivers then acted by pursuing treatment for the identified condition (e.g., E69 – Parkinson’s

disease and E209 – dementia) (see excerpts pages 51 and 53). Other caregivers attributed the PWDs’ possible pain behaviors to a specific health condition for which they believed there was no effective treatment option, and therefore did not take any action to solve the PWDs’ problem (e.g., E53 – balance problems, E135 – memory loss, vision loss, and hearing loss, and E209 – low blood pressure) (see excerpts pages 52-53). In either case, if the cause of the PWD behavior was actually pain rather than these other conditions, then an opportunity for effective response might have been lost.

Pain Management Beliefs and Knowledge (PM). When prompted by the PWDs’ pain behavior(s) and responding affirmatively (implicitly or explicitly) to one or both of the PA questions, spousal caregivers of PWDs next answered (implicitly or explicitly) three PM questions: (1) Is the pain treatable?; (2) Is it worth treating?; and (3) How do I prefer to treat it? Caregiver interview data revealed a consistent pairing of: (a) the first PM question with PM subthemes of (1) belief that pain is a normal part of aging and (2) understanding of the cause(s) of PWDs’ pain; (b) the second PM question with the PM subthemes of (3) perception of their role in PWDs’ pain management; (4) prioritizing treatment of PWDs’ other comorbid health condition; and (5) difficulties accessing appropriate medical care for PWDs’ pain; and (c) the third PM question with the final two PM subthemes of (6) concerns regarding analgesic and pharmacological pain; and (7) preference for non-pharmacological and CAM pain treatments.

Belief That Pain Is a Normal Part of Aging. The first PM subtheme is about the tendency of some spousal caregivers’ to inaccurately believe that pain is a natural and inevitable part of aging. Caregivers with this belief likely answered “no” to the first PM question (*Is the pain treatable?*). Multiple caregivers (e.g., E14, E19, E89) expressed that pain was something to be endured, rather than treated (see excerpts pages 57). Another caregiver (E209) shared that

(although little was done to treat her 83-year-old friend's bone cancer) she believed the friend's related pain was due to her age (see excerpt page 67). Notably, this caregiver's husband also had bone cancer, and thus she might similarly believe that there were not effective treatments for her husband due to his age (74 years). One caregiver (E93) that initially believed that pain was a normal part of aging expressed during the home practice review that reading the intervention supplemental material (Hadjistavropoulos & Hadjistavropoulos, 2007) taught her that pain being a normal part of aging was a myth and that there were options for managing and treating chronic pain in older adults (see excerpt page 59). When caregivers perceive the PWDs' pain as treatable rather than an inevitable, normal part of aging, they may be more likely to act in response to the PWD pain behavior(s).

Understanding Of The Cause(s) Of PWDs' Pain. The second PM subtheme is about caregivers' explanation(s) of the cause(s) of their spouse's pain. The narrower the range of pain causes believed by the caregivers, the narrower the range of potential pain treatments, and, thus, the greater likelihood that the caregivers' response to the first PM question (*Is the pain treatable?*) would be "no," directly impacting the likelihood the caregivers acted in response to the PWDs' pain behaviors. For example, one caregiver (E37) implied that she believed that the PWD's pain could be treated if it was the result of injury-related tissue damage. She gave the example of the PWD's hernia-related stomach pain and her expectation that it would be treated by the PWD's primary care doctor using pharmacological treatments and/or surgery (see excerpt page 64). In contrast, she expressed beliefs that her husband's other pain (back, leg, and shoulder pain) was due to his failure to exercise (see excerpt page 94). Her sole response to this pain was, therefore, only to encourage him to walk (despite acknowledging that movement caused him to experience pain) in addition to participation in formerly enjoyable activities (i.e.,

playing dominos). Another caregiver (E71) reported that the PWD's pain was severe due to there being no effective treatment options, other than pain medication, which did not fully eliminate his pain (see excerpt page 68). She explained that even when taking his pain medication, her husband's arthritis in his jaw caused him to experience significant pain every time he used his mouth, including any time that he ate or spoke. This causal belief may have led her to stop acting to try to help the PWD find pain relief (other than giving him his prescription pain medication when he was willing to take it). Another caregiver (E195) seemed to believe that the only available pain treatments (at least without an accurate diagnosis) were medications, expressing that she would like the PWD's pain to be better diagnosed but did not want him to be on an analgesic pain treatment for the rest of his life (see excerpt page 66). As such, the only pain relief she provided to her husband was a heating pad, and she declined information on additional pain treatments and strategies. How caregivers understand pain causation and their subsequent conclusions regarding whether the PWDs' pain is treatable (or not treatable) motivate them to action (or inaction) to help the PWDs receive pain relief.

Perception of Their Role in PWDs' Pain Management. The third PM subtheme pertains to caregivers' understanding of their role in their spouse's pain management. Caregivers that implicitly or explicitly answered "no" to the second PM question (*Is it worth treating?*) typically took a passive role in their spouse's pain management. One such caregiver (E68) did not believe that there was anything she could do to help her husband respond to his pain other than call 911 due to functional limitations from her own chronic shoulder pain (see excerpt pages 71-72). Another caregiver (E198) was unfamiliar with the PWD's pain-related PT schedule (see excerpt page 73). Two other caregivers (E89 and E173) were unaware of whether their spouses took any pain medication, indicating that they were not heavily involved in at least this aspect of their

PWDs' pain management efforts (see excerpts pages 72-73). Similarly, another caregiver (E201) was surprised to learn that her husband took OTC pain medication at least once every day (see excerpt page 73). However, in contrast to the previous examples, this caregiver shared information elsewhere in the session that may have indicated her approach was person-centered and, as such, active (rather than passive). She sought buy-in from her husband for getting additional information on different pain treatments, tried to explain to him the tendency of PWDs to under-report their pain, and described plans to get heating pads to "loosen up" and reduce his pain (see excerpts pages 73 and 98). As such, she may have taken an active role in her husband's pain treatment, while also wanting to support him in having as much autonomy and engagement in the treatment process as possible. Her example is a reminder of the complexity and multi-dimensionality of pain treatment efforts and caregiver actions in general.

Conversely, other caregivers clearly described playing active roles in the PWDs' pain management. These caregivers actively looked for additional strategies to help their husbands better manage their pain. One caregiver (E100) asked the research clinician if she could share her husband's pain diary with his doctor in the hope that this would result in improved treatment from that healthcare provider (see excerpt page 74). Another caregiver (E117) shared that she monitored and tracked her husband's prescription pain medication utilization and massaged him in any painful areas with horse liniment when he could not safely take more pain medication (see excerpts page 75). A different caregiver (E33) described trying strategies shared with her by acquaintances with the same conditions as her husband (e.g., radio for ringing in the ears) (see excerpts pages 41-42). These caregivers likely took active roles in the PWDs' pain management efforts in part due to the belief that "yes," the pain was worth treating; alternatively, the more

passive roles taken by other caregivers were likely due in part to the belief that “no” the pain was not worth treating.

Prioritizing Treatment of PWDs’ Other Comorbid Health Conditions. The fourth PM subtheme is about some caregivers’ decision to not pursue pain treatment for their spouses in the belief that this would interfere with treatment of a comorbid condition given higher treatment priority. These caregivers implicitly or explicitly answered “no” to the second PM question (*Is it worth treating?*). One caregiver (E90) explained that her husband’s pain had not been addressed because there were “so many other issues” (see excerpt page 77). As part of discussing potential options for improving pain management, another caregiver (E100) shared that her husband needed to take Risperidone at night to manage his movements and that she believed giving him pain medication with his other medications was not a “good idea” (see excerpt page 79). One possible interpretation of these data is that the caregiver conceptualized BPSD treatment and pain treatment as an “either/or” choice and chose to prioritize treatment of the PWD’s BPSD and other comorbid health conditions over his pain (rather than trying to balance and address both). Another caregiver (E54) reported that concern about her husband’s dementia had led her to make it the focus of her husband’s recent healthcare appointments rather than his pain or other comorbid health condition (see excerpts pages 79-80). While this caregiver stated that she intended to discuss her husband’s pain at his next doctor’s appointment, indicating that she did think his pain was worth treating, the final outcome was that she had not pursued treatment for his pain (despite his being on prescription pain medication in the past). One possible interpretation of these data is that the caregiver did prioritize dementia treatment over pain treatment. This example also illustrates the complexities of navigating the healthcare system, as it is reasonable to assume that the caregiver would have advocated additionally for pain

treatment if she had unlimited time with the provider. Overall, the comorbid health conditions of the PWDs may lead spousal caregivers to deem pain not worth treating, believing it would take time and resources away from treating the PWDs' comorbid health conditions.

Difficulties Accessing Appropriate Medical Care for PWDs' Pain. The fifth PM subtheme is about challenges caregivers reported experiencing while pursuing treatment for the PWDs' pain. These included poor communication with the PWDs' healthcare providers, the cost of pain treatments, and lack of transportation to pain treatment appointments. These difficulties likely contributed to caregivers answering "no," implicitly or explicitly, to the second PM question (*Is it worth treating?*). One caregiver (E63) reported that one of her husband's doctors had recommended pool PT but had not followed through with a referral (see excerpt page 81). She noted that she needed to follow up but had not yet done so. Another caregiver (E84) reported that she believed there was an effective treatment for the PWD's pain, but it was unavailable in the United States (see excerpts pages 81-82). This belief was inaccurate given the medication was revealed to be Cymbalta, which was and continues to be available in the United States, suggesting a provider communication issue. Another caregiver (E14) described getting conflicting guidance from two different doctors regarding her husband's OTC medication use (see excerpts pages 82 and 87). A different caregiver (E89) expressed uncertainty regarding with which of the PWD's numerous medical doctors and healthcare providers she should discuss potential pain treatments for her husband (see excerpt pages 82-83).

Other caregivers reported that the cost of pain treatments was a barrier, causing them to decide that the pursuit of some treatments was not worthwhile or should be postponed due to cost. One caregiver (E195) shared that a heating pad had effectively provided the PWD some pain relief, but their dog had destroyed it, causing a delay in pain relief for the PWD until they

had enough money to replace it (see excerpt page 83). Another caregiver (E181) explained that Lyrica had effectively treated the PWD's pain in the past, but they had found it was not covered by their health insurance and the out-of-pocket cost per refill (i.e., \$450) was more than she and her husband could afford, leading to his use of a less effective OTC pain medication (see excerpt page 84). Some caregivers described transportation difficulties as a significant factor in pursuing pain treatment.

One of these caregivers (E68) reported that she needed to call the non-emergency police number to get transportation to the hospital for her own pain treatment, implying that lack of transportation was also a barrier for the PWD in attending healthcare appointments (including those related to his pain) (see excerpt page 84). A different caregiver (E181) described how her spouse had to get rides from one of their adult sons to attend medical appointments (see excerpt page 85). This was a regular barrier to the PWD getting healthcare for his pain because his sons had limited availability due to their work schedules and the PWD sometimes needed emergency treatment. Challenges to accessing appropriate medical care to treat the PWDs' pain may lead some caregivers to decide against the efforts required to overcome these barriers to seek pain treatments.

Concerns Regarding Analgesic and Pharmacological Pain. The sixth PM subtheme is about spousal caregivers concerns regarding using pain medications to treat or manage the PWDs' pain. Caregiver pain medication preferences affect answers, implicitly or explicitly, to the third PM question (*How do I prefer to treat it?*). Several caregivers shared about their concerns about and efforts to address side effects and dependence. One caregiver (E02) shared that she gave the PWD OTC pain medication once daily rather than the prescribed three times daily (see excerpt page 86). A different caregiver (E53) explained that her spouse's doctor had

switched the PWD's pain medication from hydrocodone to Tramadol, due to having concerns that the former medication was making the PWD's memory worse (see excerpt page 88).

Another caregiver (E181) shared that her husband had developed Barrett's esophagus due to overuse of acetaminophen, which he only used because they could not afford Lyrica out-of-pocket (see excerpts pages 84 and 88). Another caregiver (E195) expressed fears regarding becoming dependent upon prescription pain medication herself, sharing that she took her prescription "on and off" for the past 13 months, perhaps indicative of a reluctance to use analgesic pain treatments with the PWD as well (see excerpt page 88).

Several caregivers described concerns regarding overdosing, and tolerance. Caregiver (E117) shared that she encouraged the PWD to take his prescription pain medications only when he was actively hurting as she did not want him to overdose (see excerpt page 89). Other caregivers (E53, E63, and E84) reported concerns about PWDs developing tolerance to their pharmacological pain treatments, which included beliefs that PWDs' pain medication would no longer be effective if taken regularly as prescribed (see excerpts pages 89-90). Furthermore, one of these caregivers (E63) further shared that she alternated the PWD's two prescription pain medications (Tramadol and Codeine) to prolong and increase their efficacy. E84 (both caregiver and PWD) expressed believing that he had become "immune" to his pain medication (Tramadol) due to taking them too long (see excerpts pages 90-91). Due to concerns regarding side effects, dependence, overdosing, and tolerance, many spousal caregivers communicated that they did not prefer to treat the PWDs' pain with analgesic and pharmacological pain treatments.

Preference for Non-Pharmacological and CAM Pain Treatments. The seventh and final PM subtheme is about caregivers' preferences regarding non-pharmacological and CAM treatments for managing their spouses' pain. Caregiver pain treatment preferences affect

answers, implicitly or explicitly, to the third PM question (*How do I prefer to treat it?*). Most spousal caregivers communicated their desire to use non-pharmacological and CAM treatments for treating the PWDs' pain, including those under the PWD's control (movement/exercise and adjustment of body position) and those under others' control (massage/rubbing, heat/warmth, dietary supplements, and pleasant, enjoyable activities). Some caregivers encouraged the PWDs to engage in behaviors to manage their pain, including physical activity and adjusting the position of their bodies. For example, one caregiver (E14) shared that she and the PWD walked together daily for pain management for both of them, and another caregiver (E19) praised the PWD for his daily walks, emphasizing how great it was that he did not give in to his pain (see excerpts pages 92-93). Other caregivers described recommending that the PWDs change or adjust their body position for pain relief. For example, one caregiver (E44) recommended that the PWD change the position his leg after he reported feeling "a little bother" in that leg (see excerpt page 95). Three other caregivers (E53, E63, and E71) encouraged their husbands to lie down (in addition to utilizing other pain treatments) (see excerpts page 96).

Caregivers also described using external aids, under the control of individuals other than the PWDs, to help them manage their pain. Some caregivers (e.g., E117 and E209) claimed that using massage and rubbing helped reduce the PWDs' pain "a lot" (see excerpts pages 96-97). Caregivers also reported using warmth to alleviate the PWDs' pain, through warm showers (e.g., E117 and E63) and heating pads (E195 and E201) (see excerpts page 98). A couple of caregivers (E33 and E181) shared that their spouses took dietary supplements or non-vitamin, non-mineral natural products to reduce PWDs' pain (e.g., E33 – ginger for dizziness and E181 – turmeric and fish oil for inflammation) (see excerpts page 99). Other caregivers described encouraging the PWDs' engagement in pleasant, enjoyable activities to better manage their pain,

such as church (E71 and E100) and past hobbies (E37 – dominos and E71 – bowling) (see excerpts pages 100-102). At least one caregiver (E195) asked the research clinician whether VAMCs had chiropractors, sharing that she had gone to chiropractors to treat her own pain in the past with effectiveness and thought that this might be an effective treatment for the PWD's pain (see excerpt pages 102-103). However, her husband responded that chiropractors were “quacks,” indicating that his preferences for pain treatments differed from his wife's preferences. Overall, spousal caregivers generally responded to the PM question regarding how they prefer to treat the PWDs' pain with non-pharmacological and CAM treatments.

Synthesis

In the preceding section the author justified the first portion of the proposed pain mental model (see Figure 2) by demonstrating how the two PA questions play out within each of the PA subthemes and how the three PM questions play out within each of the PM subthemes. In this section, the author will justify the final portion of the model, demonstrating connections between caregivers' answers to the PA/PM questions and subsequent caregiver action or inaction in response to the PWDs' pain behavior(s). Eight examples demonstrating how disconnects lead to inaction (and conversely, how connections lead to action) are provided. Four of these caregivers (in order of appearance: E07, E37, E54, and E90) exhibited possible inaccuracies in how they answered PA and/or PM questions, and a subsequent failure to “connect the dots” that led them to inaction and missed opportunities to provide the PWDs with pain treatment. Conversely, four caregivers' PA and PM answers helped them “connect the dots”, leading them to take action and seize opportunities to provide the PWDs with pain relief (in order of appearance: E33, E122, E02, and E93).

Examples of Missed Connections Leading to Caregiver Inaction.

E07. This caregiver reported that the PWD's pain was constant and severe. She reported the PWD had numerous painful conditions, including osteoarthritis, rheumatoid arthritis, back pain, knee pain, and leg pain (see Table 2).

E07: I said it's almost like it's [PWD's pain is] constant.

RC: It is?

CG: So, it's just like at a certain point at like at night it's just a little bit more severe.

Because if he take his medicine in the morning then he's okay[and] then later on before he goes to bed that's when I give him his additional medication. But his pain is constant.

RC: How would you say he [PWD] rates his pain?

CG: Severe.

RC: Severe. Okay, and how do you rate it?

CG: Well, like I, you know, you really can't feel someone else's pain. So, when he say that, I can tell that [when] he starts rubbing his knees and his elbows and then he'll say say... [CG did not finish sentence]. I'll say, "Are you okay?" He'll say, "No, I'm kinda hurting." So then I know he's in pain.

The above excerpt demonstrates that the caregiver placed more weight on her spouse's verbal self-report than her observation of his nonverbal behavior (rubbing), even though her husband had dementia and therefore may not have always been able to put his pain experience into words. She indicated that she looked for a verbal confirmation from her spouse before concluding that he was in pain. Later in the interview, the caregiver shared an anecdote about a time in which she did not give the PWD his prescribed evening dose of pain medication (Tylenol 3 with codeine) because he did not verbally complain of pain.

E07: Now sometimes at night if I see that he's not really complaining it or anything, he'll go to bed without taking any medication.

Yet she also shared that her spouse would sometimes wake up in the middle of the night complaining of pain.

E07: But then every now and then he'll wake up in the middle of the night and I'll say, "What's wrong?" [PWD says,] "Well, I'm hurting."

The interview included two other instances of this caregiver's strong reliance on verbal self-report, likely indicating limited understanding of the potential negative impact of dementia on self-report ability. First, she described her husband's mood as "very negative" when he first started having memory problems, and she noted that his mood had improved over time, as indicated by his current lack of verbal mood complaints (see excerpt page 39). It is certainly possible that the PWD's mood had improved, but the caregiver did not note any changes that would explain his mood improvement nor did she indicate any awareness of the alternative explanation that the PWD's mood had not actually improved but rather his ability to verbalize his distress had diminished (which, if true, would mean that there had been a missed opportunity to take action to reduce the PWD's distress). Second, she shared that the PWD regularly reported high levels of pain ("6 or 7" on a scale of 1 to 10) during his healthcare appointments before his memory problems began, and she noted that his pain was now effectively treated, as indicated by his lack of verbal vocal complaints (see excerpt page 40). Again, it is possible that the pain had actually improved, but the caregiver did not note any changes in his pain treatment to explain the improvement, nor did she note the possibility of the alternative explanation that her husband was in pain but no longer able to accurately self-report (even though in another portion of the interview she said that he had self-report difficulties). Third, she described the absence of pain-related complaints as her evidence for the efficacy of the PWD's current pain medication. It is possible that this potentially flawed understanding of efficacy was then related to her pain management strategies being heavily reliant on the PWD's pain medication, with no other active (non-pharmacologic) pain management strategies described other than encouraging her husband to lie down when he returned home from the senior center for pain relief.

The caregiver's understanding of the PWD's functional disability provides another example of a potentially inaccurate PA answer potentially leading to a missed opportunity for action. When asked if the PWD had stopped participating in any activities because of his pain, the caregiver replied no. Instead, she attributed her husband's inability to walk to muscle "deterioration" from sitting all the time, and his difficulties with dressing and bathing to a "difference in his ability" (see excerpt page 95 and excerpt below).

E07:

RC: Does his pain keep him from doing things like being able to dress himself or bathe himself? Do you do that? Or is there an aide?

CG: I assist him with that.

RC: Okay. Is it because of the pain is an issue for him? Or is it just a difference in his ability to be able to that?

CG: Difference in his ability. Not being able to.

It is possible that the functional disability causes were not pain, but the caregiver did not indicate an awareness of the alternative explanation that pain had led to lack of mobility and engagement which then had led to deterioration in strength, mobility, and ability. It is possible that a different PA answer would have opened up opportunity for other actions, such as pursuing alternative pain management techniques and rehabilitation to recover lost function.

E37. This caregiver had chronic pain herself (arthritis and shoulder pain), and her spouse had multiple sources of chronic pain, which included a hiatal hernia (and related stomach pain), back pain, leg pain, and shoulder pain (see Table 2). She described the PWD's pain as significantly interfering and impairing his ability to help with daily household chores and to walk without the assistance of a cane (see excerpt page 64 and excerpt below).

E37: His pain is in his legs; he can't stand up or walk too long. Like this morning I was doing some cleaning. No, [it was] last night. He was going to help me cook. Well, he said, "Oh, I'm hurting so bad!" His pain, it was across here. He said if he stand up too long or try to move around. The other pain is his stomach. [...] They did a scan on his stomach, and they found out that he has a hiatal hernia. We haven't gone to the primary care yet to see what he would recommend but he has pain there a lot...and then his legs,

oh his legs hurt him. They gave him a walking cane and twice he fell in the back yard and I didn't know. He was just walking around, you know. And I didn't know. But pain keeps him from doing...I guess his memory too, doing many things. He used to be able to help me. He can't help me now.

With these statements, this caregiver evinced that her responses to the PA questions (*Is there a problem?, Is the problem pain?*) were “yes,” but her implied response to the PM questions (*Is the pain treatable?, Is it worth treating?*) were less clear. She reported “the doctor prescribed something for agitation and sleep” (both BPSD), but “had never been” on any medication for pain (see excerpt page 29). A possible interpretation of these circumstances is that this caregiver’s implied answer to one or both of the PM questions was “no,” and that the PWD’s pain was not treatable and/or not worth treating given her current resources. The consequence was a disconnect between her acknowledgement of the PWD’s significant pain interference and subsequent lost opportunities for acting to decrease his pain.

Evidence that this caregiver struggled with the PM questions (*Is the pain treatable?, Is it worth treating?*) was that she described the PWD’s arthritic pain as impairing his ability to complete ADLs (e.g., dressing) and Instrumental Activities of Daily Living (IADLs) (e.g., meal preparation and housework), but reported that the only pain management techniques encouraged by her were exercise (walking – see excerpt page 94) and participation in formerly enjoyable activities (playing dominos – see excerpts pages 101-102). Her muddled responses to the PM questions regarding whether pain was treatable and whether pain was worth treating likely led to her failing to connect the dots (especially his daily pain interference to needing effective pain treatments) and missed opportunities to help her husband better manage his pain and distress.

E54. Caregiver E54 reported that her spouse suffered from arthritic pain, especially in his knees. She appeared to be unaware of dementia’s negative impact on language, because she continued to rely on the PWD’s self-report to identify when he was experiencing pain and/or

distress over his nonverbal pain behaviors (groaning) and reported that she only provided her husband with OTC pain medication when he verbally requested it, which did not happen “many days” (see excerpt page 80). Thus, her implied answer to the PA questions (*Is there a problem?*, *Is this problem pain?*) was “no.” And yet there was evidence that this was likely an inaccurate assessment. During the subsequent home practice review, caregiver E54 reported that the PWD’s pain intensity had ranged from moderate to quite bad every day during the past week.

E54: It's just an overview of what happened this week. 'Cause it's the same thing that happens all the time. So...

RC: Okay, everyday it [the pain] is between moderate and quite bad.

CG: Uh-huh.

RC [reading note]: "OK, it is worse when he tries to get up and down. Afterwards when he's sitting he knows [that he feels pain]."

CG: He knows the knees are there.

RC: But not uncomfortable enough to moan or groan, which he does getting up or down.

CG: Ah, but he did go, "Ouch" right after you left last time. That's the only time I heard "ouch" all week.

In the above excerpt, this caregiver also expressed that her husband only verbally expressed his pain one time, saying “ouch” once after the previous PAVeD session, which may further demonstrate a failure to connect the dots and recognize the PWD’s untreated pain.

This caregiver also expressed that the PWD needed knee replacement surgery to effectively treat his pain, but he was unwilling to have this surgery (see excerpts pages 68-69). As a result of the PWD’s unwillingness to have this treatment, her implied answer to the PM question (*Is the pain treatable?*) appeared to also be “no.” With knee replacement surgery not being an option, this caregiver may have concluded that his arthritic knee pain was untreatable.

Her responses to the PA/PM questions may have led to incorrect conclusions that the PWD did not have pain in the absence of his self-report and, when he did have pain, that it was untreatable, leading to her inaction to manage her husband’s pain. Evidence for this includes that the PWD was on no current pain medication (other than receiving OTC pain medication on

the rare occasions in which he asked for it), despite his being on prescription medication in the past (see excerpt page 80). She further reported that the PWD's healthcare providers had recommended knee braces to help alleviate some of his knee pain, but, similar to the knee replacement surgery, the PWD was unwilling to try them, with this caregiver seemingly in agreement.

E54: They talked about maybe some braces, and, oh, they're so cumbersome. You know?

RC: Like for leg braces?

CG: Right. So, he said no. So here we go.

It may be that this caregiver had a limited awareness of or openness to the full range of pain treatment options, including some of the non-pharmacological and CAM treatments for pain. This likely led her to the inaction of failing to pursue an alternative treatment for the PWD's knee pain (other than sometimes using massage to provide him with some pain relief) when knee replacement surgery was determined to be not an option (see excerpt pages 68-69 and 97). Caregiver E54 consistently failed to take action in response to the PWD's nonverbal pain behaviors due to her gaps in PA and PM, leading to numerous missed opportunities to provide her husband with pain relief.

E90. The final exemplar caregiver who repeatedly failed to take action in response to her husband's pain behaviors to help him better manage his pain was E90. She shared that her husband had neuropathy, foot pain, joint pain, and shoulder pain (see Table 2) and expressed beliefs that the PWD's pain was a "constant dull ache" (see excerpt page 77 and excerpt below).

E90: I think it's a constant dull ache.

She demonstrated having awareness of her husband's poor memory, using the recent experience where he cooked bacon, burnt it, and forgot that he did this as an example and connecting this to his lack of regular self-reported pain (see excerpt pages 40-41).

E90:

RC: And I know he wasn't here last week, so we really didn't get into the home practice part, but have you noticed over the past week that he's been in pain?

CG: We were talking about that. And he says, "How can I remember?" You know, if he was in pain at a certain time.

She further described the PWD's significant daily pain interference, reporting that he did not "expose himself" to situations that would cause pain, which included going across the street to play with his grandchildren (see excerpt page 77). These examples indicate that E90 answered the PA questions (*Is there a problem?*, *Is this problem pain?*) as "yes." However, she appeared to answer "no" to the PM question, *Is it worth treating?*, as she explained that she had not pursued pain medication for the PWD due to there being "so many other issues" (or comorbid health conditions) to treat (see excerpt page 77).

The caregiver's answers to the PA/PM questions may have led her to a disconnect and missed opportunity for action to decrease her spouse's pain. Evidence for this includes that she stated that she did not think that he needed pain medication (see excerpt page 77), demonstrating her failure to connect the dots between his significant and constant daily pain (and related pain interference) to his needing better, more effective pain treatment. Other than her sometimes rubbing the PWD's feet for pain relief, he received no pain treatments. She shared that she had considered getting the PWD a massage for pain management at a local college, but had not done this due to her numerous caregiving time demands (see excerpt page 78). This indicates that the time demands of non-pain-related caregiving tasks prevented her from taking action and pursuing additional pain treatment options for the PWD. Ultimately, E90 (like E07, E37, and E54) failed at numerous points to connect the dots to recognize the presence of pain or make efforts to provide the PWD with pain relief.

Examples of Successful Connections Leading to Caregiver Action. Unlike the four previous exemplar caregivers who repeatedly failed to take action to assist PWDs in obtaining pain relief, four other caregivers successfully connected the dots, taking action to help PWDs better manage their pain.

E33. One caregiver (E33) demonstrated the best understanding of the dementia disease process of all spousal caregivers, and this understanding of dementia appeared to help her to more effectively identify the PWD's problems, including pain, and recognize opportunities to provide him with pain and distress relief. Her husband experienced ringing in the ears, dizziness, and hemorrhoids (see Table 2). She answered the two PA questions (*Is there a problem?, Is this problem pain?*) and the two PM questions (*Is the pain treatable?, Is it worth treating?*) with "yes." She explained that the PWD could not express how bad he felt due to his dementia (see excerpt page 39). This understanding led her to speak with cognitively intact individuals with the PWD's same conditions (i.e., ringing in the ears, dizziness, and hemorrhoids) to better understand his daily experiences and to learn additional pain management strategies for these conditions (see excerpts pages 41-42). She also described awareness of the PWD's nonverbal indicators of pain and distress (e.g., his facial expression) (see excerpt page 45). This caregiver expressed understanding of the significant pain and distress interference experienced by the PWD daily, which included him being unable to fold clothes, wash dishes, or help with any other household chores. Perhaps due to her attribution of the reduction in the PWD's physical ability to his pain and dizziness (perceived as out of his control), rather than personality-driven factors (that might have been perceived as within his control), E33 did not express any negative feelings in response to her husband's inability to help with household chores, as this excerpt indicates.

E33: We help him [inaudible]. He used to help me fold clothes. [He] Used to help me wash the dishes. I cook. He washed the dishes. He dropped everything. He don't do

that anymore because he say he can't hang clothes like when he [was not in pain], the hangers and hold them when I get them out of the dryer. He don't help anymore. He say, "I'm dizzy. I cannot do it anymore."

Caregiver E33 demonstrated openness to both pharmacological and non-pharmacological treatments, implying that her answer to the final PM question (*How do I prefer to treat it?*) was in any way that provided him some relief from his pain and distress. Perhaps this openness to a breadth of treatment possibilities contributed to her perseverance in her advocacy with her husband's medical providers. For example, she continued to pursue additional strategies to provide her husband with pain relief even though four separate doctors were unable to determine any causes for the PWD's ringing in the ears and dizziness (see excerpt page 66); the absence of a medical diagnosis did not deter her efforts to help the PWD experience less pain and distress. Her openness may have also contributed to her strong follow-through after receiving treatment advice. For example, she tried strategies recommended by the PWD's healthcare providers (e.g., using suppositories for hemorrhoids), those recommended by cognitive intact individuals with the PWD's conditions (e.g., listening to a radio for ringing in the ears and using a non-squat portable bidet to clean up after using the restroom to avoid irritating his hemorrhoids), those endorsed as effective by the PWD (e.g., chewing animal cookies and gum and taking dietary supplements), and those that she herself recognized as helpful for the PWD (e.g., attending the senior center) (see excerpts pages 41-42, 76, and 99-100). She further described making plans for him to have activities with friends on the weekend days when the senior center was closed after noticing that he experienced more pain and distress when he stayed at home without such activities. She also expressed that she continued to use pain management strategies that the PWD found helpful, even if she did not fully believe they actually helped him (e.g., supplement from GNC for his ringing in the ears – see excerpt page 99).

E122. The other caregiver who successfully linked the PWD's novel nonverbal behavior (i.e., limping) to a need to take action prior to her participation in the PAVeD intervention was E122. She described observing a disconnect between her husband's limping and his denials of pain (see excerpts page 47). In other words, she correctly answered the first PA question (*Is there a problem?*) with "yes." She expressed that she was with him all the time and knew that he had not fallen, eliminating injury as an explanation for the PWD's new behavior. She shared that she took her husband to the doctor three times until a cause for his limping as well as an effective treatment were identified, with her actions indicating that her answer to the PM questions (*Is it worth treating?*) was "yes." The PWD was ultimately diagnosed with rheumatoid arthritis, with resulting knee and leg pain, and prescribed OTC pain medication twice daily. This led to her answering the second PA question (*Is this problem pain?*) as well as the PM question regarding whether the pain was treatable with "yes." She now ensured that the PWD took this OTC pain medications twice daily as prescribed. This caregiver provided evidence for the efficacy of this pain treatment, sharing that her husband no longer limped and denied experiencing current pain, even during an activity that she expected would cause the PWD pain (i.e., during a leg exercise) (see excerpt page 70). Caregiver E122 also described observing no other nonverbal pain indicators in other situations that commonly caused pain in those with arthritis (i.e., cold weather).

E122: And that's another thing usually 'cause we had had a lot of cold weather. [In] The mornings it was kinda cool, and I know they always say...'cause a lot of times [if] you have arthritis [it] react with the cold weather. And I would ask him. He'll say, "No, I'm not hurting. My leg ain't hurting. My leg ain't hurting." You know, I would ask him, "Are you comfortable?" [He'll respond] "Yeah, I'm comfortable." So I mean in his expression on his face doesn't change or anything. It be the same. So I have to go with what he's saying.

She further reported that she asked the PWD “constantly” whether he was having pain, explaining that she thought he sometimes demonstrated nonverbal behaviors indicative of pain and distress.

E122: Sometimes (like I say) when he's in the mood where he just don't want to be bothered, I feel like maybe something... I don't know. Well, I constantly ask him is he in pain. And he'll say "Well, no." You know? I say, "You sure you're not hurting? Your leg or anything?" [He'll respond] "No, I'm not hurting. I'm not in pain." But I know he's in these mood[s] where either he's like kinda just feeling down or like you say, you know? And he might not be in pain, but he's just not in the mood where he want to be bothered. Maybe it's like a little slight depress...
RC: Depression.

In doing this she showed that she continued to look for signs of pain and distress in the PWD, even though she believed he had an effective treatment for his pain.

E02. This caregiver’s husband had back and hip pain. Caregiver E02 began the first PAVeD session by sharing that her husband’s withdrawal to the bedroom to lay down made her “angry” (see excerpt page 94). She further expressed that her anger may have prevented her from inquiring further with her husband about his experience. It may have been that this caregiver attributed the PWD’s behaviors to an attempt by the PWD to be antisocial and/or to avoid the caregiver herself rather than attributing them to pain management efforts. As such, she seemed to answer the first two PA questions (*Is there a problem?, Is this problem pain?*) with “no”, leading to inaction as indicated above through her statement that she did not ask the PWD why he went back to bed. However, this appeared to change after the research clinician provided psychoeducation on pain in PWDs, including their diminished ability to self-report and manage ADLs (e.g., cooking and eating) and IADLs (e.g., managing medications) (e.g., see excerpt pages 49-50). Caregiver E02 then stated that she had to remind herself to view the PWD’s behaviors in the context of his dementia, explaining that she would forget this and continue thinking that he was like he had been pre-dementia (see excerpt page 36).

Subsequent to the conversation with the research clinician, this caregiver began to recognize nonverbal indicators of pain (restlessness) and identify situations that might have been causing the PWD to experience pain and distress, including sitting in his chair with a pillow behind him.

E02: I've never asked him, but I've noticed him in the chair doing this and that [shifting].”

This caregiver suggested that, while she had placed a pillow behind him in his wheelchair in an effort to make him more comfortable, it may have been instead causing him to have more pain and discomfort (see excerpt page 94). She later expressed that it might be uncomfortable for the PWD to sit for extended periods of time due to his hip replacements.

E02: You know, I forgot all about the hip replacements too. That pain could be from sitting a long time.

RC: And if your cushion's not right [it can be uncomfortable and/or painful].

CG: That's right!

Her efforts to make the PWD comfortable suggest that her response to the PM question, *Is it worth treating?*, was “yes,” but she was unable to recognize the PWD’s pain (i.e., PA question, *Is this pain?*) due to not viewing his pain in the context of dementia in the past.

Further evidence of E02’s improved ability to make connections between her husband’s behaviors and actions needed to reduce his related pain and distress came during the home practice review. Rather than expressing anger regarding the PWD’s pain behaviors as she had at the start of the first session, she expressed that her husband was unable to tell her about his pain as the result of his dementia.

E02: He can’t voice it and tell me what’s going on.

This caregiver went from anger due to her poor understanding of pain and dementia to acknowledging the need to re-evaluate her past pain management strategies for the PWD (e.g.,

pillow behind him in his wheelchair) to determine whether they still provided pain relief or whether they had been causing him greater discomfort. As such, with the help of the PAVeD psychoeducation, E02's ability to make connections and take effective action to help the PWD obtain pain relief appeared to be significantly improved, in addition to his pain behaviors being less frustrating to her.

E93. Caregiver E93's spouse had a prior injury in addition to having ankle pain, back pain, knee pain, and shoulder pain. She reported that his pain had stopped his participation in activities and made it difficult for him to stand for extended periods of time.

E93: Over the years I've noticed that he can't stand for long periods of time.

RC: Okay, so standing.

CG: His lower back and periodically his knees bother him.

She demonstrated an inflexible understanding of the PWD's words that indicated that he was experiencing pain. Specifically, she expressed confusion and frustration regarding her husband's frequent complaints about his shoulder since he described his shoulder as a "bother" rather than pain, which appeared to have led her to implicitly answer the PA question (*Is this pain?*) as "no" (see excerpts pages 48-49). The research clinician helped this caregiver obtain clarification from the PWD regarding his shoulder experience that helped her understand it was distressing, and, as a result, she agreed to pursue treatment of his shoulder "bother," even if she and PWD did not consider it to be pain.

This caregiver also expressed confusion regarding the connection between physical pain and mental pain, sharing that she had never previously related pain to emotion (see excerpt page 60). At the start of the second session and home practice review she reported the information on mental pain to have been helpful to her, causing her to begin to understand "how deep the mental pain could be" and evincing a shift and expansion of her beliefs regarding what was considered

to be pain (see excerpt pages 62-63). This caregiver explained further that she read a chapter from the optional, supplemental material in between the first and second PAVeD sessions (i.e., Pain Management for Older Adults: A Self-help Guide (Hadjistavropoulos & Hadjistavropoulos (Eds.), 2007) (see excerpt page 59). She described material from the first chapter on pain among seniors, including the vignette about a man named “Stan” whose doctor told him that pain was a normal part of aging and did not suggest to him any possible pain treatments. Caregiver E93 expressed that she now understood that it was a “myth” that pain was a normal part of aging and that she now knew that there were things that could be done to better manage pain in older adults. This demonstrated a shift in her implicit response to the first PM question (*Is the pain treatable?*) from “no” to “yes.”

While this caregiver reported using both pharmacological (OTC pain medication) and non-pharmacological (warm water in shower) treatments for the PWD’s pain prior to her epiphanies described above, the reluctance to pursue shoulder treatment until the research clinician intervened illustrates that improved PA/PM understanding did lead to increased connections and action for this caregiver. Thus, it may be reasonable to expect that these additional epiphanies would also result in expanded caregiver action when needed in the future.

Conclusion

Spousal caregivers’ responses to two PA questions (*Is there a problem?*, *Is this problem pain?*) affected whether they did or did not engage in actions to assist the PWDs in obtaining strategies and treatments for pain management. When they answered “yes” to the two PA questions, these caregivers pursued medical care, including pharmacological treatments and surgeries and non-pharmacological and CAM treatments. Importantly, they also needed to answer “yes” to first three PM questions (*Is the pain treatable?*, *Is it worth treating?*) and have

access to pain treatments that they preferred in order to help the PWDs use them (the third PM question). These answers led caregivers to successfully identify (or fail to identify) the presence of pain in the PWDs. Inaccurate answers to the two PA questions and the three PM questions led to caregivers not “connecting the dots” between the observed the PWDs’ behaviors and the pain-related meanings of those behaviors, resulting in caregiver inaction. Caregivers of PWDs needed to first recognize that the PWDs were experiencing pain in order to then engage in pain management efforts. Ultimately, the proposed pain mental model of spousal caregivers asserts that their PA and PM directly impact whether they act or fail to act in response to the PWDs’ pain (see Figure 2).

DISCUSSION

Discussion of Findings

This is, to the author's knowledge, the first study to examine and describe the pain mental models of spousal caregivers of PWDs. The findings revealed two main themes, Pain Assessment Beliefs and Knowledge (PA) and Pain Management Beliefs and Knowledge (PM), which were both involved in caregivers' pain mental models (see Figure 1). Findings further provided evidence of these caregivers' pain mental models in which answers to PA/PM questions facilitated connections (or missed connections), leading them to action (or inaction) (see Figure 2).

The PA theme involves how spousal caregivers identify and assess for pain in PWDs. Caregivers use their knowledge (or lack thereof) of the dementia disease process, their understanding of the PWDs' pain behaviors pre-dementia as well as their daily patterns since their dementia diagnosis, their knowledge of which words when used by the PWDs mean that they are experiencing pain and distress, and their understanding of the cause(s) of the PWDs' behaviors as a result of pain (as opposed to comorbid conditions or personality-driven causes). The theme further includes the caregivers' knowledge of the PWDs' pain history, pain duration, and past responses or behaviors when experiencing pain and/or distress. PA also contains the verbal and nonverbal behaviors that currently notify the spousal caregivers that the PWDs are experiencing pain, as well as which activities or situations cause the PWDs to feel more pain. Gaps in knowledge regarding the dementia disease process, chronic pain, and/or pain in the

context of dementia can lead to these caregivers' failure to correctly identify when the PWDs have pain.

Once spousal caregivers recognize pain in PWDs, they use their PM to determine whether and how to act in response. The PM theme covers how these caregivers decide to act (or not act) to assist PWDs in treating their pain. It includes spousal caregivers' general beliefs about pain in older adults, the causes of pain, and whether they perceive their role in the PWDs' pain management as active (their responsibility) or passive (PWDs' responsibility). PM also encompasses how some caregivers prioritize the treatment of the PWDs' non-pain comorbid health problems as well as barriers experienced by these caregivers in obtaining medical care necessary to effectively treat the PWDs' pain, including communication difficulties with healthcare providers, cost of pain treatments, and lack of transportation to healthcare appointments. The theme further describes caregivers' concerns regarding the PWDs' use of pharmacological treatments along with their preferences for the PWDs' use of non-pharmacological and CAM pain treatments. Gaps in knowledge regarding the full range of pain treatment options as well as inaccurate beliefs regarding pain (e.g., "pain is a normal part of aging") can lead to these caregivers' failing to act to help the PWDs obtain pain relief.

These caregivers answered two PA questions (*Is there a problem?, Is this problem pain?*) to determine whether the PWDs were experiencing pain. When they explicitly or implicitly answered "no" to either or both of the PA questions, caregivers failed to connect the dots and did not act to help the PWDs to better manage their pain. When these caregivers identified pain in the PWDs, they then answered three PM questions (*Is the pain treatable?, Is it worth treating?, How do I prefer to treat it?*) to decide whether they needed to take action to aid the PWDs in treating their pain. Spousal caregivers must have believed that pain was treatable and worth

treating (answering “yes” to the first two PM question) in addition to having access to pain treatments that they were comfortable using with the PWDs in order for them take action to help the PWDs alleviate their pain and/or distress.

Situating Results within Existing Literature

This study’s findings are consistent with and build on previous research suggesting that informal caregivers’ PA and PM may be insufficient to allow them to effectively recognize and treat PWDs’ pain. Congruent with the present study’s findings, a study of spouses of individuals with chronic pain found that personal experiences with pain were unrelated to their beliefs about their partners’ pain (Cano et al., 2009). Past research related to PA has examined informal caregivers’ understanding of the dementia disease process, their agreement in the importance of “knowing the person” in providing PWDs with effective pain treatment, and their attribution of the PWDs’ pain behaviors to causes other than pain (especially to BPSD). Prior research related to PM has examined informal caregivers’ belief in the myth that pain is a normal part of aging, their understanding of the cause(s) of PWDs’ pain, their perception of their role in PWDs’ pain management, their prioritizing of treatment of PWDs’ comorbid health conditions over pain, their difficulties accessing medical care needed to treat PWDs’ pain, their concerns regarding the use of pharmacological treatments for PWDs’ pain, and their preference for using non-pharmacological and CAM treatments for pain.

Pain Assessment Beliefs and Knowledge (PA)

Understanding of the Dementia Disease Process. The typical course of dementia involves progressive declines in cognition and overall functioning that increase in severity, ultimately requiring PWDs to need high levels of care and supervision (Gallagher-Thompson et al., 2020), and 92% PWDs receive this care from informal caregivers, which are often family

members, including spouses (Alzheimer's Association, 2020). This may be problematic due to the robust findings across numerous studies of familial caregivers, including the present study, that they had poor understanding and knowledge of dementia, including beliefs that dementia was not treatable (e.g., Seo et al., 2015). This may be due to little or unclear information provided to familiar caregivers by the PWDs' doctors and other healthcare providers about the disease itself and about its progression (Stokes et al., 2015). For example, caregiver E209 in the present study shared that the PWD's healthcare providers told her that his chronic pain had caused his memory loss and dementia, but she expressed uncertainty regarding whether she agreed with this assertion (see excerpt page 35). Her confusion was likely (at least partially) due to the information provided (or not provided) by the PWD's healthcare providers when they explained the relationship between the PWD's pain and dementia. A qualitative analysis of 50 familial caregivers of PWD exploring their illness representations found that these caregivers primarily attributed uncontrollable factors (e.g., biology) as cause(s) of dementia, but had significant uncertainty regarding the timeline for the progression of the disease (Quinn et al., 2017). Another qualitative study of 92 familial caregivers explored their explanatory models about the nature and cause of dementia found that most of these caregivers explained the cause of dementia as a mixture of biomedical and folk models (Hinton et al., 2005). Folk models included attributing dementia to psychological stress or part of the normal aging process. Moreover, ethnic minority (Black, Hispanic, and Asian) caregivers were found to more commonly provide folk explanations for dementia than non-Hispanic White caregivers. This contrasts with the present study's findings in which the 10 caregivers who expressed poor understanding of the dementia disease process, including poor awareness of dementia's negative impact on PWDs' self-report abilities, consisted of equal numbers of non-Hispanic White

spousal caregivers (4) and Black caregivers (4) and fewer Hispanic caregivers (2) (see excerpts pages 34-39). The poor or incomplete understanding of dementia leading to decreased ability to self-report pain might be reflected in the findings of Thuné-Boyle et al. (2010) in which the majority of the relatives of PWDs participating in that study did not believe that the PWDs had pain, despite PWDs having painful diagnoses (e.g., arthritis and pressure sores), with at least one spouse of a PWD reporting a lack of verbal complaint as evidence. Other studies found that laypersons (including non-healthcare professionals) believed that Alzheimer's disease (AD), the most common type of dementia, was a normal part of aging (Lowe et al., 2015; Seo, Lee, Sung, 2015; Werner, 2005). Worldwide, two in three people think dementia is caused by normal aging, and 35% of caregivers had hidden the diagnosis of dementia from PWDs (ADI, 2019).

Furthermore, one study found that 86% of non-healthcare professionals believed that helpful memory aids (reminder notes) caused further decline in people with AD (Lowe et al., 2015). At least one of the spousal caregivers in the present study (E135) expressed similar beliefs, telling her spouse during the session that he needed to “push his brain” in order to remember to take his medication at night because if he did not use it he would lose it (see excerpt page 34).

Importance of Knowing the Person. Another finding of past research supported by the present study's findings is “knowing the person” as an important factor for familial caregivers accurately recognizing when PWDs are experiencing pain (Bullock et al., 2020; Corbett et al., 2016; Falls et al., 2004). Similarly, a qualitative study examining the experiences of 35 informal caregivers of community-dwelling PWDs (most of which were spouses) with recognizing and managing oral pain identified the “need for day to day contact” as a vital component in identifying when PWDs had oral pain and discomfort (Newton et al., 2018). In the present study, most spousal caregivers (e.g., E25, E73, E100, E117, and E195) expressed similar beliefs

that their daily knowledge of PWDs' behavior patterns as well as their responses to pain and distress pre-dementia (including a tendency to minimize their pain) allowed them to recognize when the PWDs were experiencing pain (see excerpts pages 43-44). Multiple studies found that familial caregivers reported high levels of confidence in their ability to accurately detect pain in PWDs (Falls et al., 2004; Thuné-Boyle et al., 2010; Weiner et al., 1999). The many spousal caregivers in the current study similarly expressed high levels of confidence regarding their ability to recognize pain in PWDs, including two (E19 and E181) that reported knowing the PWDs better than they knew themselves (see excerpts page 43). At least two prior studies provided evidence that this confidence is well-founded (i.e., moderate concordance between caregivers' proxy report of PWDs' pain intensity and PWDs' self-report of pain intensity (Shega et al., 2004) and significant positive correlation between caregivers' proxy report of PWDs' pain interference and PWDs' self-report of pain interference (Amspoker et al., 2020)), but at least one supported that PWDs' caregivers were overly confident due to low levels of concordance between PWDs' self-reported pain intensity and caregiver proxy reports of PWD pain intensity (Weiner et al., 1999). Furthermore, a meta-analysis examining pain assessment accuracy among caregivers of PWDs and their healthcare providers suggested that caregivers having an established personal relationship with care recipients was important for understanding changes in pain intensity, with physicians and strangers tending to underestimate care recipients' pain more (Ruben et al., 2018).

Due to their familiarity with the PWDs, many spousal caregivers in the present study described using PWDs' nonverbal pain behaviors to recognize the presence of pain, especially facial grimaces and wincing, moans and groans, and verbal, vocal pain complaints (see excerpts pages 44-46). Similarly, Falls et al. (2004) found in their qualitative analysis of PWDs' informal

caregivers' perceptions of pain that these caregivers used nonverbal behaviors (e.g., facial expression, agitation, and vocalizations) to determine whether PWDs had pain, but they did not tend to use a common set of pain indicators, instead using nonverbal behaviors specific and unique to the PWDs (Falls et al., 2004). Consistent with this, multiple past studies have found informal caregivers used observable physiological and behavioral behaviors (e.g., facial expressions, mood changes, body language) that did not require clinical expertise to inform them of the presence of pain (e.g., Bullock et al., 2020; Newton et al., 2018). In contrast, one study found that informal caregivers of PWDs in long-term care facilities did not utilize the nonverbal behavior when assessing PWDs' pain, which may reflect a decreased familiarity with the PWDs since they did not live with the caregivers, further highlighting the importance of knowing the person in PWDs' pain assessment (Eritz & Hadjistavropoulos, 2011).

Understanding of PWDs' Pain Language. A qualitative study of 51 informal caregivers' experiences with PWDs' pain receiving home hospice care identified difficulty communicating with PWDs due to their dementia-related aphasia as a barrier for them helping PWDs manage their pain (Tarter et al., 2016). Caregivers in that study described strategies for overcoming these communication difficulties, including generating "new languages" to discuss pain with PWDs and learning to how to accurately interpret the meaning of PWDs' jumbled self-report. The present study expands on the findings of Tarter et al. (2016) by describing how some spousal caregivers (e.g., E14 and E93) were inflexible in which words when used by PWDs indicated that they were in pain (i.e., only the word "pain" meant pain), leading to missed opportunities to help PWDs manage their pain (see excerpts page 48). It also demonstrated how spousal caregivers (e.g., E51, E84, and E209) who were flexible with which words signaled that PWDs had pain (e.g., words such as "tired" meant pain) were better able to successfully

recognize when PWDs had pain and distress (see excerpts pages 50-51). This was further supported by the observed shift in caregiver E02 after the research clinician described an example of another PWD with whom she worked who would deny pain if asked whether he had pain but would acknowledge being tired instead. She connected this to her own husband's pain behaviors and subsequently expressed changed views regarding his pain behaviors (i.e., no longer reporting anger in response but instead expressing understanding that he could not "voice" his pain and distress to her) (see excerpt page 132).

Attributing PWDs' Pain Behaviors to Causes Other Than Pain. Past research has demonstrated the trend of informal caregivers of PWDs as well as formal care providers (e.g., primary care physicians) in struggling to determine the correct cause of PWDs' behavioral and physiological symptoms, including when they were caused by pain. For example, Newton et al. (2018) found that informal caregivers of PWDs with oral pain and discomfort reported that they were able to recognize PWDs' symptoms of distress, but they were sometimes unsure whether pain was the cause of certain behaviors (e.g., anger). In addition to informal and/or familial caregivers, another qualitative study found that general practitioners and geriatric psychiatrists also reported difficulties distinguishing between dementia, BPSD, and pain (Bullock et al., 2020). Correspondingly, several spousal caregivers (e.g., E69, E135, E198, E209) in the current study described attributing the PWDs' possible pain behaviors to non-pain causes, especially comorbid health conditions (e.g., Parkinson's disease) and personality-driven causes (e.g., avoidance) rather than untreated pain (see excerpts pages 51-56).

The spousal caregivers (E02 and E198) that attributed PWDs' possible pain behaviors to personality-driven causes (and, thus, under PWDs' control) expressed anger and irritability in response and took no actions to reduce PWDs' pain and/or distress (see excerpts pages 54-56 and

94). Similarly, one study found that caregivers who believed that PWDs' behaviors were under their control were more critical, hostile, and rejecting (TARRIER et al., 2002). Conversely, believing that behavior was less under the PWDs' control was associated with caregivers' having more warmth and enjoyment in the PWDs' company. This was demonstrated in caregiver E02 who, after receiving psychoeducation on PWDs' dementia-related difficulties, stopped reporting anger in response to the PWD's possible actions to reduce his pain, instead expressing that her husband was unable to tell what was going on internally/physically in regards to his pain and that she had to remind herself to view his behaviors within the context of dementia (see excerpts pages 36 and 132). A qualitative study of 205 caregivers' attributions of the causes of PWDs' problematic behaviors further revealed that dementia was frequently not identified to be the cause, leading them to believe that these behaviors were under the PWDs' control (PATON et al., 2004). Additionally, when aggressive behavior was identified as PWDs' most problematic behavior, many caregivers, including both informal caregivers and paid caregivers, attributed it to the PWDs' premorbid personality or their childhood experiences rather than dementia. Another qualitative study of 30 Hispanic caregivers of community-dwelling PWDs found that these caregivers were more likely to attribute neuropsychiatric symptoms or BPSD (e.g., depression, aggression, apathy, irritability) to causes other than dementia (HINTON et al., 2009). A different qualitative study of seven familial caregivers, which included monthly interviews over a six-month period, discovered that these caregivers more readily attributed the PWDs' negative behaviors to internal and controllable causes, which led to increased frustration and a tendency to take those behaviors personally (POLK, 2005). These caregivers further expressed uncertainty regarding the causes of PWD displeasure and frustration regarding their subsequent uncertainty regarding how to relieve it. Correspondingly, in the present study, caregivers E02

and E198 both reported utilizing few (if any) pharmacological or non-pharmacological pain treatments with their spouses. As such, uncertainty regarding the cause of the PWDs' pain and distress likely contributes to some caregivers failing to take action to help the PWDs reduce their pain.

Pain Management Beliefs and Knowledge (PM)

Belief That Pain Is a Normal Part of Aging. Past research has established the prevalent belief among older adults that pain is an inevitable, natural part of the aging process, despite many studies finding no evidence of a direct relationship between pain and aging (Thielke et al., 2012). This misconception hinders older adults, including PWDs, in accessing effective pain treatments as they may delay or fail to report pain symptoms to their healthcare providers, believing that there are no possible treatments for their pain (Gagliese & Melzack, 1997). In the current study, seven spousal caregivers (E14, E19, E89, E53, E63, E93, E209) expressed having this belief and often indicated that they believed that pain was something to be endured rather than something to treat (see excerpts pages 57-58). All but two of these caregivers (E53 and E63) had chronic pain themselves, and caregivers E53 and E63 both reported that the PWDs' current pain treatments were ineffective. As such, caregivers' perceptions of the PWDs' pain treatments as limited in their efficacy may reinforce beliefs that pain was an inevitable, normal part of aging, leading to inaction in response to PWDs' pain behaviors.

Understanding of the Cause(s) of PWDs' Pain. Tarter et al.'s (2016) qualitative study of informal caregivers of PWDs receiving home hospice care identified uncertainty regarding the etiology of the PWDs' pain as a barrier to providing them with effective pain treatments. Similar to the results of the present study (see excerpts pages 60-70), they also found that many caregivers described biomedical explanations of the causes of the PWDs' pain. Furthermore,

when informal caregivers did not understand the etiology of their loved ones' pain, they expressed concerns regarding the use of prescribed pharmacological treatments to treat the PWDs' pain, which may have led to underutilization of this medication and unnecessary untreated pain. Correspondingly, one caregiver (E195) in the current research reported that she did not want her husband "to be on pain pills for the rest of his life," instead sharing that she just wanted his pain "to be better diagnosed" (see excerpt page 66). Furthermore, caregivers viewing the cause of the PWDs' pain in ways consistent with the biomedical model may fail to act to help the PWDs reduce their pain if and when they believe that the cause of the PWDs' pain had healed and/or could have been healed if not for the PWDs' inaction. Caregiver E37 demonstrated this through her lack of action to help the PWD manage his arthritic pain that significantly impaired his ability to complete ADLs and IDLs due to her belief that it was caused by his failure to exercise (see excerpts pages 64 and 94). She shared that the PWD's only pain treatment was her encouraging him to exercise and participate in formerly enjoyable activities (see excerpts pages 94 and 101-102). This contrasted with her views regarding the treatment of the PWD's hernia-related stomach pain that she implied was pain, expecting his doctor to treat it using surgery or medication.

Perception of Their Role in PWDs' Pain Management. Bullock et al. (2020) found that many informal caregivers described themselves as responsible for the PWDs' pain management (both non-pharmacological and pharmacological treatments). As such, it supported the present study's finding that some spousal caregivers (e.g., E33 and E117) took active roles in the PWDs' pain management (e.g., tracking PWDs' use of analgesic pain treatments and searching for additional CAM pain treatments) (see excerpts pages 74-76). The current study expanded on prior research by revealing that some spousal caregivers (e.g., E68, E89, E173, and

E198) maintained passive roles in the PWDs' pain treatment (see excerpts pages 71-73). When spousal caregivers had passive roles in the PWDs pain management, the PWDs were left to manage their pain themselves, despite having increasingly decreased abilities to do this due to dementia-related functional declines, and there were likely missed opportunities for pain relief. Furthermore, multiple studies (e.g., Bullock et al., 2020; Newton et al., 2018) indicate that the PWDs' formal care providers rely on informal caregivers' daily knowledge of the PWDs' symptoms and behaviors in order to accurately identify the PWDs' problems, including pain, to provide them with effective treatments for all of their problems. Increased awareness that some spousal caregivers may continue to take passive roles in the PWDs' pain treatment can cue various formal healthcare providers to provide psychoeducation on pain in PWDs to help these caregivers better help their husbands.

Prioritizing Treatment of PWDs' Other Comorbid Health Conditions. Newton et al.'s (2018) qualitative exploratory study of informal caregivers of PWDs with oral pain and distress identified that the competing demands of different caregiving tasks led some caregivers to deprioritize oral pain treatment. Bullock et al. (2020) also found familial caregivers expressed concerns about the potential interactions among pain medications and the PWDs' other medications, as well as about increasing the number of total pills taken by the PWDs (Bullock et al., 2020). Similarly, multiple caregivers (E54, E90, and E100) in the current research reported that they had not pursued pain treatment for the PWDs because of their numerous comorbid health conditions (see excerpts pages 77-80). Caregiver E100 shared that she did not think the PWD taking pain medications with his Risperidone and other medications was a "good idea" and consequently did not give him pain medication, and caregiver E90 explicitly stated that the various time-consuming caregiving tasks, including cooking three meals per day and managing

all of his medications, was the reason why she had not pursued getting her husband a massage for pain relief at a local college. As such, the varied and competing demands of caring for the PWDs, especially when they have numerous comorbid health conditions, as well as the treatments for comorbid health conditions likely contribute to these caregivers making fewer attempts to help the PWDs obtain pain treatment.

Difficulties Accessing Appropriate Medical Care for PWDs' Pain. Past research has established various barriers to PWDs accessing medical care necessary for them to obtain effective pain treatments, including most of those identified in the current study (i.e., poor communication with PWDs' healthcare providers, PWDs obtaining care from numerous doctors for all of their comorbid health conditions, and the cost of pain treatments). Tarter et al. (2016) found that inconsistent guidance from PWDs' formal care providers regarding how to treat PWDs' pain was a barrier to informal caregivers providing adequate pain treatment. Correspondingly, multiple caregivers (E14, E63, and E84) in the present research reported experiencing poor communication as well as inconsistent guidance from the PWDs' formal healthcare providers, hindering their ability and confidence in their ability to provide their husband's with effective pain treatment (see excerpts pages 81-82 and 87). For example, caregiver E63 explained that one of the PWD's doctors had recommended pool PT, but neither the PWD nor caregiver had received information to follow through on that referral. Newton et al. (2018) also found that many informal caregivers struggled with obtaining medical care for the PWDs from multiple healthcare providers and the cost of pain treatments. One such caregiver reported being "pushed from pillar to post," meaning she felt punted to different healthcare providers when trying to get treatment for the PWD's pain treatment (Newton et al., 2018, p. 7). In the present study, caregiver E89 expressed confusion regarding which of her husband's

numerous healthcare providers (e.g., primary care doctor, cardiologist, neurologist, and dentist) to discuss additional and/or adjustments to improve the PWD's pain treatment (see excerpt pages 82-83). She further reported that she had not been aware that there were physicians that specialized in pain treatment. Two other caregivers (E181 and E195) shared that the cost of pain treatments prevented them from obtaining adequate pain treatment for the PWDs (e.g., unable to afford out-of-pocket cost of Lyrica when not covered by the PWD's insurance – E181) (see excerpts pages 83-84). Accessing the medical care needed to effectively manage the PWDs' pain was and likely continues to be a barrier to spousal (and other types of informal) caregivers obtaining effective pain treatments for the PWDs.

Concerns Regarding Analgesic and Pharmacological Pain Treatments. A narrative review of 10 studies that examined the role of informal caregivers in PWDs' medication management (which included pain medications) found that these caregivers had limited understanding of pharmacologic pain treatments (Gillespie et al., 2014). Furthermore, multiple qualitative studies examining the experiences of seniors' (including PWDs') informal caregivers (in addition to healthcare providers and PWDs) in assessing and managing pain in those under their care, established that many informal caregivers had concerns regarding the potential side effects of analgesic pain treatments, which may have led them to under-utilize such treatments (Bullock et al., 2020; Martin et al., 2005). These caregivers described experiencing difficulties in administering PRN pain medications, especially in determining when to administer these medications (Martin et al., 2005), and some PWDs reported resistance to taking pain medication (Bullock et al., 2020). These results were similar to those of the current study in which some spousal caregivers (e.g., E02, E14, and E53) shared concerns regarding the use of pharmacological pain treatments, especially side effects (see excerpts pages 86-88). For

example, caregiver E02 only provided the PWD with one OTC pain pill once daily rather than three times daily as prescribed due to concerns of potential negative side effects, and caregivers E14 and E53 reported that the PWDs' pain medications had been switched on the PWDs' doctors recommendations to avoid and/or reduce negative side effects. When spousal caregivers are hesitant to use analgesic pain treatments with their husbands, they may under-utilize pain treatments, causing the PWDs to experience untreated pain.

Preference for Non-Pharmacological and CAM Pain Treatments. Many spousal caregivers in the present study expressed a preference for non-pharmacological and CAM pain treatments for the PWDs' pain (see excerpts pages 92-103), including some who also reported concerns regarding analgesic pain treatments (e.g., E02 and E14 – see excerpts pages 86-87). Correspondingly, three studies found informal caregivers of PWDs preferred to that non-pharmacological treatments be utilized first when treating their loved ones' pain (before trying any pharmacological treatments) (Bullock et al., 2020; Corbett et al., 2016; Martin et al., 2005). Non-pharmacological and CAM treatments used by caregivers in those studies included physiotherapy (i.e., exercise), warmth, massage, music, aromatherapy, and distraction. Similarly, the spousal caregivers in the present study reported using exercise (walking), massage/rubbing, and heat/warmth, with some caregivers describing the use of additional treatments (e.g., changing body position – E44, dietary supplements – E181, and pleasant, enjoyable activities (dominos) – E37) (see excerpts pages 94-96 and 99-102). Bullock et al. (2020) also established that some familial caregivers may be skeptical of the efficacy of nondrug treatments for pain (e.g., acupuncture and mindfulness) and thus reluctant to try them. In the present study, it was the PWDs themselves that appeared to be skeptical of CAM treatments rather than the caregivers themselves (e.g., one PWD (E195) called chiropractors “quacks” (see

excerpt pages 102-103)). Ultimately, the results of the present study provide further evidence of familial caregivers' preference for using non-pharmacological treatments for PWDs' pain.

Caregivers' Pain Mental Models

To the author's knowledge this study is the first to propose a representation of the pain mental models of informal caregivers of PWDs. The pain mental model proposal (Figure 2) is concordant with (1) research investigating how informal caregivers identify and treat PWDs' pain, and (2) research exploring the mental models used by formal caregivers (nurses and certified nursing assistants (CNAs)) to determine when and how to act to reduce the pain and distress of individuals under their care. Multiple qualitative studies have examined informal caregivers' experiences and challenges in assessing for and recognizing the presence of pain in PWDs. Falls et al. (2004) found that informal caregivers reported using different strategies to identify the PWDs' pain post-dementia than they had pre-dementia. Informal caregivers in this study voiced confidence in their ability to recognize the PWDs' pain due to their familiarity with and intimate knowledge of the PWDs' "normal" or typical behavior (Falls et al., 2004, p. 7). These caregivers relied on a variety of observed changes to the PWDs' typical behaviors (e.g., facial expression, agitation, vocalizing, withdrawal) to identify when they were experiencing pain. Building on this, informal caregivers of PWDs in hospice reported having problems assessing for the presence of the PWDs' pain due to difficulties communicating with the PWDs as the result of dementia-related changes in cognitive status and reductions in self-report ability (Tarter et al., 2016). Despite this, these caregivers were resourceful and developed new methods for communicating with the PWDs about their pain, including creating "new languages," learning to understand the PWDs' unclear speech, and using nonverbal pain indicators. This allowed them to better identify when the PWDs had pain. Another qualitative study of informal

caregivers of PWDs with oral pain and discomfort found that their daily contact and familiarity with the PWDs enabled them to identify observable PWD behaviors which, when present, meant the PWDs were experiencing pain (Newton et al., 2018). Similarly, Bullock et al. (2020) determined that familial caregivers' close knowledge of the PWDs and their related ability to recognize changes in the PWDs' behaviors were valuable tools for assessing for the presence of the PWDs' pain. These findings corroborate the present proposed model by highlighting the importance of "knowing the person" for caregivers of PWDs' pain assessment.

Many of these same studies also investigated informal caregivers' experiences and challenges in helping PWDs manage their pain. Inconsistent guidance from the PWDs' healthcare providers was identified as a barrier to providing the PWDs with effective pain treatments (Newton et al., 2018; Tarter et al., 2016). Informal caregivers of PWDs in hospice expressed that the lack of consistent guidance surrounding healthcare providers' reasons for using (or not using) certain analgesic pain treatments was especially challenging (Tarter et al., 2016). These caregivers also reported uncertainty regarding the causes of the PWDs' pain, particularly in the absence of clear physical causes, leading them to feel unsure regarding how they should respond to the PWDs' pain. Unlike with their difficulties communicating with PWDs, which affected their abilities to recognize the presence of the PWDs' pain, caregivers did not report any strategies for overcoming their deficiencies in understanding the causes of pain or how and when to use certain pain treatments, which may have led to inaction (i.e., not providing PWDs with any pain treatments). Both inconsistent guidance from the PWDs' healthcare providers and uncertainty regarding the etiology of the PWDs' pain likely contributed to these informal caregivers' feeling confused regarding whether the PWDs' pain was treatable and/or worth treating. Perhaps related to inconsistent guidance from the PWDs' healthcare providers as

established in prior research, another study found that familial caregivers had concerns regarding the use of analgesic pain treatments for the PWDs' pain, including side effects and potential interactions with other medications, as reasons for which they may have avoided or under-treated the PWDs' pain using such treatments (Bullock et al., 2020). The costs of pain treatments and the competing time demands of non-pain-related caregiving tasks have also been identified as barriers to informal caregivers providing the PWDs with effective treatments for oral pain and discomfort (Newton et al., 2018). Still, these caregivers expressed support for using non-pharmacological and CAM treatments for the PWDs' pain and recognized that it was their responsibility to help the PWDs manage pain, which likely helped them to act in order to provide the PWDs with pain relief. Additionally, Falls et al. (2004) established that informal caregivers were aware that the PWDs were no longer experiencing pain when they observed the PWDs' behavior returning to normal (e.g., cessation of their atypical behaviors, such as pacing or withdrawing). The present study reinforces these various findings regarding informal caregivers' pain management beliefs and knowledge, including their confusion regarding the etiology of the PWDs' pain, poor communication with the PWDs' healthcare providers, concerns regarding pharmacological treatments, and preference for non-pharmacological pain treatments.

While the existing body of literature provides valuable information on informal caregivers experiences and efforts (as well as challenges and barriers they face) in assessing and managing PWDs' pain, no published research was identified that explored the linkages between informal caregivers' PA and PM knowledge and beliefs and their resulting action (or inaction) to help PWDs better manage their pain. Even so, studies have proposed some linkages (albeit narrower in scope than that proposed in the current study) while examining the pain/distress management mental models of formal caregivers (nurses and CNAs). The first of these studies

identified two cognitive rules (the Golden Rule and Mother Wit) used by CNAs to guide their decision-making in providing care to nursing home residents under their care, which likely included residents with cognitive impairment (Anderson et al., 2005). CNAs using the Golden Rule treated their residents as they themselves would like to be treated by others and acted based on how they imagined they would feel in the same situation. For example, one CNA described noticing a resident wet his pants on days in which he had dialysis treatments. She encouraged him to use adult diapers on these days, assuming the desired outcome for the resident would match her own preference in such a situation. Anderson et al. (2005) noted that this may have led to the unintended consequence of this resident in question spending days in wet diapers. CNAs using the Mother Wit cognitive rule treated their residents similar to how they treated their own children, which helped these caregivers to stay patient when dealing with residents' disruptive and/or challenging behaviors and to not take those behaviors personally. For example, one CNA described using cookies to motivate one resident's cooperation with requests, while labeling another resident as a "cry baby" and largely ignoring her distress. This same CNA was observed interacting with the "cry baby" resident, who was at one point crying and whimpering after the CNA straightened her arm, perhaps indicating that the resident was expressing untreated pain. Thus, while the Golden Rule and Mother Wit rules can assist these formal caregivers in taking action to reduce residents' pain and distress, they may have also contributed to new problems and missed opportunities for providing pain and distress relief. The findings are similar to the current study in that multiple caregivers pursued Golden Rule pain management strategies they themselves found helpful, but the PWDs did not believe were helpful (e.g., E195 suggested that her husband see a chiropractor for pain relief (see excerpt page 102-103)). This was similar to how the CNAs made care-related decisions when they used the Golden Rule as a

guide. However, only one caregiver (E19), who was the only ex-wife included in the present sample, appeared to use a framework similar to Mother Wit, praising the behaviors she wanted to see continue and/or increase in frequency (i.e., walking) and condemning behaviors she wanted to see decrease and/or cease in frequency (i.e., verbal pain complaints) (see excerpts page 93). This may suggest that spousal caregivers are unlikely to use a cognitive rule in which they view their husbands similar to how they view children.

The second study linking informal caregivers' PA and PM to their actions explored nurses' mental models for opioid administration in hospitals. The authors determined that nurses who had more practice giving opioids and receiving feedback on their effectiveness (including discussing these experiences with colleagues) were less likely to be afraid of using opioid treatments as well as less worried that individuals receiving such treatments would overdose (Guest et al., 2017). Similarly, Anderson et al. (2005) detailed two examples of more highly trained, professional staff (i.e., a department head and a nurse) observing CNAs' mistakes in their understanding of the causes of residents' behavior. In response these supervisors provided advice to help these CNAs more effectively recognize and act to reduce residents' distress. For example, a department head described instructing a well-intentioned CNA to scrub residents less hard, as she had been hurting them and rubbing off their skin in her efforts to help them become clean. This led to an improvement in the CNA's bathing procedures. As such, both studies concluded that additional informal learning, especially hands-on learning, was essential to changing and improving unskilled caregivers' cognitive rules of care, leading to an improvement in their concrete actions.

In sum, the present study's findings are concordant with these previous studies in demonstrating the important influence of caregivers' cognitive frameworks for pain

identification, for understanding pain management options, and for translating knowledge into action. These studies described informal caregivers of PWDs' PA and PM, including challenges and barriers to their efforts to identify and treat PWDs' pain and distress due to gaps in PA and PM. Unlike the previous research on informal caregivers' experiences and beliefs regarding pain assessment and pain management in PWDs, the present study offers a model for how they might use their PA and PM knowledge and beliefs to answer PA/PM questions. These responses when accurate may lead them to take action, but when they are inaccurate may lead to missed opportunities for pain relief as they fail to take action. Furthermore, the insight gained from past research into the cognitive rules that guide formal caregivers' care (including use of opioid pain treatments) provides guidance for the format needed for potential interventions to effectively change and improve informal caregivers' pain mental models, thus reducing the undertreatment of pain and distress in PWDs.

Limitations

This study has several limitations. One limitation is that it is a secondary data analysis. The caregivers included in the present study were not explicitly asked questions intended to elicit information about their pain mental models. This precluded certain types of qualitative methodologies, such as being able to conduct member checking or being able to iteratively modify participant interview questions. On the other hand, the challenges and barriers in recruiting PWDs and their caregivers to research studies are well established (e.g., Carr et al., 2010), with recruitment and retention of non-White caregivers identified as being particularly difficult (e.g., Gallagher-Thompson et al., 2003). As such, the data collected by the parent study provided a valuable resource toward understanding spousal caregivers' pain mental models.

A second limitation was that all participants were wives of American veterans, limiting the generalizability of the results. It is possible that male spousal caregivers and/or caregivers of the PWDs without military service differ in their pain mental models, including gaps that cause them to miss opportunities to alleviate the PWDs' pain. On the other hand, the present study included spousal caregivers from the three largest racial groups in the United States (i.e., non-Hispanic White, Hispanic, and Black), which may increase the generalizability of the results (United States Census Bureau, 2019). However, these results may not be generalizable to informal and/or spousal caregivers of PWDs in countries outside of the United States.

A third limitation involved Hispanic caregivers for whom English was not a first language. Describing complex abstract information such as that involved in sharing information related to pain mental models is a challenging endeavor, even in one's native language. There may have been miscommunications in some of the author's interpretations of these caregivers' reports. The study would have been strengthened if these caregivers had been provided the intervention in their first language. An additional limitation was that there was not a participant demographics question in the data set regarding native language, so this is inferred information. On the other hand, in the author's subjective opinion she was able to consistently understand most of what was described, despite observed instances of caregivers struggling to find English words for some objects and/or concepts and erring in their used verb tenses. And in fairness, there is always an intention/impact communication gap even between native speakers and listeners. Examples include caregiver E33 who exhibited the most adaptive and effective pain mental model for recognizing and treating the PWD's pain and distress of all of the spousal caregivers, and caregiver E90 who provided multiple examples of failing to connect the dots due to gaps in her PA and PM (see pages 126-129 for more details). Furthermore, the pain-related

beliefs and knowledge of the Hispanic caregivers were as well represented in the data in both themes and their corresponding subthemes as the non-Hispanic White and Black caregivers.

Implications

This study revealed several concepts related to pain mental models which may be helpful in guiding future intervention and research efforts involving spousal caregivers of PWDs. The first of these findings was that many spousal caregivers were unable to adjust their mental models of their loved ones' pain in the context of dementia. Generally, spousal caregivers of PWDs tended to have limited understanding of dementia and its expected progression. This negatively impacted the effectiveness of their (perhaps previously effective) pre-dementia pain mental models, especially when they failed to take into account the PWDs' increasing difficulties with processing and producing verbal language. In these cases, caregivers usually continued to rely on the PWDs' verbal vocal pain complaints rather than integrating the information conveyed through the PWDs' nonverbal pain behaviors, and in the absence of verbal vocal pain complaints caregivers often failed to engage in efforts to help the PWDs alleviate their pain.

Most caregivers also failed to account for pain interference (i.e., pain leading to functional limitations) in their mental models of PWDs' pain. They frequently reported significant PWD functional limitation, yet often failed to explicitly note the possibility that such limitations were caused by pain. For example, spousal caregivers often described that the PWDs had difficulties walking and helping in household chores, leading to the caregivers' distress and increased caregiver burden. Importantly, they did not connect observed pain interference to needing to take action to help the PWDs obtain better pain treatment. These caregivers appeared to not be aware that providing the PWDs with effective pain treatment could improve their ability to engage in physical and social activities.

Many of the caregivers in this sample (8 of 30) expressed concerns regarding long-term use of analgetic treatments, including OTC pain medications (e.g., acetaminophen), and expressed preferences for non-pharmacological and CAM treatments for PWDs' pain. Side effects (including overdose) and tolerance were the most commonly reported concerns regarding pharmacological pain treatments. Some caregivers (at least 5) also expressed polypharmacy concerns regarding the potential interaction of analgesic pain treatments and the PWDs' medications for comorbid health conditions. Adjustment or changing the PWDs' body position, including having them lie down, was the most commonly utilized CAM treatment as reported by these caregivers, with 16 caregivers (just over half) the sample using this CAM treatment. Pleasant activities (n=7), exercise (especially walking), and massage (n=6) were also encouraged by caregivers to reduce the PWDs' pain. Fifteen caregivers reported using both pharmacological and non-pharmacological pain treatments (e.g., OTC pain medication, massage (with and without topical ointments), and changing body position) with 8 of these caregivers also utilizing more than one CAM treatment. Despite many caregivers expressing preferences for CAM treatments, all 30 caregivers demonstrated awareness of traditional medical treatments (i.e., medication and surgery), with 27 reporting past or present use of such treatments for PWDs' pain. In contrast, 23 caregivers stated that they used non-pharmacological treatments (and 5 of these reported only using the CAM treatment of adjustment/changing body position). This difference in utilization of pharmacological versus non-pharmacological treatments may reveal a lack of awareness of the breadth of CAM for PWDs' pain among these caregivers, especially warmth (n=3) and dietary supplements (n=2). Furthermore, only 6 caregivers reported using massage/rubbing, and 7 caregivers described encouraging the PWDs' engagement in enjoyable activities to provide PWDs with pain relief, even though massage, touch, and human interaction

have been found to be effective CAM treatments for pain and agitation in PWDs (Anderson et al., 2017). Conversely, PWDs are at risk for adverse side effects when using pharmacological pain treatments, especially medications other than acetaminophen (Flo et al., 2014). The present study identified at least three areas in which spousal caregivers may have gaps in their PA and PM, leading to missed opportunities for pain management. Better understanding of these gaps can guide researchers and clinicians in modifying and developing interventions. This could improve both the recognition of PWDs' pain as well as its treatment, reducing the under-recognition and under-treatment of pain in PWDs that has been established by a robust body of research.

The results of this study may provide valuable information to guide how future interventions might improve caregivers' pain mental models, increasing their ability to recognize PWDs' pain and take action to provide pain relief. Evidence of this potential for altering spousal caregivers' pain mental models was exhibited by two of the cases in this sample in which caregivers (E02 and E93) demonstrated improved understanding and openness to both the presence of PWDs' pain and treatments for that pain. The research clinician provided caregiver E02 a teaching example of a veteran with pain who always denied having pain, instead only endorsing that he was "tired" (see excerpt pages 49-50). The caregiver was able to make the connection to her own husband's behavior, and described a recent experience when the PWD was sitting for an extended period of time and, when asked what was wrong, explained that he was tired. This caregiver subsequently connected other pieces of the psychoeducation to her husband's behavior, sharing that the PWD withdrew in response to loud noises (which she never connected to pain) and suggesting that the pillow she placed behind the PWD may have been causing discomfort due to his shifting and restlessness (see excerpt pages 54, 94, and 132).

Reflecting on the home practice, she was able to conclude that her husband could not self-report his pain, demonstrating a significant shift in her thinking from the start of the first session where she had reported that she got angry at her husband for withdrawing to the bedroom to lay down, appearing to take this behavior personally (see page 132 for more details). Along the same lines, caregiver E93 initially expressed confusion about if and how physical pain and mental pain were connected (see excerpts pages 60-61). However, at the start of the second session this caregiver was able to express that the psychoeducation at the first session had been helpful, allowing her to see “how deep the mental pain could be” (see excerpt pages 62-63). She also shared that the vignette about a man named “Stan” from the session reading about pain among seniors had led to her new understanding that pain was not an inevitable part of aging, and that there were ways to better manage pain in older adults (see pages 59 and 133-134 for more details).

Both of these examples suggest that illustrative examples and/or vignettes may be effective caregiver behavior change methods. These examples are concordant with the results of the aforementioned two studies examining mental models of nurses and CNAs (Anderson et al., 2005; Guest et al., 2017), in which experiential learning appeared to yield positive changes in care-related mental models. Finally, the example provided by caregiver E02 supports the inclusion of additional psychoeducation regarding PWDs’ progressive difficulties with self-report, including words that PWDs may use to communicate that they are experiencing pain and/or distress (especially words other than “pain”). Such education might allow spousal caregivers to more effectively connect the dots and recognize when they should act in order to reduce PWDs’ pain and distress.

Future Directions for Research

The findings of the present study point to multiple paths for future research. Interventions aimed at improving pain management for community-dwelling PWDs might consider an explicit focus on changing informal caregivers' pain mental models, and in particular might consider using case vignettes and interactive psychoeducation to move informal spousal caregivers from a place of receiving knowledge to a place of connecting the dots to recognize PWDs' pain and distress and subsequently take action to reduce that pain and distress. Future research might also aim for research designs that could examine potential causality between PA and PM responses and action or inaction. Establishing any resulting changes in spousal caregivers' pain mental models, including their PA and PM, and whether this led to improved pain assessment and management would be valuable for improving pain management in community-dwelling PWDs.

Additionally, future research might aim for research designs that could examine differences in PA and PM among spousal caregivers of different racial groups. Although this study sample was stratified to allow for diversity, the actual distribution of caregiving situations among the race subsamples was not conducive to specific comparative analyses. Yet, there were some interesting patterns that suggest future comparative studies could be worthwhile. The author noted a least one difference between two of the Hispanic caregivers (E33 and E181) compared to non-Hispanic White and Black caregivers in CAM treatment utilization. Specifically, these two Hispanic caregivers were the only two to report that their spouses used dietary supplements to treat their pain. Perhaps PA and PM might differ among caregivers of different racial backgrounds, but further examination of this was beyond the scope of the present research. Past research has established differences in knowledge and attitudes about AD among

Hispanic, non-Hispanic White, and Black individuals (Connell et al., 2007) as well as differences in perceived benefits of CAM treatments among midlife and older adults of those same three racial groups (Johnson et al., 2019). A better understanding of the differences in pharmacological and non-pharmacological treatments among caregivers of diverse cultural and racial/ethnic backgrounds would help future researchers and clinicians to better tailor interventions designed to eliminate gaps in PA and PM. Ultimately, the present study and research that builds on it could lead to improvements in pain assessment and pain management in PWDs, potentially reducing healthcare and related financial and personal costs.

Conclusion

In conclusion, this was the first study, to the author's knowledge, to propose a connective pain mental model of spousal caregivers of PWDs. Caregiver responses during a psychoeducation intervention comprised two main themes, Pain Assessment Beliefs and Knowledge (PA) and Pain Management Beliefs and Knowledge (PM). The study findings suggest that PA and PM serve as the foundation from which caregivers attempt to understand the behaviors of their spouses with dementia. Caregivers interact with this information through PA/PM questions, which facilitate their making connections (or missing connections), and prompting them to take action (or not). These findings have implications for future research and clinical interventions in illuminating how caregivers may need to not only be provided with dementia and pain education, but also receive explicit support and application practice in applying such new knowledge to pain management decision-making.

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Table 1. Phases of thematic analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Note: Reprinted from “Using Thematic Analysis in Psychology,” by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology*, 3(2), p. 87. Copyright 2006 by Edward Arnold Publishers Limited.

Table 2. Individualized demographic and pain details of participants

Dyad	Relationship	Race	Age, years	Current painful conditions^b
E02	Wife	Black	69	-
E02 ^a	Husband	Black	70	Back pain, hip pain
E07	Wife	Black	69	-
E07 ^a	Husband	Black	79	Osteoarthritis, rheumatoid arthritis, back pain, knee pain, leg pain
E14	Wife	Hispanic	65	Back pain
E14	Husband	Hispanic	69	Pinched nerve, headaches, back pain, shoulder pain
E19	Ex-wife	Non-Hispanic White	67	Unspecified chronic pain
E19	Ex-husband	Non-Hispanic White	77	Arthritis (unspecified), spider bite, knee pain
E25	Wife	Black	57	-
E25	Husband	Black	63	Arthritis (unspecified), headaches, leg pain
E33	Wife	Hispanic	73	-
E33 ^a	Husband	Non-Hispanic White	79	Ringing in ears / dissonance, hemorrhoids
E37	Wife	Black	82	Arthritis (unspecified), shoulder pain
E37 ^a	Husband	Black	86	Hiatal hernia, back pain, leg pain, shoulder pain, stomach pain
E44	Wife	Hispanic	72	-
E44	Husband	Hispanic	83	Back injury, headaches, leg pain
E51	Wife	Hispanic	81	-
E51	Husband	Hispanic	86	Foot pain, knee pain, leg pain
E53	Wife	Non-Hispanic White	77	-
E53	Husband	Non-Hispanic White	85	Arthritis (unspecified), knee injury, shoulder injury, back pain
E54	Wife	Non-Hispanic White	65	-
E54	Husband	Non-Hispanic White	69	Arthritis (unspecified), knee pain
E63	Wife	Black	75	-
E63	Husband	Black	79	Arthritis (unspecified), ankle injury, back pain (sciatic nerve), leg pain

E68	Wife	Non-Hispanic White	86	Knee pain, arm pain
E68	Husband	Non-Hispanic White	82	Knee pain
E69	Wife	Black	76	Back injury
E69 ^a	Husband	Black	82	Arthritis (unspecified), hip pain, leg pain
E71	Wife	Black	75	-
E71 ^a	Husband	Black	90	Arthritis (unspecified), headaches, neck pain
E73	Wife	Hispanic	74	-
E73	Husband	Hispanic	76	Knee pain, shoulder pain
E84	Wife	Non-Hispanic White	80	-
E84 ^a	Husband	Non-Hispanic White	79	Arthritis (unspecified), back pain, knee pain, leg pain, neck pain
E89	Wife	Non-Hispanic White	76	Rheumatoid arthritis
E89 ^a	Husband	Non-Hispanic White	79	Leg injury, spinal stenosis, back pain, foot pain, hand pain, leg pain
E90	Wife	Hispanic	66	Foot pain
E90 ^a	Husband	Hispanic	67	Neuropathy, foot pain, joint pain (unspecified), shoulder pain
E93	Wife	Black	64	Shoulder injury
E93	Husband	Black	70	Hip injury, ankle pain, back pain, knee pain, shoulder pain
E100	Wife	Black	80	Unspecified chronic pain
E100 ^a	Husband	Black	81	Osteoarthritis, arm pain, hip pain, knee pain, shoulder pain
E117	Wife	Hispanic	72	-
E117 ^a	Husband	Non-Hispanic White	73	Gout, back pain, hip pain, knee pain, leg pain, shoulder pain
E122	Wife	Black	68	-
E122 ^a	Husband	Black	76	Rheumatoid arthritis, knee pain, leg pain
E135	Wife	Non-Hispanic White	85	-
E135	Husband	Non-Hispanic White	91	Headaches, back pain
E173	Wife	Hispanic	79	-
E173 ^a	Husband	Hispanic	82	Arthritis (unspecified), gout, foot pain, knee pain
E181	Wife	Hispanic	73	-
E181	Husband	Hispanic	72	Back surgery recovery, back pain, leg pain

E195	Wife	Non-Hispanic White	57	Unspecified chronic pain
E195	Husband	Non-Hispanic White	71	Back pain
E198	Wife	Black	70	-
E198	Husband	Black	74	Arthritis (unspecified), knee surgery, neuropathy, back pain, leg pain, shoulder pain
E201	Wife	Non-Hispanic White	67	Osteoarthritis
E201	Husband	Non-Hispanic White	66	Deformed spine, back pain, neck pain
E209	Wife	Non-Hispanic White	70	Arthritis (unspecified), migraines, hand pain
E209 ^a	Husband	Non-Hispanic White	74	Arthritis (unspecified), arm sore, bone cancer, headaches, neuropathy, shoulder injury, back pain, hip pain, leg pain

^a = PWD did not participate in PAVeD intervention session(s); ^b = current painful conditions and/or locations of pain as reported by spousal caregivers

Table 3. Descriptive characteristics and demographics of participants

	Caregivers N=30	PWDs N=30
Sex (n, %)		
Female	30 (100%)	0 (0%)
Male	0 (0%)	30 (100%)
Race (n, %)		
Black	11 (36.67%)	11 (36.67%)
Non-Hispanic White	10 (33.33%)	12 (40%)
Hispanic	9 (30%)	7 (23.33%)
Age (<i>M, SD</i>)	72.33 (7.20)	77.0 (7.02)
Education Level (n, %)		
Less Than High School	2 (6.67%)	5 (16.67%)
High School or GED	11 (33.33%)	10 (33.33%)
Some College	13 (3.4%)	5 (16.67%)
College	2 (39.7%)	5 (16.67%)
Graduate or Professional Degree	2 (3.4%)	4 (13.33%)
Not Reported	0 (0%)	1 (3.33%)
Annual Income (n,%)		
<\$10,000	15 (50%)	3 (10%)
\$10,000 to \$19,999	8 (26.67%)	8 (26.67%)
\$20,000 to \$29,999	5 (16.67%)	9 (30%)
\$30,000 to \$39,999	1 (3.33%)	3 (10%)
≥\$40,000	0 (0%)	5 (16.67%)
Not Reported	1 (3.33%)	2 (6.67%)
PWD Participated in PAVeD Session(s) ^a (n, %)	--	16 (53.33%)

^a = Refers only to the portions of the PAVeD intervention included in this study

Figure 1: Themes and Subthemes

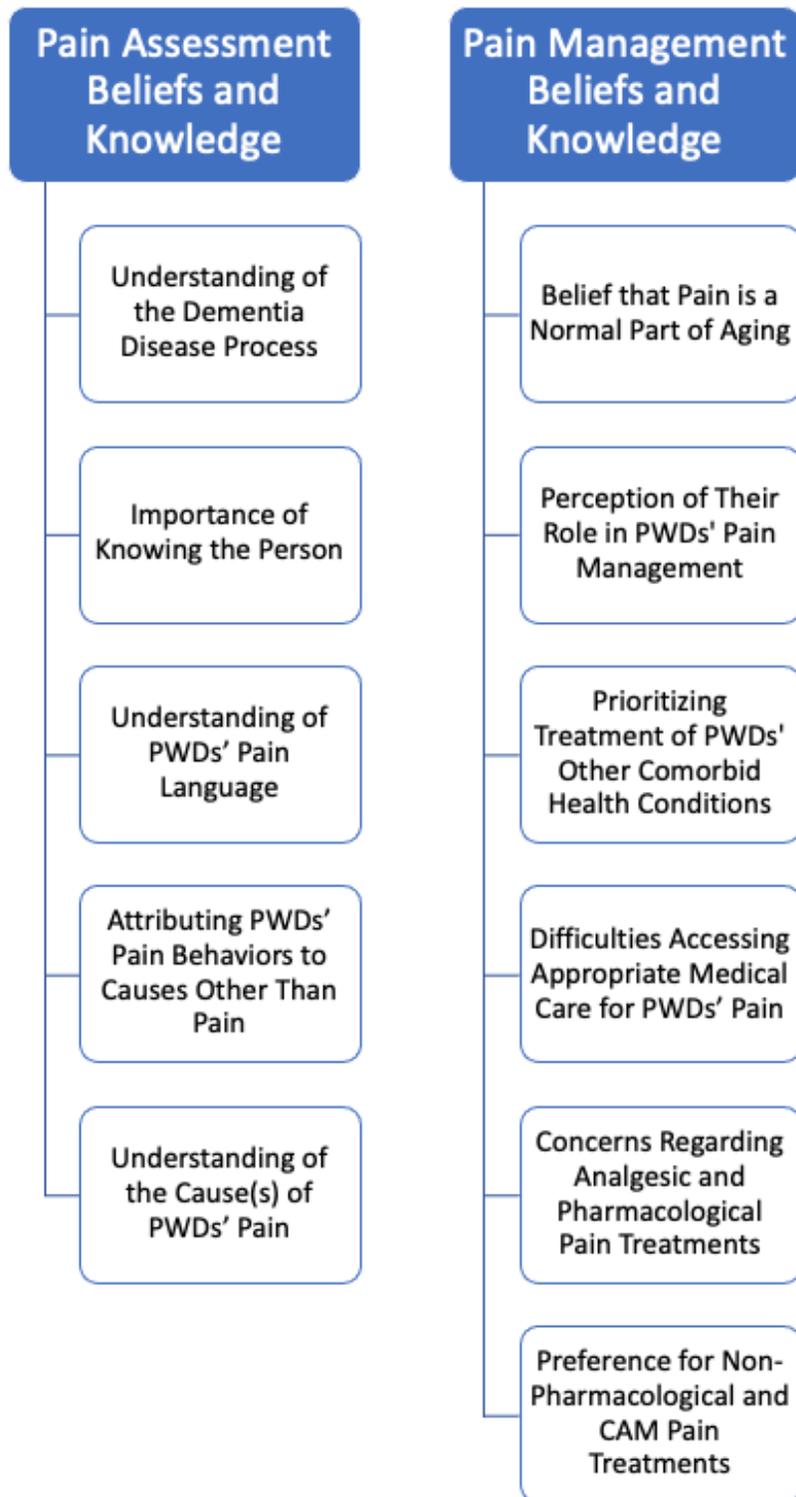
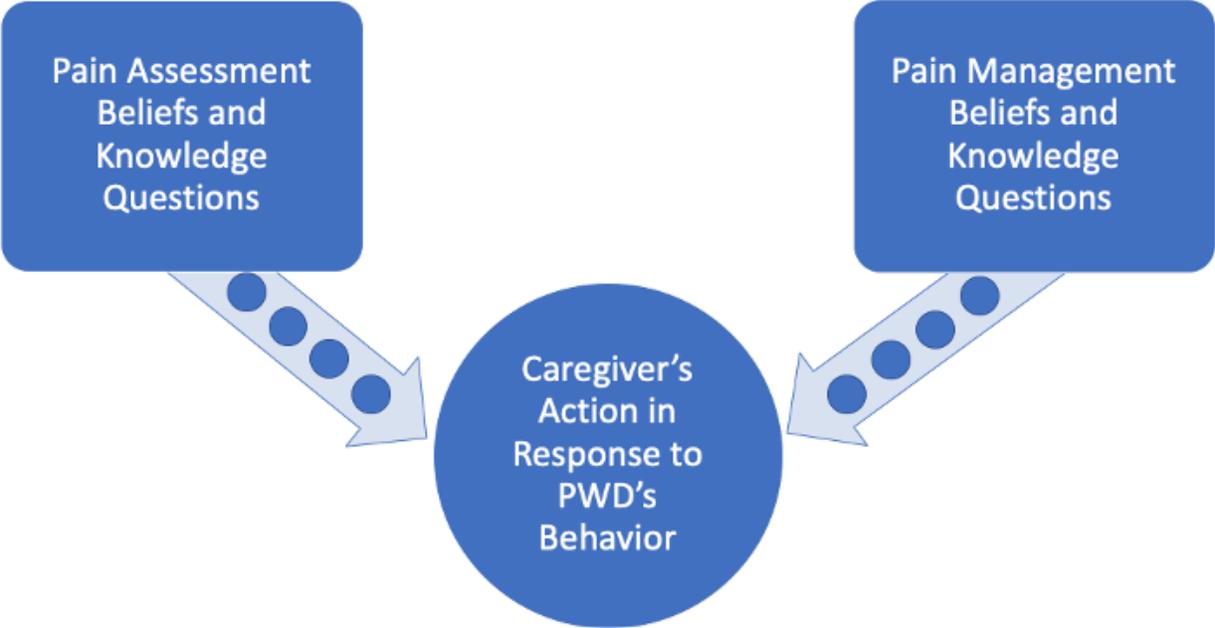


Figure 2: Connecting the dots leads to caregiver action



Recognizing Pain Module 1:1(C)

Recognizing Pain

Session goals:

- Introduce yourself, the intervention, and the specific goals for this session
- Identify participants' experiences of pain and psychoeducational needs
- Understand how pain is defined (What is pain?)
- Understand the effects of pain, and how common it is
- Learn about other types of distress
- Learn about behaviors that can indicate pain or distress
- Choose session content
- Introduce home practice (keeping a diary of pain and distress)

Materials needed:

- Caregiver workbook binder
- *Pain Management for Older Adults: A Self-Help Guide* book
- Printout of caregiver workbook forms for Session 1:1
- 7 copies of the "Pain Diary", 1 copy of the Pain Thermometer Graphic

Session outline:

- A. Introduction
- B. Pain Assessment
- C. What is Pain? What is Distress? And How Can I Spot Them?
 - a. What is pain?
 - b. Effects of pain
 - c. Recognizing pain and distress
 - d. Nonverbal Pain Indicators
 - e. Establish Pain Management Program/Outline
 - f. Using a Pain Diary
 - g. Getting help for pain and distress
- D. Home practice assignment – Pain & Distress Diary

Introduction (include Veteran)

At the first session, review of the study's purpose and content. This is an opportunity to build rapport with the dyad and to address any questions or concerns they have about the study in general. The following elements should be covered in the introduction:

- Remind the dyad of the purpose of the intervention
- Identify yourself and define your role on the project as a research-based clinician.
- Give pertinent contact information for study staff.
- Orient the patient and caregiver to the study procedures and general session structure. Establish parameters for Veteran involvement.
- Discuss confidentiality and limits to confidentiality.
- Verify permission to audiotape session

“The primary purpose of this study is to improve pain & distress management of veterans with memory problems. We encourage the participation of the veteran when he/she is able to actively participate.

*My name is _____. I am a research clinician. I have given you my contact information; please call me if you have any questions in between sessions. I will be making weekly home visits for 6-8 weeks, each meeting lasting about 45 minutes. In these meetings, we will **provide you with information** on different strategies you can use to help with your loved one's pain & distress.*

During the sessions, I will be using a teaching manual and you will have a workbook to learn from. The manual has 3 modules. The first module will help you and your loved one identify symptoms of pain & distress, and explain medical and behavioral approaches to the treatment of pain. The second module will focus on improving communication and the last module will cover increasing pleasurable activity. Three of the modules are mandatory, and then you have a choice to pick additional tools from the remaining options based on what you and your loved one need. At the end of each meeting, we will ask you to practice the skills/tool covered in the session.

Everything we talk about is confidential/private and will only be shared with research team members for research purposes, however there are some limitations. I must report to the appropriate authorities if I suspect any type of abuse including physical, sexual or financial, neglect/self-neglect, or exploitation.

If you disclose the intention or a plan to harm another person, I am legally required to warn the intended victim and report this information to legal authorities. If you disclose or imply that you have a plan for to harm or kill yourself, I, as a therapist, as required by law, must take precautions to keep you safe, which includes contacting a family member or friend to watch over you for a specified amount of time, a referral to a psychiatric hospital or police intervention if necessary.

As explained, all meetings will be audio taped to be reviewed by another staff member to ensure that meetings are being conducted correctly and provide an opportunity for the treatment team to offer other suggestions.

Are there any questions before we begin to learn the first tool for today?

Pain Assessment (include Veteran)

Prepare the Pain Assessment Interview and Module Selection from Appendix (p. 58).

Before we begin to talk about pain in general, I would like to get a good sense of what your experience with pain has been and how it impacts your everyday functioning.

Your responses to the following questions will also help me understand how to best tailor our program to your needs.

Using the Pain Interview and Module Selection questions in the Appendix, inquire about the nature and consequences of the patient's pain, paying careful attention to potential areas that suggest a need for intervention or education. Briefly summarize the veteran's current pain **symptoms, severity and functional impact** based on their responses.

Skill Training

What is Pain?

Provide the caregiver with the Session 1:1 Caregiver Workbook Pages. Go over the following information.

We tend to think of Pain as an unpleasant physical experience caused by damage to our bodies, even though there are types of pain that occur long after the physical tissue has healed. (Point to figure in workbook p.1)

Pain isn't just a physical experience; it's an emotional experience too. Fear, sadness, hopelessness, and feeling blue are some emotions that can be a part of pain. Pain has effects on our thoughts and our behaviors. Pain can lead to behavior changes, like being inactive, which can lead to muscles becoming weak and tight, which makes them easier to injure, which can lead to more pain. Finally, pain can lead to sadness, hopelessness, and catastrophizing thoughts like "this is never going to end," "I can't do anything when I feel like this." And pain can even make it harder to think.

Have you ever had a headache that is so bad that it's hard to think straight?



Assess caregiver understanding.

Thinking about the pain experience you described for me earlier (remind caregiver about that experience), were there effects on [care recipient's] thoughts, behaviors, and mood?

Caregiver should display understanding of the relationships among pain, thoughts, moods, and behaviors by giving at least one example of how a specific pain experience affected (or could affect) thoughts, behaviors, and mood.

Now one thing that's very interesting about pain and mood, thoughts, and behavior, is that there is a two-way street (point to double-headed arrows in figure p. 1). More pain can cause a low mood, hopeless thoughts, and can make a person become inactive. So it makes sense that treating the pain could improve a person's mood, thinking, and behavior.

In our meetings, we'll be talking about how to identify and get treatment for pain that will also help with mood, thinking, and behavior problems [care recipient] might have. But it is also true that doing things to improve mood and increase activity levels can help a person's pain. So we'll also be talking about ways to do this over the next several weeks.

[Additional reference information if the therapist thinks it would be helpful: The International Association for the Study of Pain (IASP) defines pain as "... **an unpleasant sensory and emotional experience which we primarily associate with tissue damage, or, describe in terms of such damage, or both.**" This definition may be helpful to some caregivers.]

Why It Is Important to Recognize and Treat Pain

Direct caregiver to next page of the workbook p. 2, "Why It Is Important to Recognize and Treat Pain."

Pain is an unpleasant experience for anyone, and that's reason enough to take steps to reduce a person's suffering.

Review "Effects of Undertreated Pain." (p. 2)

Review "Effects of Over-treated Pain" (p. 2). *While there are good reasons to not let pain go untreated, it's also important to recognize the risks of over-treating pain with too much medication.*

Review “Solution: Appropriately Treated Pain” (p. 2). *The ideal method to treat pain effectively is finding a solution with the fewest possible side effects. This might take some trial-and-error to find the best treatment, but the first step is being able to recognize when pain is happening and take action.*

After reviewing the handout with caregiver, make note of any potential risk factors that are of particular concern for the individual patient.

Recognizing Pain (p. 3)

Direct caregiver to the workbook, “Recognizing Pain and Distress” (p. 3).

*A commonly used definition of pain in dementia care settings is **"Pain is whatever the experiencing person says it is, existing whenever he says it does"** [reference information: quote by Margo McCaffrey].*

Pain is a very personal experience. To make it even more complex, we know from clinical observations and from experimental evidence that what causes pain to one person may not cause pain to another.

Have you ever noticed that? Can you think of people you know who have higher pain tolerances or lower pain tolerances than you?

(p. 3) A complaint tells you that something is wrong. Clinical and research evidence indicate that something is wrong when a person with dementia complains about pain or some other kind of upsetting experience.

You also have to be on the lookout because research also tells us that people with dementia often under-report the true intensity of their pain.

Direct Caregiver to the Checklist of Nonverbal Pain Indicators (p. 4)

Let's talk about other ways (nonverbal) to recognize when [care recipient] is in pain, and fill out this form looking back to how [care recipient] has been over the past week.

Treatment Plan

Review “Your Pain Management Program” (p. 5). Using data gathered from the Pain Interview Assessment (Appendix) and subsequent discussion of pain topics; collaborate with the caregiver to select intervention content.

- Distinguish core versus elective sessions.
- Review the main focus of each of the core and elective session.
- Invite the caregiver/veteran to identify elective sessions they think will benefit them.

- Feel free to recommend sessions that you think might be helpful to the dyad (based on the “Module Selection” in appendix).
- Decide on which elective sessions will be covered in the program.
- Determine the order of sessions (after session 2). Some caregivers may wish to plan all sessions in a particular order, whereas others may only prioritize one or two topics or none at all. Offer suggestions (e.g., address priority areas first, hold related sessions consecutively) as appropriate.

Home Practice for Next Week: Pain Assessment/Pain Diary

Explain the rationale for monitoring the patient’s pain level each day and instruct the caregiver in the use of the Pain Thermometer (p. 6) for daily monitoring. Show the caregiver where to indicate the patient’s pain level on the Pain Diary (p. 7).

One of the reasons why we suggest that you track your loved one’s pain is simply to be aware of how his/her pain changes over time. Another reason is that a day-to-day record of your loved one’s pain level can help you decide whether any changes you’ve made are helpful. For example, this can be useful if you change the type or dose of a pain medication.

Direct Caregiver to the Pain Diary (p. 7).

Complete the first day’s practice assignment by observing the caregiver while he or she administers the Pain Thermometer tool to the patient.

There are other ways to ask about pain using words like “hurt and uncomfortable.” Prompt the caregiver to ask, “How bad is your pain?” and/or appropriate alternative questions. Also be on the lookout for other signs of distress like on p. 4 of the workbook.

This is a simple and quick tool you can use to keep track of your loved one’s pain over time. Try to do this around the same time each day. Let’s practice together right now using the Pain Thermometer and Pain Diary form.

Work with the caregiver to identify and troubleshoot any potential barriers to daily practice. Schedule the following week’s appointment.

Schedule the next appointment.

Recognizing and Responding to Pain and Distress: How to Look, Listen, Guess and Respond Module 1:2(C)

Responding to Pain and Distress: Look, Listen, Guess and Respond Core Session

Session goals:

- Learn more about recognizing and acting on signs of pain and distress
- Learn to Look, Listen, Guess and Respond
- Practice a strategy for responding to pain and distress

Materials needed:

- Session Review Sheet from previous session
- Printout of caregiver workbook forms for Session 1:2
- 7 copies of the Look, Listen, Guess and Respond Pain and Distress Record
- Clinician Copy of Workbook page 11 for review with caregiver

Session outline:

- A. Review home practice assignment from previous week
- B. Explain how dementia impacts report of pain
- C. Learn about other types of distress
- D. Explain Look, Listen, Guess and Respond
- E. Home practice assignment – Look, Listen, Guess, Respond Pain and Distress Record

Review Home Practice

Briefly summarize the previous session and invite the caregiver and patient to ask any questions. Review Home Practice forms and discuss the patient and caregiver's experiences of monitoring pain. Elicit any problems, questions, or concerns that arose during the assignment. Discuss the patient and caregiver's opinions and feelings about ongoing monitoring of pain during the intervention.

Pain Assessment Interview

Now I am going to ask you some questions about the physical pain [care recipient] has been experiencing lately.

Question A

In what year did [care recipient] start having this pain? _____

Question B

Where on/in [care recipient] body is the pain? _____

Question C

Is there anything that makes [care recipient] pain worse? _____

Question D

Is there anything that makes [care recipient] pain better? _____

Question E

During the past four weeks, would [care recipient] describe this pain as:

- a. Sharp or stabbing? Yes No
- b. A dull ache? Yes No
- c. A burning feeling? Yes No
- d. A tingling feeling? Yes No
- e. A throbbing? Yes No
- f. Being deep in (his/her) body? Yes No

Question F

During the past four weeks, has this pain kept [care recipient] from:

- a. Doing personal care tasks such as bathing or dressing? Yes No
- b. Doing daily household chores? Yes No
- c. Sleeping well at night? Yes No
- d. Being able to concentrate? Yes No
- e. Doing social things with other people? Yes No
- f. Feeling happy? Yes No

Question G

Does [care recipient] take any prescription medications for pain? Yes No

Question H

Has [care recipient] ever had any treatments for pain other than medications; such as surgery, physical therapy, or special exercise? Yes No If yes, please explain: _____

Elective Module Selection

Medical Treatments and Working with Healthcare Providers

I would like to know what you and [care recipient] need to know about pain treatments. I am going to read a few statements. Tell me if you need more information about or need help with:

- | | | |
|---|-----|----|
| 1. Getting treatment/care that your [care recipient] needs? | Yes | No |
| 2. Taking medications in the right amounts at the right times? | Yes | No |
| 3. Understanding the possible side effects of medications? | Yes | No |
| 4. Keeping written notes when talking to your [care recipients] physicians or other healthcare providers? | Yes | No |
| 5. Getting instructions on how to care for [care recipient]? | Yes | No |

If Yes to any of the above → recommend “Medical Treatments and Talking to Your Doctor.” (1:3)

Communication Difficulties

Now I am going to ask you some questions about your [care recipient] ability to communicate and (his/her) behavior.

In the past week, has your [care recipient] had difficulty with:

- | | | |
|--|-----|----|
| 1. Understanding/ following conversations, television programs, or directions? | Yes | No |
| 2. Expressing (himself/herself) or understanding others? | Yes | No |
| 3. Communicating (his/her) basic needs? | Yes | No |

Next, I would like to know if [care recipient] has recently acted in the following ways:

- | | | |
|---|-----|----|
| 1. Gets upset with those trying to care for (him/her) or resist activities such as bathing or changing clothes? | Yes | No |
| 2. Act uncooperative, resistive to help from others? | Yes | No |

If Yes to any of the above → recommend “Communication Problems and Challenges.” (2:2)

Sleep and Anxiety

I would like to know more about how [care recipient] has been sleeping lately.

Does [care recipient]:

- | | | |
|---|-----|----|
| 1. Have difficulty concentrating or not have enough energy during the day because (he/she) was tired? | Yes | No |
| 2. Take medication (prescribed or over the counter) to help (him/her) sleep? | Yes | No |

Next, I'd like to know if [care recipient] has recently:

- | | | |
|--|-----|----|
| 1. Worried a lot? | Yes | No |
| 2. Seemed fearful of anxious? | Yes | No |
| 3. Had periods of feeling shaky, unable to relax, or very tense? | Yes | No |

If Yes to any of the above → recommend “Rest/Relaxation Strategies You Can Use At Home.” (1:4)

Pleasant Activities

Next I would like to ask about [care recipient] daily activities. Has [care recipient]:

- | | | |
|---|-----|----|
| 1. Lost interest in activities (he/she) once enjoyed? | Yes | No |
|---|-----|----|

2. Stopped participating in an activity because of pain?

Yes No

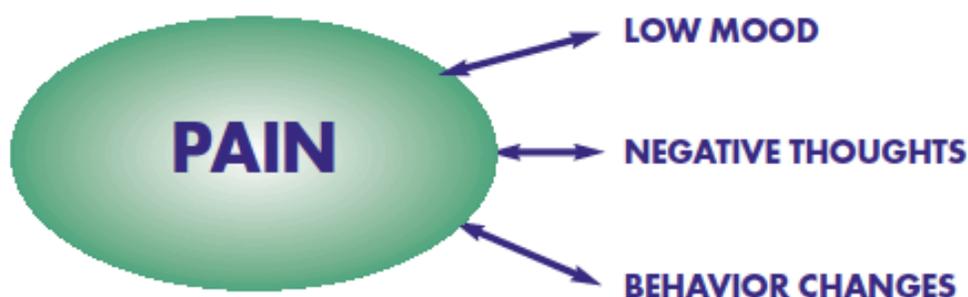
If Yes to any of the above → recommend “Increasing Pleasant Activities.” (3:2)

APPENDIX B: PAVeD Workbook Excerpts

WHAT IS PAIN?

Pain is an unpleasant physical experience. We talk about and think about pain as being caused by physical damage to our bodies, but pain can occur long after the visible damage has healed.

Pain is more than a feeling – it is a complex experience that includes changes in mood, thoughts, and behaviors. These changes may, in turn, make the experience of pain even worse.



PAIN IS COMMON.

A study of 1000 older adults found that seven out of ten experienced pain at least some of the time. Among older adults who reported having pain, about half reported daily pain, and one out of four reported severe pain.

(Source: University of Alabama at Birmingham Study of Aging)

WHY IT IS IMPORTANT TO RECOGNIZE AND TREAT PAIN?

EFFECTS OF UNDERTREATED PAIN:

- ◆ Increased risk of falls
- ◆ Lower activity level, which can lead to de-conditioning and more pain
- ◆ Poor mood or depression
- ◆ Poor sleep
- ◆ Increased risk of developing other medical problems
- ◆ Increased mortality rates

EFFECTS OF OVERTREATED PAIN:

- ◆ Grogginess, sleepiness
- ◆ More difficulty thinking
- ◆ Increased risk of falls
- ◆ Lower activity level, which can lead to de-conditioning and more pain

SOLUTION:

APPROPRIATELY TREATED PAIN, WHICH REQUIRES:

- ◆ Recognizing the pain
- ◆ Starting treatment
- ◆ Adjusting treatment as needed to get it “just right”
- ◆ Working with your clinical providers for all of the above

RECOGNIZING PAIN AND DISTRESS

“Pain is whatever the experiencing person says it is, existing whenever he says it does.”

Margo McCaffrey, RN, MSN, FAAN, Pain Expert



A complaint tells you that something is wrong.

Clinical and research evidence indicate that something is wrong when a person with dementia complains about pain or some other kind of upsetting experience.

Be on the lookout for other signs of pain and distress.

Clinical and research evidence also tell us that people with dementia often under-report the true intensity of their pain.

CHECKLIST OF NONVERBAL PAIN INDICATORS

Today's date _____

INSTRUCTIONS:

Write a 0 if the behavior was not observed, and a 1 if the behavior occurred even briefly during activity or rest.

	WITH ACTIVITY?	WHILE AT REST?
VOCAL COMPLAINTS: NONVERBAL Expression of pain, no in words, moans, groans, grunts, cries, gasps, sighs	<input type="checkbox"/>	<input type="checkbox"/>
FACIAL GRIMACES/WINCES Furrowed brow, narrowed eyes, tightened lips, dropped jaw, clenched teeth, distorted expression	<input type="checkbox"/>	<input type="checkbox"/>
BRACING Clutching or holding onto siderails, bed, tray table, or affected area	<input type="checkbox"/>	<input type="checkbox"/>
RESTLESSNESS Constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still	<input type="checkbox"/>	<input type="checkbox"/>
VOCAL COMPLAINTS: VERBAL Words expressing discomfort or pain ("ouch," "that hurts"), cursing during movement, or exclamations of protest ("stop," "that's enough")	<input type="checkbox"/>	<input type="checkbox"/>

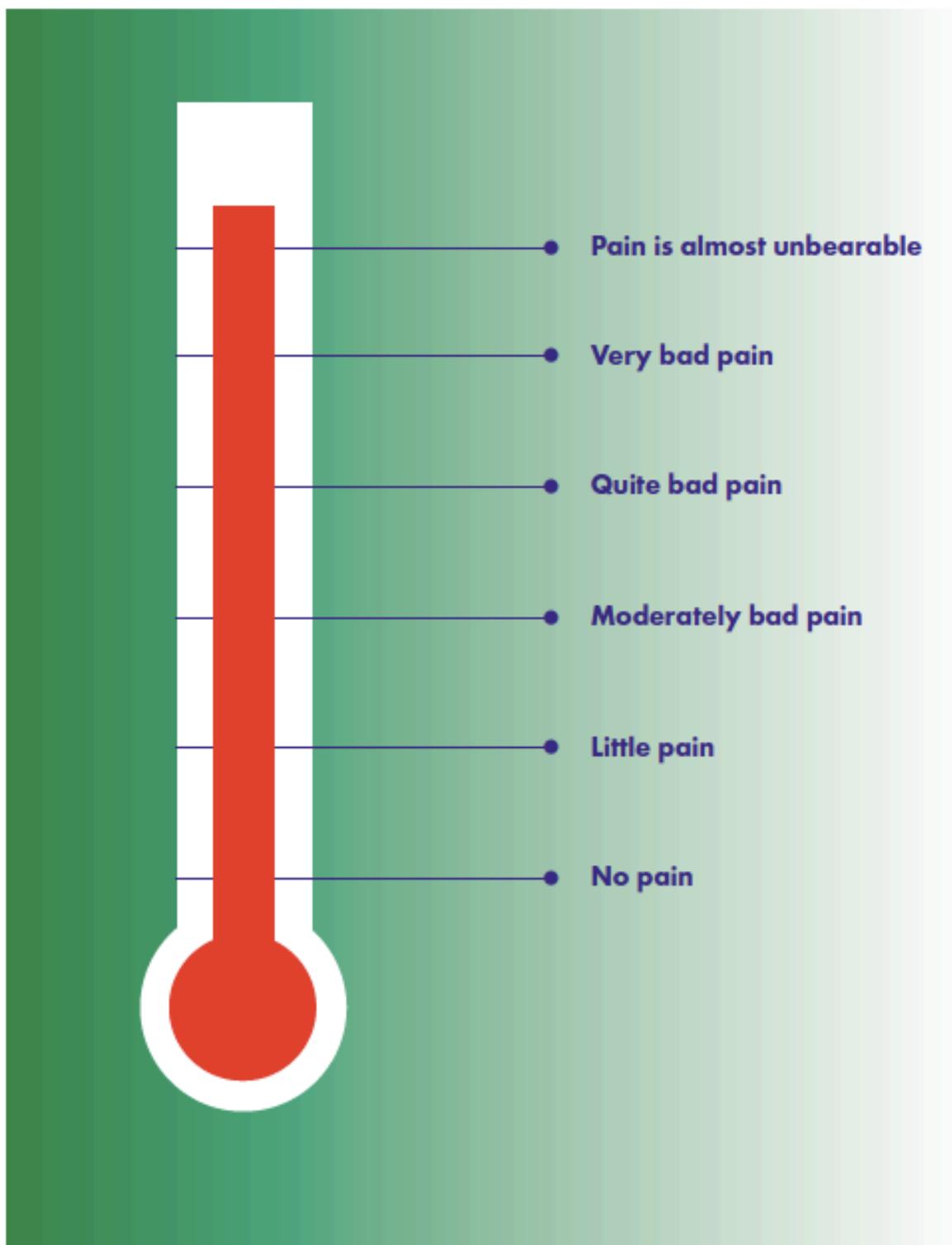
Record any verbal complaints here:

YOUR PAIN MANAGEMENT PROGRAM

Below are the topics for our meetings. Four meetings (already checked) will focus on “core” topics. You can choose an additional 2 to 4 topics that best meets your needs.

<input checked="" type="checkbox"/>	<p>RECOGNIZING PAIN An introduction to the program and discussion of pain management.</p>
<input checked="" type="checkbox"/>	<p>LOOK, LISTEN, GUESS, AND RESPOND Introduces a technique for recognizing and responding to signs of pain and distress.</p>
<input type="checkbox"/>	<p>MEDICAL TREATMENTS AND TALKING TO YOUR DOCTOR</p> <ul style="list-style-type: none"> • Choosing medications and using them safely • Understanding dependence versus addiction • How to talk to your doctor to get the right treatment
<input type="checkbox"/>	<p>REST AND RELAXATION STRATEGIES YOU CAN USE AT HOME</p> <ul style="list-style-type: none"> • Relaxation training • Good habits for better rest • Body positioning
<input checked="" type="checkbox"/>	<p>ENHANCING COMMUNICATION</p> <ul style="list-style-type: none"> • How dementia affects communication • Tips for communicating with someone who has dementia
<input type="checkbox"/>	<p>COMMUNICATION PROBLEMS AND CHALLENGES</p> <ul style="list-style-type: none"> • How to deal with challenges that make communication difficult • Managing problem situations • Hands-on communication skill practice
<input checked="" type="checkbox"/>	<p>MAKING DAILY ACTIVITIES MORE COMFORTABLE AND ENJOYABLE</p> <ul style="list-style-type: none"> • Learn more about how activity, mood, and discomfort are related • Find opportunities to make daily activities more comfortable or enjoyable
<input type="checkbox"/>	<p>INCREASING PLEASANT ACTIVITIES</p> <ul style="list-style-type: none"> • Benefits and challenges of trying new activities • How to identify new activities to try • Plan for a new activity

PLEASE RATE HOW BAD YOUR PAIN IS RIGHT NOW



PAIN DIARY

INSTRUCTIONS:

Using the pain thermometer, record your loved one's level of pain at least once per day.

NO PAIN	<input type="checkbox"/>						
LITTLE PAIN	<input type="checkbox"/>						
MODERATELY BAD PAIN	<input type="checkbox"/>						
QUITE BAD PAIN	<input type="checkbox"/>						
VERY BAD PAIN	<input type="checkbox"/>						
PAIN IS ALMOST UNBEARABLE	<input type="checkbox"/>						
DATE AND TIME	/ / — AM PM						

APPENDIX C: IRB Approval Letter



Office of the Vice President for
Research & Economic Development
Office for Research Compliance

March 9, 2020

Phoebe Block, MA
Doctoral Candidate
Department of Psychology
College of Arts & Sciences
The University of Alabama
Box 870348

Re: IRB # EX-17-CM-032-R3 "Qualitative Study of the Preventing Aggression in Veterans with Dementia (PAVeD)"

Dear Ms. Block:

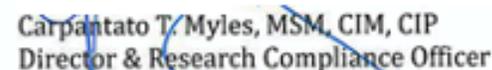
The University of Alabama Institutional Review Board has granted approval for your renewal application. Your renewal application has been given exempt approval according to 45 CFR part 46.101(b)(4) as outlined below:

(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

The approval for your application will lapse on March 8, 2021. If your research will continue beyond this date, please submit the annual report to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Good luck with your research.

Sincerely,

Carpentato T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer

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