

Original Article

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Partnering to cope with pain: A pilot study of a caregiver-assisted pain coping skills intervention for patients with cognitive impairment and dementia

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Abstract

Objective. To develop a new caregiver-assisted pain coping skills training protocol specifically tailored for community-dwelling persons with cognitive impairment and pain, and assess its feasibility and acceptability.

Method. In Phase I, we conducted interviews with 10 patient–caregiver dyads to gather feedback about intervention content and delivery. Phase II was a single-arm pilot test to evaluate the intervention’s feasibility and acceptability. Dyads in the pilot study ($n = 11$) completed baseline surveys, received five intervention sessions, and then completed post-intervention surveys. Analyses focused on feasibility and acceptability.

Results. Dyads responded positively to the pain coping skills presented in the interviews; their feedback was used to refine the intervention. Findings from the pilot study suggested that the intervention was feasible and acceptable. 69% of eligible dyads consented, 82% completed all five intervention sessions, and 100% completed the post-treatment assessment. Caregivers reported high satisfaction ratings. They also reported using the pain coping skills on a regular basis, and that they found most of the skills helpful and easy to use.

Significance of results. These preliminary findings suggest that a caregiver-assisted pain coping skills intervention is feasible and acceptable, and that it may be a promising approach to managing pain in patients with cognitive impairment.

Introduction

Currently over five million persons in the United States are affected by some form of cognitive impairment including mild cognitive impairment (MCI) and Alzheimer’s disease and related dementias (hereafter referred to as “persons with dementia” or PWD). This number is anticipated to grow to 13–16 million by 2050 (Hebert et al., 2013; Alzheimer’s Association, 2020). While in the advanced stages of dementia patients often live in long-term care facilities, a growing number of PWD are living in the community due to person/caregiver preferences and a growth in non-institutional support by Medicaid (Harrison et al., 2019). Even those with early to moderate disease can require significant help from informal family caregivers, and the burden on family caregivers is well documented (Chiao et al., 2015).

Pain is a common, undertreated, and often disabling condition in PWD that impacts both the person and their caregivers (Shega et al., 2006; Achterberg et al., 2013; Hoffmann et al., 2014; Hunt et al., 2015). Nearly two-thirds of PWD report bothersome pain (Hunt et al., 2015). For PWD, pain may cause substantial distress, adversely impact quality of life, and be associated with physical disability and neuropsychiatric dysfunction that manifests as agitation and aggression (Bradford et al., 2012; Pieper et al., 2013; Corbett et al., 2014; Husebo and Corbett, 2014). Pain also increases stress for family caregivers who are themselves at risk for adverse mental and physical health outcomes (Chiao et al., 2015).

To date, the overwhelming majority of literature on pain evaluation and management in PWD focuses on those with advanced disease living in long-term care facilities (Pieper et al., 2013; Husebo et al., 2016). Given the prevalence of pain in community-dwelling patients with less advanced disease, and the impact of pain on patients and caregivers, it is important to develop relevant pain management programs that target these vulnerable individuals. Nonpharmacological approaches for pain management, particularly those based on cognitive

behavioral principles such as pain coping skills training (PCST), have been found efficacious among older adults without dementia (Keefe et al., 2013; Niknejad et al., 2018). While they have been recommended for PWD (Norelli and Harju, 2008; Keefe et al., 2013), to our knowledge, there have been no methodologically rigorous trials examining the efficacy of PCST in this population. Systematically involving both patients and family caregivers in PCST is a novel approach that may benefit both patients and caregivers. We have previously developed and tested caregiver-assisted PCST protocols for patients with osteoarthritis and cancer and have found they lead to improvements in outcomes for both patients and caregivers (Keefe et al., 1996, 1999, 2005). The goal of this study was to develop a new caregiver-assisted PCST protocol specifically tailored for community-dwelling PWD and pain and assess its feasibility and acceptability. In Phase I of the project, we conducted interviews with patients and caregivers to help develop and refine the protocol. Phase II was a single-arm pilot test to evaluate the intervention's feasibility and acceptability.

Method

Eligibility and recruitment procedures were identical for Phase I and Phase II. Participants in Phase I were not eligible for Phase II. Patients were recruited from the Duke Memory Disorders and Geriatric Evaluation and Treatment Clinics. Patient inclusion criteria were a diagnosis of MCI or mild to moderate dementia (as documented by their physician), score ≥ 3 on the PEG, and living at home with an informal caregiver. The PEG consists of three items (pain severity, interference with enjoyment of life, and interference with general activities, each rated from 0 to 10) which are averaged for a composite score. Additional inclusion criteria were age ≥ 18 years and English speaking (both patients and caregivers). Exclusion criteria were inability to complete study activities (e.g., due to hearing impairments or severe behavioral problems) as determined by the patient's healthcare provider or reported by the caregiver.

All study procedures were approved by the Duke University Health System Institutional Review Board (IRB). Potential participants were introduced to the study by the patient's healthcare provider verbally or by an IRB-approved introductory letter. This was followed by a telephone call from research staff to provide information, answer questions, and determine eligibility, including administration of the PEG. For those who were eligible and interested, a visit was scheduled to complete informed consent and conduct the interview (Phase I) or collect baseline measures (Phase II). Due to COVID-19 restrictions on in-person research activities instituted in March 2020, all study activities were conducted remotely after this time.

Caregivers were consented using a standardized IRB-approved protocol and completed written consent. Rather than assess patients for competency to provide consent, we operated under the assumption that patients may lack decision-making capacity and obtained assent (written and verbal) from the patient and consent from the caregiver (who in each case was the patient's legally authorized representative).

Phase I: Refinement of intervention

We collected demographic information from patients and caregivers and then conducted a 45-min interview in which we presented information about the intervention to dyads and elicited their

feedback using a standardized interview guide. The interviewer described and/or demonstrated five pain coping skills (see Table 1) and elicited feedback about each. Participants were also asked about their preferred mode of intervention delivery (e.g., in person versus remotely by telephone or videoconferencing, and participating individually or together with their partner). Patients and caregivers each received \$40 for completing the interview.

Interview data were managed and evaluated in a systematic format (Hsieh and Shannon, 2005). Interviews were audio recorded and transcribed as they were conducted. Recordings and transcriptions were reviewed by the study team and analyzed using thematic content coding (Braun and Clarke, 2006). After 10 interviews, we determined we had reached thematic saturation. To assess and categorize the valence of responses regarding perceptions of the pain coping skills, two coders (L.S.P. and K.R.) independently rated each dyad's responses to each of the skills as negative, neutral (or equally positive and negative), or positive. Ratings were consistent for 43/50 responses (86%), and discrepancies were resolved through discussion. We used these formative data to adapt and refine the intervention.

Phase II: Pilot study

Dyads in the pilot study completed baseline surveys, received five intervention sessions, and then completed post-intervention surveys. Originally, surveys were conducted in person via paper and pencil. Following implementation of pandemic restrictions, participants completed surveys at home either electronically or on paper, via mail. Patient medical information was collected via medical chart review. Patients and caregivers received a total of \$100 each.

Measures

At baseline, patients and caregivers provided demographic information and caregivers completed a measure of comorbidities (Sangha et al., 2003).

Feasibility was assessed through caregiver reports of coping skills use throughout the intervention period and post-intervention. At the start of sessions 2–5, caregivers reported the frequency of their practice of skills taught at the previous session. They also rated the perceived helpfulness of the skills and their confidence in using the skills (on a scale from 0 = "not at all helpful/confident" to 4 = "extremely helpful/confident"). At the post-intervention survey, caregivers completed a measure assessing the frequency with which they used each skill during the past week and their perceptions of the skills' ease of use and helpfulness (on a scale from 0 = "not at all easy to use/helpful" to 4 = "extremely easy to use/helpful").

Acceptability of the intervention was measured with the Client Satisfaction Questionnaire (Nguyen et al., 1983) which assesses the effectiveness of/satisfaction with services received. Caregivers completed this scale at post-intervention only. Additional items were added to assess satisfaction with the number and length of sessions, preference for treatment modality (in person/videoconferencing/telephone), and aspects of the intervention they found most/least helpful (open-ended).

Patient pain and functioning was assessed via patient self-report and caregiver proxy reports completed at baseline and post-intervention. Patients completed four items from the Brief Pain Inventory (BPI) (Daut et al., 1983): usual, average, and worst pain intensity rated on a 0–10 scale, and pain interference

Table 1. Pain coping skills presented in the interviews

Skill	Description and presentation
Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden et al., 2003)	The PAINAD is a reliable assessment tool that can be used with both verbal and nonverbal patients. It includes five dimensions of nonverbal pain expression (breathing, negative vocalizations, facial expression, body language, and consolability) and for each provides descriptors of behaviors indicating the presence of pain. The PAINAD was presented as a tool that caregivers could use to help them assess the patient's pain. Caregivers were given a handout of the scale which the interviewer reviewed with them.
Brief relaxation	The interviewer described the benefits of relaxation, including decreasing pain, stress, and tension and improving mood, and the steps of doing a brief relaxation exercise. This information was summarized in handouts. The interviewer then guided the dyad through a 30-s relaxation exercise.
Integrative movement (Barnes et al., 2015; Casey et al., 2020; Mehling et al., 2020; Wu et al., 2015)	The integrative movement exercises were derived from the Preventing Loss of Independence through Exercise (PLIÉ) program (https://plie4dementia.com/), which is a gentle, mind-body program developed for people living with cognitive impairment and dementia. The PLIÉ program includes seven 9- to 13-min online videos of exercises including waking up the body through tapping, breathing, and movements of the feet; preparation for sit to stand; seated partner movements; moving from sitting to standing; balancing while standing; turning in sitting; and using spiky balls for sensory stimulation. During the interview, the interviewer played segments of two of the videos and described how the dyad might use them.
Activity-rest cycle (Gil et al., 1988)	The activity-rest cycle is a method of pacing activities to manage pain. The interviewer discussed the tendency of patients to either overdo activities, leading to severe pain, or avoid activities to try to prevent pain flares. She then described the steps involved in the activity-rest cycle. This information was summarized in handouts.
Pleasant activity scheduling (Gil et al., 1988)	The interviewer described the benefits of engaging in pleasant activities and presented guidelines for brainstorming about activities the patient and/or caregiver would enjoy and value. The dyad completed a brief brainstorming exercise and developed a list of pleasant activities which was recorded on a handout.

Table 2. Intervention content

Session	Skills training	Behavioral rehearsal	Home practice
1	Pain assessment; brief relaxation	Caregiver coaches patient in relaxation and using relaxation to manage stress	Relaxation once/day using audio recording
2	Use of PAINAD scale and pain thermometer; pain communication	Caregiver guides patient in relaxation exercise and uses the PAINAD scale to assess pain before and after	Use PAINAD to assess pain each day; continue practicing relaxation daily
3	Integrative movement	Use of integrative movement exercises to apply pain coping skills during activities	Integrative movement 2x/week; relaxation daily
4	Pleasant activity scheduling; music for pain management	Integrative movement with music	Schedule 2 pleasant activities per week
5	Booster session	Identify obstacles to implementing pain coping skills and strategies for coping with them	Continued practice of skills as per maintenance plan

rated 0 (none) to three (extreme). The BPI has demonstrated reliability and validity (Daut et al., 1983). The three pain intensity items were averaged; Cronbach's alpha was 0.77. Patients also completed the Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al., 2002), a 13-item dementia-specific quality of life scale. The measure has good psychometric properties and can be completed by people with a wide range of severity of dementia. Cronbach's alpha was 0.83.

Caregivers completed proxy measures of the QOL-AD scale and the five-item pain interference scale from the BPI. Cronbach's alpha was 0.88 for the QOL-AD and 0.90 for pain interference. Caregivers also completed the Checklist of Nonverbal Pain Indicators (Feldt, 2020) which assesses pain behaviors (e.g., moaning, wincing, bracing) in cognitively impaired older adults. Scores range from 0 to 10 with higher scores indicative of more pain expression.

Caregiver outcomes. Caregivers completed the following measures at baseline and post-intervention:

Caregiver self-efficacy was measured using the pain management subscale of a standardized measure that assesses caregiver self-efficacy for helping the patient manage symptoms. This subscale includes seven items worded as questions and rated on a 10–100 scale (e.g., “How certain are you that you can help the patient control his/her pain?”). Items are averaged. Prior studies support the scale's reliability and validity (Lorig et al., 1989; Keefe et al., 2005; Porter et al., 2011). Cronbach's alpha was 0.95.

Caregiver burden was measured with the Zarit Burden Interview (ZBI) (Zarit et al., 1980), a 22-item scale assessing burden experienced by dementia caregivers in the home care context. The ZBI has high internal consistency and good test–retest reliability. (Hérbert et al., 2000) Scores range from 0 to 88 with higher scores indicating greater burden. Cronbach’s alpha was 0.95.

Caregiving satisfaction was measured using the Caregiving Satisfaction scale of the Caregiver Appraisal measure (Lawton et al., 1989) which assesses benefits associated with caregiving (e.g., feeling closer to the patient). The scale has demonstrated good test–retest reliability and internal consistency. (Lawton et al., 1989) Cronbach’s alpha was 0.74.

Intervention

The caregiver-assisted PCST protocol consisted of five 45–60 min sessions conducted jointly with the patient and caregiver (Table 2). The first four sessions were intended to occur weekly, but participants were given up to eight weeks to complete these sessions to accommodate factors such as travel and illness. The last session was a booster session that occurred 1 month following the fourth session. Based on findings from the interviews, we planned to conduct the first session in person and then give dyads the option of completing the remainder of the sessions either in person or remotely via telephone or videoconference. Starting in March 2020, all sessions were conducted remotely due to pandemic-related restrictions on in-person research activities.

Sessions were conducted by a master’s level social worker experienced in PCST and working with older adults. At the outset of the study, the therapist received training in the protocol. She followed a detailed treatment manual, and sessions were audio recorded and reviewed in supervision sessions with the first author. Sessions included training in four skills presented in the interviews (PAINAD, brief relaxation, integrative movement, and pleasant activity scheduling) plus the pain thermometer for patient reports of pain severity and music as a specific pleasant activity that can help with pain management (McConnell et al., 2016).

Statistical analyses

Analyses of the pilot data focused on feasibility and acceptability. Feasibility was assessed by examining overall accrual, attrition, and adherence to the study protocol. To evaluate accrual, we describe the total number of patients and caregivers screened and rates and reasons for non-eligibility and refusal. With regard to attrition and adherence, we examined the number of dyads who successfully completed study participation (i.e., provided post-intervention assessments); completion by 70% served as our feasibility benchmark. We examined caregiver use of skills and their perceived helpfulness and ease of use. Acceptability was assessed by post-intervention ratings of satisfaction with the intervention, with a benchmark of 70% of caregivers reporting satisfaction with the intervention (mean score of 3 on the four-point CSQ). Finally, we examined individual baseline to post-intervention difference scores on outcome measures and describe the pattern of changes observed. As recommended by guidelines for pilot studies with small sample sizes (Kraemer et al., 2006; Eldridge et al., 2016), we did not conduct statistical tests of change scores.

Table 3. Ratings and quotes from Phase I patient–caregiver interviews

Skill	Illustrative Quotes	Ratings
Relaxation	“I think that this is something that you could do regularly, [or when] not planned, or when you see yourself tensing up or stressed out or something, just stop, and do this [relaxation activities].” (Caregiver)	10 positive
Integrative Movement	“It’s great for getting mobility, getting push pull to exert some pressure, if you want. For us it probably would be better either in the morning you know, more of a stretching, starting like you know, she was doing the waking up of everything. That would be a good time. I think as the afternoon goes on you know, (name) gets tired and then in the evening, it seems the evening is like, gone. So, yeah, I would say morning would be best.” (Caregiver)	8 positive, 2 neutral
PAINAD Scale	“Everything here fits. What I’ve been experiencing. ...some of these, the groaning when she was going to the bathroom or the crying out, I mean that was very common. I think [the scale] is dynamite if you’ve got something like that and if it’s something that people could learn early on it would help them because they know things are gonna change, but you’ve got this [scale and tool] that you can look at and...I can think of different circumstances where, maybe I didn’t know...that would be indicators of pain.” (Caregiver)	9 positive, 1 neutral
Pleasant Activity Scheduling	“I enjoy reading a book, sitting on the couch reading a book. Now, I might go to the library but I’m not gonna cook a meal and work in a garden any more than I absolutely have to.” (Patient)	10 positive
Activity-Rest Cycle	“[This can help] cause a lot of times we do things and we push through to try to get it done. We’re out there raking leaves and we say, just got to finish this up. [Now I can say] I can get this little bit, and I’m gonna take a rest.” (Caregiver)	6 positive, 4 neutral
Format	Illustrative Quotes	
Frequency	“It would seem like initiating it on more of a monthly basis you know, tied it in with one of the [dementia] support organizations might be a way to get it started and then [again] some people might benefit from weekly [if the dementia is in] the early stages. Then yes, they can do weekly cause then they go	

(Continued)

Table 3. (Continued)

Skill	Illustrative Quotes	Ratings
	out to lunch, they [can] make it a thing.” (Caregiver)	
Delivery	“Personally, I like the one on one with the person. Well...I’m okay, whether it’s on Skype or whether it’s in person.” (Caregiver) “It just depends on your priorities.” (Patient)	
Dyadic or Individual	“I’d rather do something with him. Cause I would know what he feels about something and whether we’re either are gonna do it or not do it you know, or we’re gonna change how we’re doing it.” (Patient)	

Results

Phase I: Interviews

Ten patient–caregiver dyads completed the interviews. Patients’ mean age was 77.7 years (SD = 6.8, range = 67–87), 70% were female, and 80% were non-Hispanic white. Patient diagnoses included MCI ($n = 3$), AD ($n = 5$), mild dementia ($n = 1$), and mixed AD/vascular dementia ($n = 1$). Caregivers’ mean age was 73.7 years (SD = 11.3, range = 52–89), 40% were female, and 80% were non-Hispanic white. Eight caregivers were spouses and two were daughters of the patient.

Interview data are summarized in Table 3. All ten dyads responded positively to the relaxation exercise. After the interviewer guided them through the practice, many noted that it helped reduce stress, tension, and pain, and was definitely a skill that would be useful. All ten dyads also responded positively to pleasant activities; dyads participated enthusiastically in the process of identifying enjoyable activities and left the interview with plans for engaging in activities meaningful to both the patient and caregiver. Some noted that the patient’s condition posed challenges to engaging in activities they previously enjoyed (e.g., playing cards), and that more recently the COVID-19 pandemic limited many of their usual activities. However, they recognized the importance of finding creative ways to engage in pleasant activities as a way of reducing patient isolation and improving both patient and caregiver mood as well as managing pain. Nine of ten dyads commented positively on the PAINAD tool, noting that it would be useful in helping them assess the patient’s pain and communicating this information to healthcare providers; one dyad responded neutrally to the tool (e.g., “It makes sense”). Eight dyads had positive responses to the integrative movement exercises which they thought would be fun and encourage physical activity. Two were neutral, noting that while the exercises could be beneficial, they did other physical activities which they preferred (e.g., riding a stationary bicycle). In reaction to the activity-rest cycle, six dyads had mostly positive comments, and four had mixed positive and negative comments. While most participants believed that the skill was beneficial, many reported that at this point in their lives they had learned to do this on their own.

In addition, some caregivers commented that the way in which patients and caregivers would learn and apply skills would depend

to some degree on the severity of the patient’s cognitive impairment. For example, one caregiver noted that integrative movement would need to be introduced early in the disease trajectory for the patient to be able to follow along. Another noted that relaxation would need to be started in the earlier stages, “then you don’t know how long it will stay, but if they’re doing it together it may work.”

With regard to format and mode of delivery, all 10 dyads responded positively to the plan to conduct sessions weekly with the patient and caregiver together, noting that this format was likely to be the most effective way for them to learn and apply the skills. Half of the dyads preferred that sessions be conducted in person at the clinic, noting that they often needed a reason to get out of the house and that they were more likely to give their undivided attention in this setting. However, one dyad stated they would be most comfortable having the sessions at home, and several did not have any strong preferences. The idea of videoconferencing was met with mixed responses; several dyads stated definitively that they did not like using technology, several others were skeptical but open to the possibility, and two caregivers noted that they would prefer videoconferencing for its convenience and flexibility.

Conducting these interviews also provided useful information that helped shape decisions about the content and process of the intervention sessions. Patients exhibited fluctuations in their ability to comprehend skills and were often only able to focus on a topic for a short time. This suggested the importance of keeping the content simple (i.e., one skill per session), limiting the number of skills included, emphasizing home practice to consolidate learning, and including strategies for maintenance enhancement. The fact that dyads had different needs and preferences with regard to location and mode of delivery suggested the importance of allowing dyads to participate either in person or remotely.

Based on these findings, we decided to offer five sessions with the first four scheduled weekly to promote continuity and a booster session 1 month later to trouble shoot and promote maintenance. Given the need to limit the number of coping skills included in the intervention, we decided to exclude the activity-rest cycle which received the fewest favorable responses.

Phase II: Pilot study

Feasibility. Thirty-one patients were approached for participation. Of these, 15 were ineligible (no pain, $n = 10$; pain but PEG score < 3 , $n = 1$; patient living in assisted living/memory care, $n = 2$; patient not living with caregiver, $n = 1$; patient did not speak English, $n = 1$). Of the 16 eligible dyads, 5 declined to participate. Reasons included patient or caregiver lack of interest ($n = 3$), distance ($n = 1$), patient being too ill ($n = 1$), and being too busy ($n = 1$).

Eleven dyads consented and provided baseline data. Patients’ mean age was 77.7 years (SD = 4.8, range = 71–84); 70% were non-Hispanic white. Patient diagnoses included MCI ($n = 5$), AD ($n = 3$), unspecified dementia ($n = 2$), and Parkinson’s related dementia ($n = 1$). Pain diagnoses included knee or hip osteoarthritis ($n = 6$), chronic low back pain ($n = 6$), headache ($n = 1$), sciatica ($n = 1$), unspecified foot pain ($n = 1$), and back/leg pain from a gunshot wound ($n = 1$). Caregivers’ mean age was 69.6 years (SD = 13.3, range = 43–83); 91% were non-Hispanic white. Eight caregivers (73%) were spouses, two were daughters, and one was the sister of the patient. Two caregivers were employed

full-time and nine were retired. Caregivers reported an average of 3.9 medical conditions, the most common being back pain ($n = 8$), high blood pressure ($n = 4$), and depression ($n = 4$).

Nine dyads (82%) completed all five sessions on schedule (within 10 weeks). Two dyads completed three sessions, one dropping out due to the caregiver's work schedule and the patient's declining health and the other because they did not find the skills helpful. Two dyads completed all of the sessions in person, four completed at least one session in person and the remainder by telephone, and five completed all sessions by telephone. All eleven dyads completed post-treatment questionnaires.

Table 4. Weekly reports of skill use, helpfulness, and confidence

	Frequency of use			
	None N	1–2 days N	3–4 days N	5+ days N
Relaxation with partner	4	2	2	3
Relaxation on own	0	2	3	6
PAINAD scale	2	0	2	7
Pain thermometer	8	1	2	0
Integrative movement	1	4	2	3
Pleasant activities	0	0	3	6
Listening to music	0	1	2	6
	Helpfulness ^a		Confidence using skill ^a	
	Mean (SD, range)		Mean (SD, range)	
Relaxation for pain	2.3 (1.6, 0–4)		1.4 (1.3, 0–4) ^b	
Relaxation for stress	2.9 (1.6, 0–4)			
PAINAD scale	3.4 (1.3, 0–4)		3.8 (0.4, 3–4)	
Pain thermometer	1.6 (1.5, 0–4)		3.4 (1.3, 0–4)	
Integrative movement	2.0 (1.7, 0–4)		2.4 (1.8, 0–4)	
Pleasant activities	3.6 (0.9, 2–4)		3.6 (0.7, 2–4)	
Listening to music	3.3 (1.1, 1–4)		3.4 (0.9, 2–4)	

^aRange = 0 (not at all easy/confident) to 4 (extremely easy/confident).

^bOne item assessed confidence in using relaxation for both pain and stress.

During the course of the intervention, almost all of the caregivers reported practicing the skills taught in the previous session at least once or twice, with the majority of caregivers practicing each of the skills three or more times per week (see Table 4). The exception was the pain thermometer which was used by only three caregivers. Average ratings of helpfulness ranged from 1.6 (a little bit to somewhat helpful) for the pain thermometer to 3.6 (very to extremely helpful) for pleasant activities. The PAINAD scale and music were also rated as very to extremely helpful. Caregivers reported high levels of confidence in using the PAINAD, pain thermometer, pleasant activities, and music (3.4–3.8, very to extremely confident). Relaxation for stress management was rated as very helpful, although confidence in using relaxation was low (1.4, a little bit to somewhat confident).

After completing the intervention, most caregivers reported continued use of the skills at least once or twice in the preceding week (see Table 5). Most skills were rated as somewhat to quite a bit easy to use. Pleasant activities and music were rated as quite a bit to extremely helpful, with other skills rated as somewhat to quite a bit helpful.

Acceptability. Caregivers reported a mean satisfaction score of 3.4 (SD = 0.35, range = 3.0–4.0). Eight caregivers said the number of sessions (five) was about right; one said it was too few and one said it was too many. Nine caregivers said the length of the sessions (45–60 min) was about right; one said they were too long. Five caregivers reported that they would prefer participating by telephone, three preferred videoconference, and two preferred in-person sessions. Comments about the most and least helpful aspects of the intervention are shown in Table 6. One caregiver did not complete this measure.

Patient pain and functioning. Means on baseline and post-intervention measures and average difference scores are displayed in Table 7. On average, patients and caregivers reported decreases in patient pain severity and interference from baseline to post-intervention. Patients reported slight decreases in their QOL while caregivers reported slight increases in their perceptions of patient QOL.

Caregiver outcomes. There were notable variations in baseline levels of caregiver self-efficacy for helping the patient manage pain, with some caregivers reporting high levels of confidence and others reporting very low levels. Overall, they reported small increases in self-efficacy, increases in caregiver burden, and decreases in caregiving satisfaction. There were large ranges of change on each of these variables.

Table 5. Caregiver post-assessment reports of skill frequency use, ease of use, and helpfulness over the past week

	Frequency of use N					Ease of use ^a Mean (SD, range)	Helpfulness ^a Mean (SD, range)
	Not at all	1–2 times	Several times	Once/day	>Once/day		
Relaxation	1	4	2	0	2	2.6 (1.7, 0–4)	2.6 (1.5, 0–4)
PAINAD	1	4	3	0	1	2.2 (1.5, 0–4)	2.2 (1.5, 0–4)
Pain thermometer	3	2	2	0	1	2.2 (1.8, 0–4)	1.9 (1.6, 0–4)
Integrative movement	3	2	2	2	0	2.0 (1.7, 0–4)	2.1 (1.7, 0–4)
Pleasant activities	1	2	2	2	2	2.9 (1.3, 0–4)	3.3 (0.9, 2–4)
Music	1	0	1	1	6	3.0 (1.4, 0–4)	3.4 (1.0, 1–4)

^aRange = 0 (not at all easy to use/helpful) to 4 (extremely easy to use/helpful).

Table 6. Comments in response to open-ended questions about the most and least helpful aspects of the intervention during Phase II pilot-testing

Dyad characteristics	Most helpful	Least helpful
Male patient with Parkinson's related dementia and back and leg pain; spousal caregiver; all in-person sessions	Breathing exercises (relaxation) extremely helpful. Audio link to access at will very helpful, and much appreciated	Integrative movement exercises
Female patient with early AD and stomach pain; spousal caregiver; all in-person sessions	Integrative movement exercises	Surveys had too many questions
Male patient with early AD and back pain; spousal caregiver; four sessions in person, one by telephone	Relaxation and integrative movement exercises	
Male patient with MCI and hip pain; spousal caregiver; one session in person, four by telephone	Relaxation	Pain scales
Female patient with foot pain; spousal caregiver; all telephone sessions	Integrative movement videos	Telephone issues
Female patient with early AD and knee pain; daughter caregiver; three telephone sessions, then discontinued due to time and patient's health	Interactions with therapist	
Female patient with knee pain; daughter caregiver; one session in person, four by telephone	Skills helpful for caregiver	Patient had trouble learning new skills
Male patient with back and leg pain from gunshot wound; spousal caregiver who was wheelchair bound due to arthritis and pain; all telephone sessions		The physical exercises were not relevant to someone with a physical handicap
Male patient with back/sciatic nerve pain; spousal caregiver; all telephone sessions	Relaxation. "Everything I learned has helped me become more centered, allowing me to be more aware of how my husband was really doing."	

Table 7. Scores on baseline and post-intervention measures

	Baseline Mean (SD, range)	Post-Intervention Mean (SD, range)	Post-Baseline Difference Mean (SD, range)
Patient reports			
Pain severity	4.4 (1.7, 2–7.3)	3.2 (1.4, 0.7–6.0)	–1.15 (1.8, –4.0 to 0.67)
Pain interference	1.9 (0.7, 1.0–3.0)	1.3 (1.5, 1.0–2.0)	–0.64 (0.67, –2.0 to 0)
Quality of life	36.5 (5.7, 23–42)	34.5 (5.0, 27–41)	–1.9 (6.5, –14.0 to 9.0)
Caregiver reports			
Patient pain interference	3.8 (1.9, 1.0–6.4)	3.8 (2.1, 0.1–7.1)	–0.07 (1.56, –2.0 to 2.1)
Nonverbal pain	4.5 (3.5, 0–10)	4.3 (2.8, 1–10)	–0.18 (3.15, –6.0 to 5.0)
Patient quality of life	32.5 (6.6, 23–42)	33.5 (6.5, 26–47)	1.0 (5.29, –4.0 to 14.0)
Caregiver self-efficacy	61.7 (26.8, 11.4–92.9)	64.0 (20.8, 35.7–95.0)	2.22 (25.0, –38.6 to 61.4)
Caregiver burden	31.2 (15.0, 12–60)	34.4 (17.4, 13–58)	3.18 (7.8, –8.0 to 18.0)
Caregiver satisfaction	4.2 (0.5, 13.3–4.8)	4.1 (0.6, 3.1–4.9)	–0.13 (0.56, –1.5 to 0.8)

Discussion

The aims of this study were to adapt a caregiver-assisted PCST intervention for PWD and their family caregivers and assess its feasibility and acceptability. Findings supported the feasibility of this approach. Eleven of 16 (69%) eligible dyads consented to participate in the pilot study, 82% of dyads completed all five intervention sessions, and caregivers reported high satisfaction ratings. Importantly, caregivers reported that they used the pain coping skills on a regular basis, and that they found most of the skills helpful and easy to use.

The most helpful and frequently used skills were pleasant activity scheduling and listening to music, while the least helpful/used skill was the pain thermometer. Many caregivers noted

that the pain thermometer was not necessary in the context of MCI or mild dementia as the patients were readily able to verbalize pain. Interestingly, while relaxation and integrative movement exercises were not as highly rated as others on the quantitative surveys, they were most frequently mentioned as helpful in response to the open-ended item on the post-intervention survey. With regard to relaxation, many caregivers found it helpful for managing their own stress, however they may not have had enough time to practice it to develop their confidence in using it effectively. For integrative movement, there tended to be a bimodal response; participants who were already physically active and those who had significant physical limitations were less likely to find it helpful than those who were more sedentary but able to engage in the exercises.

The pattern of changes on outcome variables was mixed. Patients and caregivers reported decreases in patient pain severity and interference from baseline to post-intervention, and caregivers reported increases in their self-efficacy for helping the patient manage pain. However, caregivers reported increases in burden and decreased caregiving satisfaction. These difference scores should be interpreted with caution due to the small sample size, large ranges, and lack of control group. While it is possible that caregivers experienced the study protocol as burdensome, only a small minority reported any burden associated with the study. Findings likely were influenced by the fact that most of the dyads participated in the study during the early months of the pandemic when caregivers may have been experiencing increased stress.

The pandemic also significantly impacted the implementation of the study. Consenting patients and caregivers and collecting data remotely was challenging and time-consuming. Many caregivers were unable to complete these activities via internet, thus we often had to mail materials and provide instructions by telephone. Also, during the interviews and at the onset of the pilot trial, many if not most dyads reported a preference for participating in the intervention in person. While caregivers who participated by telephone reported satisfaction with this format, we believe that they may have derived more benefit from having at least some in-person (or even videoconference) sessions so that the therapist could better evaluate their engagement, model skills, and provide feedback.

Lessons learned from this pilot study include the potential importance of including a qualitative assessment of caregivers' reactions to the intervention to better understand their experiences. For example, anecdotally caregivers noted increases in positive interactions over the course of the sessions (e.g., rediscovering mutually enjoyable activities) that may not have been captured in quantitative surveys. Based on caregivers' favorable responses to the relaxation exercise combined with relatively low levels of confidence in applying this skill, we believe that caregivers might benefit from having one or more initial individual sessions (without the patient) focused on relaxation. By first learning to use relaxation to manage their own stress and pain, caregivers may be better prepared to assist the patient in learning and applying the pain coping skills. We plan to incorporate these elements in a subsequent larger randomized controlled pilot study.

Additional limitations of the study include the small sample size, lack of comparison group, and no long-term follow up. Nonetheless, these preliminary findings suggest that a caregiver-assisted pain coping skills intervention is feasible and acceptable, and that it may be a promising approach to managing pain in patients with cognitive impairment.

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Conflicts of Interest. D.E.B. is co-inventor of the Preventing Loss of Independence through Exercise (PLIÉ) program and has the potential to earn royalties. The following authors have no conflicts to report: L.S.P., D.K.W., K.E.S., K.R., L.G., C.S.R., and F.J.K.

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